

# Psychosocial Challenges among Caregivers of Children with FPIES

## SOCIAL ISOLATION

-Allergen avoidance may make it challenging to participate in social gatherings, playdates & eating outside the home.

## FINANCIAL STRAIN

-High cost of specialized formula, hypoallergenic foods.  
-Cost of medical visits.  
-Missed wages due to time off work.

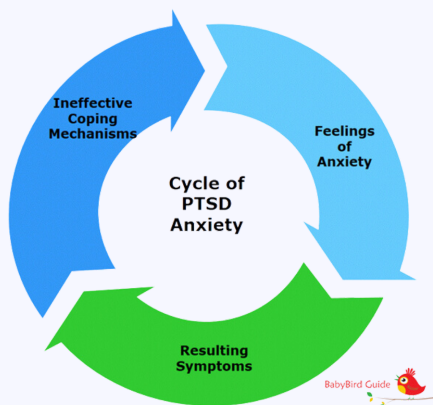
## EMOTIONAL DISTRESS

-Constant worry about severe allergic reactions.  
-Daily dietary management.  
-Loneliness & frustration related to social isolation.  
-Education/advocacy for child safety & inclusion.  
-Health system navigation.

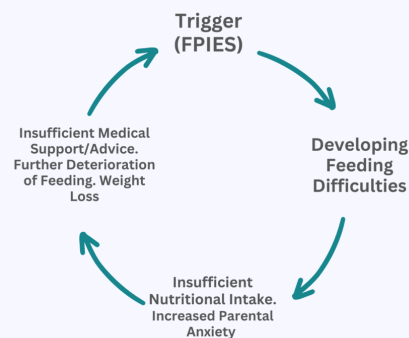
Physical & Emotional  
Caregiver Burnout

## TRAUMA INFORMED SUPPORT

“Mother is quite anxious about introducing new foods, and Jack is refusing new foods”



### Management of Feeding Difficulties in FPIES



### Questions Healthcare Providers Can Ask To Understand the Impact of FPIES on Parents

FPIES Management	FPIES Treatments	Emotional Aspects	Social Activities
Tell me about what is going well with FPIES management. Tell me about what is most challenging.	Tell me what questions you have about how your child's FPIES is being managed.	Has this FPIES experience been traumatizing for you?	Are there times when your family does not feel that you're able to participate in social activities or other activities outside the home? Tell me more about these situations.
Do you have any concerns about your child's FPIES management in daycare/school? If so, tell me more about them.	How do you feel about the treatment options that we've discussed?	Do you/your child ever feel sad or down about FPIES? When do you typically have these feelings?	What are the aspects of this situation that make it challenging?
Do you have concerns about your family's ability to afford allergen-free foods or medical costs?	Tell me your thoughts on [xx] food introduction/oral food challenge. What contributes to your decision? How can we support your family as you make this decision?	Do you/your child ever feel anxious or worried about FPIES? When do you typically have these feelings?	When have you felt successful navigating these social activities?



Session 1531 Allied Health: A Multidisciplinary Approach to the Management of Food Protein-Induced Enterocolitis Syndrome (FPIES)

Speakers: Fallon Schultz,  
MSW, LCSW, CAM  
CEO & Founder

International FPIES Association (IFPIES)

Linda Herbert, PhD  
Associate Professor, Department of Psychology  
& Behavioral Health  
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### Importance of Shared Decision Making and Patient Autonomy in FPIES Management

Empowerment	Improved Communication	Tailored Care	Comprehensive Support
- Promotes active participation in care and have a voice in treatment plans - Leads to a sense of control and ownership over health	- Facilitates open/honest communication between healthcare providers and patients. - Leads to better understanding, trust, and improved outcomes	- Permits tailored treatment plans that align with patient preferences, values, and lifestyle	- Encourages healthcare providers to address overall well-being- including psychosocial health