Spotlight on FPIES:

Continuing awareness, education and support following the closure of FPIES UK

By Annette Weaver, Clinical Dietetic Advisor, Allergy UK

Introduction

Food Protein-Induced Enterocolitis Syndrome (FPIES) is a non-IgE-mediated food allergy that remains under-recognised in clinical practice. Unlike many other non-IgE-mediated food allergies, FPIES has the potential to cause life-threatening reactions, including hypovolaemic shock. Increasing awareness among healthcare professionals is essential to ensure timely recognition, appropriate management - and improved outcomes for affected individuals and families.

The UK FPIES community has recently undergone a significant change. FPIES UK, a dedicated patient support organisation that has provided invaluable resources and advocacy for many years, has sadly closed. The contribution of FPIES UK to raising awareness, supporting families, and promoting understanding of this complex condition has been considerable and its impact has been felt across both patient and professional communities.

Allergy UK is committed to ensuring that this vital work continues. We are currently in the process of amalgamating incorporating the FPIES UK resources onto the Allergy UK website (www.allergyuk.org), ensuring accessibility for healthcare professionals and the public. This includes patient information and educational content designed to support recognition and management of FPIES. In addition, Allergy UK aims to expand its resources to include greater coverage of areas such as adult FPIES, reflecting increasing recognition that this condition is not confined to childhood. Although FPIES most commonly presents in infancy, it can occur at any age, including in older children and adults.

Recognition, diagnosis and management of FPIES

FPIES typically presents with delayed, repetitive vomiting occurring 1–4 hours (can range from 30 minutes to 6 hours) after ingestion of the trigger food, often accompanied by lethargy and pallor. Diarrhoea may also occur and be longer lasting. In more severe cases, ongoing emesis and fluid loss can lead to dehydration, hypotension and, in some cases, hypovolaemic shock.

Individuals with FPIES are recommended to carry a BSACI FPIES allergy action plan or an emergency letter to alert healthcare professionals of the condition and appropriate management as the presentation can mimic sepsis or gastrointestinal illness, which may result in misdiagnosis and inappropriate management. Symptoms do not respond to antihistamines or adrenaline typically used in IgE-mediated allergic reactions.

Common trigger foods in the UK include cow's milk, egg, fish, soya, oats, rice, fruit and vegetables. A wide variety of implicated foods have been reported and individual triggers vary. Importantly, FPIES can be triggered by common weaning foods that are not typically considered common allergens, such as banana, avocado and sweet potato. The vast majority of individuals react to one or two foods.

Given the non-IgE-mediated nature of FPIES, standard allergy testing such as skin prick tests or serum-specific IgE tests are typically negative and diagnosis relies on careful clinical history. Awareness of the characteristic delayed reaction pattern is key. Early recognition can help to reduce delays in diagnosis, significantly improve patient care and reduce healthcare-related costs. Many cases of FPIES present during the introduction of complementary feeding - a particularly sensitive period for families - and can be associated with significant parental anxiety.

FPIES is associated with an increased risk of feeding difficulties, food aversion and reduced quality of life. These challenges may persist beyond resolution of the allergy and can have a significant impact on nutritional intake, child development and family wellbeing.[1]

AllergyUK

In the UK, mild-to-moderate non-IgE-mediated food allergies to cow's milk and soya are often managed in primary care. There is a real risk that FPIES may be misclassified within this group, leading to delayed recognition and referral and inappropriate management. As FPIES has the potential for severe reactions, suspected cases require prompt referral to specialist allergy services for diagnosis and management. The use of home re-introduction of foods such as ladders is not recommended.

Diagnosis is typically made within specialist allergy services and timely access to specialist dietetic support is essential to guide safe feeding progression. A multidisciplinary approach, involving both allergy specialists and dietitians, is crucial to support appropriate nutritional intake, ensure optimal child development and build parental confidence during what can be a highly challenging period.

Management focuses on strict avoidance of trigger foods, nutritional support where required and clear emergency plans for acute reactions. In many cases, children will outgrow FPIES in childhood, though the natural history varies.

Diagnostic criteria for FPIES

International consensus guidelines for the diagnosis and management of FPIES[2] were published in 2017 followed by a proposed adult-specific medical algorithm[3] published in 2024. The diagnostic criteria for acute FPIES proposed by the international consensus guidelines are shown below. Healthcare professionals are encouraged to read the articles in full as they include other important information, including epidemiology, pathophysiology, differential diagnosis and management. It is important to note that while international publications describe both acute and chronic FPIES, the concept of chronic FPIES remains an area of controversy in UK clinical practice.

Table 1. Diagnostic criteria for acute FPIES. Adapted from Nowak-Węgrzyn et al. (2017)[2].

Major criterion:	Minor criteria:
Vomiting in the 1- to 4-h period after ingestion of the suspect food and absence of classic IgE-mediated allergic skin or respiratory symptoms	1. A second (or more) episode of repetitive vomiting after eating the same suspect food 2. Repetitive vomiting episode 1-4 h after eating a different food 3. Extreme lethargy with any suspected reaction 4. Marked pallor with any suspected reaction 5. Need for emergency department visit with any suspected reaction 6. Need for intravenous fluid support with any suspected reaction 7. Diarrhoea in 24 h (usually 5-10 h) 8. Hypotension 9. Hypothermia

The diagnosis of FPIES requires that a patient meets the major criterion and ≥3 minor criteria. If only a single episode has occurred, a diagnostic OFC should be strongly considered to confirm the diagnosis, especially because viral gastroenteritis is so common in this age group. Furthermore, although not a criteria for diagnosis, it is important to recognise that acute FPIES reactions will typically completely resolve over a matter of hours compared with the usual several-day time course of gastroenteritis. The patient should be asymptomatic and growing normally when the offending food is eliminated from the diet.

Allergy UK's commitment to FPIES

Allergy UK will continue to play a central role in raising awareness of FPIES among healthcare professionals, as well as supporting individuals and families affected by the condition. We recognise that access to specialist allergy services can be challenging and therefore offer free dietetic clinics that provide interim support for individuals with concerns about food allergy in themselves or their child. Through these clinics, we have supported numerous families with suspected FPIES in children, as well as adults with possible FPIES, helping them to navigate diagnosis, dietary management and referral to appropriate specialist services. Through this work, we have observed delays in diagnosis and referral when FPIES is not recognised early in primary care, as well as a particular gap in services for adults with suspected FPIES. This highlights the need for greater awareness, improved referral pathways and increased access to specialist care.

Although the closure of FPIES UK marks the end of an important chapter, Allergy UK is committed to building on its legacy - improving recognition, understanding and the management of FPIES in the UK.

Further resources

Allergy UK FPIES resources

Providing accessible, evidence-based information on FPIES. This is currently being expanded so do check back later.

Currently includes:

- The Allergy UK FPIES Factsheet.
- Complementary Feeding and FPIES.
- FPIES Information for GPs.

BSACI FPIES action plans

Practical guidance for managing acute reactions.

- FPIES Action plan 1 is for children with additional IgE-mediated allergies.
- FPIES Action plan 2 is for children without additional IgE-mediated allergies.

The International FPIES Association (I-FPIES)

Provides global educational resources and research updates on FPIES, includes:

- Dedicated sections for paediatric and adult FPIES.
- A range of resources for healthcare professionals and patients with FPIES.
- Updated information about research as well as a FPIES journal club that healthcare professionals can join.
- Summary documents of the International Consensus guidelines, nutritional guidelines and a range of other resources.

References

1. Patel BN, Tam JS. Food protein-induced enterocolitis syndrome: Disease burden for patients and families. J Food Allergy. 2025;7(2):54-59. Published 2025 Nov 1. doi:10.2500/jfa.2025.7.250001Nowak- Węgrzyn A, Chehade M, Groetch ME, et al. International consensus guidelines for the diagnosis and management of food protein- induced enterocolitis syndrome: executive summary - Workgroup Report of the Adverse Reactions to Foods Committee, American Academy of Allergy, Asthma & Immunology. J Allergy Clin Immunol. 2017;139:1111-1126.e4. doi:10.1016/j.jaci.2016.12.966
2. Gonzalez-Delgado P, Anvari S, Entrala A, Infante S. Medical algorithm: Diagnosis and management of adult food protein-induced enterocolitis syndrome. Allergy. 2024;79(10):2881-2884. doi:10.1111/all.16142
3. Vazquez- Ortiz M, Infante S. Diagnostic criteria for food protein- induced enterocolitis syndrome: can we do better? Ann Allergy Asthma Immunol. 2021;126(5):458-459. doi: 10.1016/j.anai.2021.01.031