

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



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BACKGROUND: Food allergy education is an ongoing process that must address unique safety concerns and psychosocial challenges at each developmental stage. Families require reliable information that is targeted to specific developmental stages to support the integration of food allergy management into daily life.

OBJECTIVE: The purpose of this project was to develop age-specific, evidence-based patient education handouts with practical recommendations for managing and coping with food allergies at different developmental stages.

METHODS: Handout content was based on: (1) practice guidelines for food allergy management; (2) literature addressing psychosocial and educational needs of patients with food allergy and their caregivers; and (3) clinical experience of the project team. Fifty-seven caregivers of patients (aged 0-21 years) with food allergy and 2 young adults with food allergy reviewed a draft of the handouts and completed an online survey to assess handout acceptability and usability and identify areas for improvement. Handouts were revised based on participant feedback.

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Abbreviations used

AAAAI- American Academy of Allergy, Asthma and Immunology
NIAID- National Institute of Allergy and Infectious Diseases
PEMAT- Patient Education Materials Assessment Tool

RESULTS: The majority of participants (79%) rated the amount of information in the age-specific handouts as “just right,” versus “not enough” (9%) or “too much” information (12%). Sixty-three percent reported that they would be “very likely” to use the handouts as a resource and 35% “somewhat likely.” Almost all participants (88%-100% by item) agreed that the handouts used elements of plain language writing and clear communication.

CONCLUSION: Caregivers rated the age-based food allergy education handouts as understandable and useful. We anticipate that these handouts could be used during health care visits and directly accessed online by families. © 2022 American Academy of Allergy, Asthma & Immunology (J Allergy Clin Immunol Pract 2022;10:2552-8)

Key words: Food allergy; Education; Patient; Infant; Child; Adolescent; Parents; Caregivers; Quality of life; Child development

Effective food allergy management depends on allergen avoidance and preparedness to recognize and treat allergic reactions.¹ Comprehensive food allergy education is essential to supporting families' ability to integrate these management practices into daily life. At each stage of child development, families encounter unique safety concerns, psychosocial challenges, and roles for the child in their own food allergy self-management, highlighting the need for ongoing education that is tailored to the child's and family's needs at any particular time. National Institute of Allergy and Infectious Diseases (NIAID) Guidelines for the Diagnosis and Management of Food Allergy in the United States recommend that patients and caregivers be provided with information on allergen avoidance and emergency management that is age-appropriate, as specific quality of life concerns may change as patients mature.² Similarly, American Academy of Allergy, Asthma and Immunology (AAAAI) Food Allergy Practice Parameters recommend that food allergy education should be an ongoing process, with specific management recommendations depending on the physical and developmental age of the patient at the time of diagnosis and changing over time.³

Published reports of evidence-based educational resources for caregivers of children with food allergy (eg, videos and written materials)⁴⁻⁷ suggest that providing families with reliable educational materials can improve important outcomes such as food allergy knowledge, comfort in food allergy management, and patient and family quality of life.⁵⁻⁷ Educational materials from trusted sources are particularly important. Families commonly report seeking food allergy-related information on the internet but also report challenges determining which sources are reliable, which can increase stress and potentially compromise safety and quality of life.^{4,8-11} To our knowledge, there is no readily available food allergy education resource to address the specific needs of caregivers and children at different developmental stages.

This Work Group Report will review developmental aspects of managing and coping with food allergy and describe the creation of age-specific, evidence-based educational handouts for caregivers of children with food allergy and young adults with

food allergy. Handouts were designed to support families in integrating effective food allergy management practices into daily life and managing the psychosocial impact of food allergy at each stage of development. Our goal was to develop a resource that would be easily accessible to AAAAI members, other health care providers (eg, primary care physicians, nurses, dietitians, psychologists, social workers), and caregivers/the public.

Developmental aspects of managing and coping with food allergy

For *young children* (eg, infants, toddlers, preschoolers), caregivers are primarily responsible for food allergy management. Caregivers commonly experience anxiety about their ability to keep their child safe.¹²⁻¹⁴ Specific concerns may include introduction of new foods, monitoring for allergic reactions in preverbal children who cannot describe symptoms, and concerns about accidental exposures at a stage when children have frequent mouthing behaviors of their hands and objects.^{13,15,16} Such concerns may limit family social activities and inform choices about leaving the child in the care of other adults.^{13,14,17}

Caregivers of *school-aged children* are tasked with developing food allergy management strategies to enable the child's safe participation in activities outside of the home (eg, playdates, school, before/after school care, extracurricular activities).^{18,19} Children at this age can play an increased role in food allergy self-management.¹⁸ However, normative developmental 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.^{10,13,20-23} Around the ages of 8 to 10 years, children may also experience increased anxiety about accidental exposure to allergens and allergic reactions in situations they previously navigated with confidence.²⁴ Several factors may contribute to increased anxiety, including greater cognitive awareness of risks, misperceptions about the level of risk associated with casual contact with an allergen, and greater independence in food allergy management.^{20,24,25} Socially, school-aged children are developing a greater awareness of differences from peers due to food allergy, highlighting the need for management strategies that emphasize both safety and social inclusion to foster confidence.²⁴ They may be at increased risk for bullying or teasing by peers, particularly in the school setting, with implications for self-esteem and anxiety about their physical safety.²⁶⁻²⁹

For *adolescents*, there is a transition toward increased responsibility for food allergy self-care, requiring families to negotiate who is responsible for each management task based on the child's readiness. Adolescents benefit from continued caregiver support, particularly around the planning, problem-solving, and decision-making required for effective food allergy management.³⁰ As adolescents spend more time outside of direct adult supervision, there is greater concern for risk-taking behaviors (eg, eating foods with precautionary labeling, not reading food labels or asking about ingredients, not carrying their epinephrine autoinjector), particularly in social situations due to concerns about fitting in, feeling embarrassed, or being teased due to food allergies.³¹⁻³⁵ Barriers to epinephrine carriage and use among teens may also include issues of convenience/size of the device, attitudes of others, beliefs about risk of allergic reaction (eg, low risk for a reaction requiring emergency treatment if they do not plan on eating), and uncertainty about symptoms of anaphylaxis and how and when to use the autoinjector.^{32,36-38} In

addition, adolescents may encounter new situations (eg, romantic relationships, exposure to drugs and alcohol) that pose safety considerations related to food allergy management.

As older adolescents and *young adults* transition toward primary responsibility for day-to-day food allergy management, it is important for them to understand strategies for managing food allergies in shared living situations, college, the workplace, and romantic relationships, and also understand key aspects of managing their own health care (eg, scheduling medical appointments, filling prescriptions, understanding insurance coverage and copayments).^{39,40}

Consistent with such developmental transitions in food allergy management, caregivers report the need for “roadmaps” for educating children about food and involving them in their own self-care over time.^{4,9,10,12,41} Common caregiver concerns include how to balance safety with social inclusion and how to teach children to be aware of possible consequences of allergic reactions without instilling excessive fear and anxiety in the child.^{9,13,18,23,42} Caregivers experiencing high levels of anxiety about food allergy or low levels of self-efficacy around food allergy management may be more likely to limit the child’s role in allergy management and participation in developmentally typical social, family, and school activities, with implications for the child’s quality of life, anxiety level, and sense of empowerment.^{22,41,43-45} In contrast, “balanced” family coping with food allergy (eg, having sufficient levels of vigilance to sustain allergen avoidance and emergency preparedness, while being able to regulate anxiety and integrate food allergy management into daily life) has been associated with positive quality of life and child involvement in food allergy self-care.⁴³ Such findings highlight the need for educational materials that support caregivers in educating children about food allergies and preparing them for self-care in ways that promote balanced coping with food allergy at all stages of child development.

METHODS

Handout development

Handout content and recommendations were based on: (1) practice parameters/guidelines (Joint Task Force on Practice Parameters, NIAID Guidelines for the Diagnosis and Management of Food Allergy in the United States);^{2,3} (2) relevant published research literature addressing food allergy management, psychosocial burden of food allergy, educational needs of patients with food allergy and their caregivers, and developmental aspects of coping with food allergy; and (3) clinical experience of the project team (5 pediatric allergists and 4 pediatric psychologists with food allergy expertise). Our overarching goals were to support families in integrating food allergy management into daily life and support children in gradually assuming a larger role in self-management over time. An initial set of content areas/topics was developed by the authors. Two to three authors developed recommendations for each topic. Specific recommendations for each developmental stage were established in consideration of the child’s cognitive, language, social, and emotional development at that particular stage. Subsequently, all authors reviewed the recommendations for each age group and developed additional content as needed.

We based the age/developmental stage categories for the handouts on those used by the American Academy of Pediatrics for their Ages and Stages patient education handouts (www.healthychildren.org) and further divided the grade school and teen stages into 2 separate handouts to reflect changes in children’s self-management capacities across these stages. Stages included baby (0-12 months), toddler (1-3 years), preschool (3-5 years), early school age (5-8 years), late school age (8-11

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.

years), early teen (11-14 years), late teen (14-18 years), and young adult (18-21 years).

We included information central to food allergy management at all developmental stages in a *Food Allergy Basics for All Ages* handout. Separate handouts were then created for each specific developmental stage, using the same topic headers across stages (when developmentally appropriate), with the specific recommendations tailored by stage. Handouts were caregiver-facing, with the exception of the Young Adult handout that was written directly for the young adult patient. Topics are listed in [Table I](#).

We used strategies for plain language writing and clear communication to meet caregivers’ varied health literacy needs and support families’ ability to understand and act on handout recommendations (eg, use of common, everyday words and short sentences, simplified definitions for technical terms, concrete examples, action-oriented material, and headers to organize information).

Caregiver/patient feedback

We used an electronic survey to obtain caregiver feedback on a draft of the handouts to assess acceptability and usability of the handouts and identify areas for improvement. The caregiver feedback survey was granted exemption status by the Institutional Review Boards of Boston Children’s Hospital, Children’s National Hospital, and the University of Rochester.

Participants. Eligible participants included caregivers of children with food allergy aged 0 to 21 years and young adults with food allergy receiving care for management of food allergies in the outpatient Allergy Clinics at Boston Children’s Hospital, Children’s National Hospital, and the University of Rochester. Participants were English speaking, as the handouts were available in English only during the development process.

Procedure. Participants were asked to read the Food Allergy Basics for All Ages handout, as well as the age-specific handout for the patient’s age. These drafts included handout content but did not yet include graphics/design elements. If the child’s age fell in the cutoff between 2 developmental stages (eg, 3-year-old who could be included in either the toddler or preschool range), the caregiver was asked to review the handout for the earlier stage. Participants were emailed a link to complete a brief online survey with questions about their opinions of the handouts as well as demographic background

TABLE II. Demographic and clinical characteristics of survey respondents

Caregiver characteristics (N = 57)	% , n
Caregiver relationship to child	
Mother	89.5, 51
Father	8.8, 5
Grandmother	1.8, 1
Caregiver ethnicity	
Hispanic/Latinx	10.5, 6
Non-Hispanic/Latinx	89.5, 51
Caregiver race	
Asian	10.3, 6
Black or African American	15.8, 9
Native American or Alaska Native	3.5, 2
Native Hawaiian or other Pacific Islander	—
White	75.4, 43
Other	1.8, 1*
Caregiver education level	
High school degree	7.0, 4
GED or other high school equivalency certificate	3.5, 2
Junior/community college degree	7.0, 4
Undergraduate degree (4-y college degree)	40.4, 23
Graduate school degree	42.1, 24
Annual household income	
<\$20,000	1.8, 1
\$20,000-34,999	3.5, 2
\$35,000-49,999	—
\$50,000-74,999	5.3, 3
\$75,000-99,999	14.0, 8
\$100,000-149,999	22.8, 13
\$150,000-199,999	19.3, 11
≥\$200,000	29.8, 17
Missing	3.5, 2
Child characteristics (N = 59)	% , n
Age of child/individual with food allergies, median (range)	6 y (8 mo to 23 y)
Child's age	
Baby (0-12 mo)	6.8, 4
Toddler (1-3 y)	15.3, 9
Preschool (3-5 y)	16.9, 10
Early grade school (5-8 y)	13.6, 8
Late grade school (8-11 y)	11.9, 7
Early teen (11-14 y)	11.9, 7
Late teen (14-18 y)	11.9, 7
Young adults (18-21 y)	5.1, 3
Missing	6.8, 4
No. of food allergies, median (range)	4 (1-11)
Child's food allergies	
Tree nuts	74.6, 44
Peanuts	62.7, 37
Egg	57.6, 34
Cow's milk	47.5, 28
Sesame	39.0, 23
Shellfish	18.6, 11
Wheat	16.9, 10
Soy	15.3, 9

(continued)

TABLE II. (Continued)

Caregiver characteristics (N = 57)	% , n
Fish	11.9, 7
Other	27.1, 16
Child ethnicity	
Hispanic/Latinx	13.6, 8
Non-Hispanic/Latinx	86.4, 51
Child race	
Asian	15.3, 9
Black or African American	16.9, 10
Native American or Alaska Native	—
Native Hawaiian or other Pacific Islander	—
White	74.6, 44
Other	6.8, 4†
Clinic where the child receives food allergy care	
Boston Children's Hospital	71.2, 42
Children's National Hospital	13.6, 8
University of Rochester	13.6, 8
Missing	1.7, 1

Note: All demographic and clinical information based on participant survey responses. Demographic and clinical characteristics of the young adult survey respondents are included within the Child characteristics.

*One caregiver who reported "Other" race self-identified as Indian American.

†Three caregivers who reported the child's race as "Other" described the child's race as mixed race (White and Native South American), biracial (Black and White), and Indian American. One caregiver did not provide further information.

information (see Figure E1 in this article's Online Repository at www.jaci-inpractice.org). Survey responses were collected and managed using REDCap electronic data capture tools hosted at Boston Children's Hospital.^{46,47}

Measures. Survey questions were based on recommendations for obtaining patient feedback on health education materials,⁴⁸ with some questions adapted from the Patient Education Materials Assessment Tool (PEMAT), a validated tool for evaluating whether patients/caregivers will be able to understand and act on information included in health education materials.⁴⁹ Open-ended questions were used to assess participants' opinions about any specific information in the handouts that was helpful, confusing, difficult to understand, or upsetting, as well as suggestions for further content to include in the handouts.

RESULTS

Fifty-seven caregivers of children, adolescents, and young adults with food allergy reviewed the handouts and completed the feedback survey. Caregivers included 51 mothers, 5 fathers, and 1 grandmother/legal guardian. Two young adults with food allergy (both 23 years old) also completed the survey, for a total of 59 respondents. Demographic and clinical characteristics of the survey respondents are shown in Table II.

As seen in Table III, the majority of participants rated the amount of information included in both the Basics for All Ages (81%) and age-specific (79%) handouts as "just right." A sizable group of participants (17%) felt that the Basics for All Ages handout contained "too much information." Almost all participants reported that they would be either "somewhat" or "very likely" to use the Basics for all Ages and age-specific handouts as a reference for managing their child's food allergy. Almost all participants agreed that the handouts used elements of plain

TABLE III. Participant feedback on handout acceptability

What do you think about the amount of information included in the handouts?*	%, n		
	Not enough information	Just right	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

How likely would you be to use these handouts as a resource for managing your child's food allergy?†	%, n		
	Not at all likely	Somewhat likely	Very likely
Food Allergy Basics for All Ages Handout	3.5, 2	38.6, 22	57.9, 33
Handout for your child's age	1.8, 1	35.1, 20	63.3, 36

*Percentages based on 58 participants completing this question.

†Percentages based on 57 participants completing this question.

language writing and clear communication assessed by questions adapted from the PEMAT (see Table IV).

Participant responses to open-ended questions were organized into themes. The most commonly reported responses to the question about anything in the handouts that was particularly useful included clear writing/organization ($n = 7$), the developmental framework of the handouts ($n = 7$), information about addressing the emotional aspects of food allergy ($n = 6$), and comprehensive content ($n = 5$; see Table V). Some participants provided examples of information in the age-specific handouts that was helpful to them, such as information about ways that a toddler could come into contact with a food allergen and information about addressing kissing and alcohol use with teens. Participants also valued the Resources for Further Information section of the Basics for All Ages handout as a way to identify reliable websites if they have questions or want further details ($n = 4$). Other comments indicated that the handouts would be a good resource to share with family, friends, childcare providers, and school personnel ($n = 4$) and that participants wished the handouts were available when the child was younger/felt the handouts would be particularly useful for families of children newly diagnosed with food allergy ($n = 6$).

Participant responses to open-ended questions about anything in the handouts that was confusing, difficult to understand, or upsetting, as well as suggestions for additional content were used to revise the handouts. The most common comment was that although content was useful, draft handouts were text-heavy/"wordy" and would benefit from shorter phrasing of key points and incorporation of graphics/more white space ($n = 10$). No

comments suggested any content that should be removed. Examples of changes/additions based on participant feedback included creation of a "definitions" section on the Basics for All Ages handout to clarify terms and reduce "wordiness" within the text; proposed graphics to provide additional information while reducing text (eg, symptoms of an allergic reaction, ways that allergens can be listed on an ingredient label); and specific suggestions for certain sections (eg, clear examples of brands/names for epinephrine autoinjectors, language for explaining food allergies to other people caring for the child, language for teens to use with peers at restaurants, greater acknowledgment of stress for parents of young children with food allergy). We updated the draft handouts to reflect participant feedback from the surveys. Final versions of the educational handouts may be found in Figure E2, available in this article's Online Repository at www.jaci-inpractice.org.

DISCUSSION

The Food Allergy Stages Handouts were developed to address an unmet need for a reliable educational resource to support family integration of food allergy management into daily life at different stages of child development. Feedback from a group of caregivers and young adults suggests that the handouts are understandable and useful to families, and that families value information about how to engage children in food allergy management and address the psychosocial impact of food allergy at different developmental stages. Feedback also highlighted the need to use layout and visual elements to reduce the "text-heavy" feel of the handouts.

TABLE IV. Participant responses to items adapted from the PEMAT

Please tell us if you agree or disagree with the following statements	Agree with the statement %, n
The purpose of the handouts is clear	98.3, 58
The handouts use common, everyday language	98.3, 58
Medical terms are clearly defined	100, 58*
The material breaks or "chunks" information into short sections that are easy to follow/understand	88.1, 52
The section headings (eg, "Label Reading") are clear/informative	94.9, 56
Material is presented in a logical order	96.6, 56*
The handouts give clear actions families can take to help children manage food allergies	96.4, 54†
The handouts break down actions families can take into manageable, clear steps	94.7, 54‡

PEMAT, Patient Education Materials Assessment Tool.

*Percentage based on 58 total responses to this item.

†Percentage based on 56 total responses to this item.

‡Percentage based on 57 total responses to this item.

TABLE V. Participant open-ended responses about useful aspects of the handouts

Theme	n	Representative examples
Clear writing/organization	7	The language was clear and gave good instructions
		I like the way they are written using basic, everyday language
		The breakdown was incredibly helpful. The sections were concise but gave enough information to help the reader feel comfortable in that area
Developmental framework	7	I like the messaging for how to talk to and engage your child in their allergy management based on their age
		I haven't seen them tailored to age before and I think this helps with the mental/emotional side of managing an allergy
		I found it helpful that it covered... tips on supporting your child and helping them understand at a young age
Information about emotional aspects of food allergy	6	Addressing stress and anxiety with food allergies is a good idea to have in the manuals
		How to help children ease their anxiety
		References to not using scary language around food allergies
Comprehensive content	5	It covers everything, and if I used it, I wouldn't feel like I was forgetting something
		They covered a good breadth of topics
		I found it helpful that the content was comprehensive

Note: Examples based on responses from 40 participants who responded to the questions about useful aspects of the handbook.

The finalized handouts are available on the AAAAI website as a publicly available resource and can be accessed at <https://www.aaaai.org/Tools-for-the-Public/Conditions-Library/Allergies/Food-Allergy-Stages-Handouts>. Handouts will be reviewed and updated periodically to ensure that families have access to accurate, up-to-date information. We envision that these handouts could be used by health care professionals as a teaching tool and educational resource in the clinic and easily disseminated to families in the context of telemedicine visits. A practical strategy to facilitate dissemination may include development of a 1-page flyer with QR codes linking to each handout, which could be available in the allergist's or primary care provider's office or posted in waiting and/or examination rooms for easy access by families. As highlighted by caregivers in the feedback survey, the handouts would also serve as a tool for educating other individuals caring for the child, such as daycare and school personnel, babysitters, family, and friends. The primary intent of this project was to create caregiver-facing educational handouts. Further work is needed to create patient-facing handouts for older children and adolescents.

It is important to note that the sample of caregivers reviewing the handouts was highly educated, high income, primarily White and non-Hispanic, and English-speaking. This is a limitation of the project, especially in light of disparities that affect health outcomes for patients with food allergy and the importance of improving access to food allergy education in racial and ethnic underserved populations. Black and Hispanic children with food allergy in the United States have increased rates of anaphylaxis and emergency department visits and reduced access to epinephrine and specialty care. In addition, caregivers with lower health literacy experience knowledge gaps related to food allergy management.⁵⁰⁻⁵³ Although we aimed to make handouts accessible for caregivers with varied levels of health literacy by using strategies such as plain language writing, our highly educated sample limited our ability to evaluate whether this was successful. We will continue to gather feedback on the handouts from a more diverse group of caregivers and patients as part of our ongoing handout review process, to help ensure that these resources will meet the needs of all families of children with food allergy. Furthermore, handouts will be translated into Spanish so that they can be accessible to a broader group of families.

A primary goal when developing the handouts was to provide information that promotes child health and safety, as well as child and family empowerment and positive quality of life. Directions for future research include evaluation of the impact of these handouts on important outcomes, such as child and family confidence in food allergy management and food allergy-related anxiety and quality of life.

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