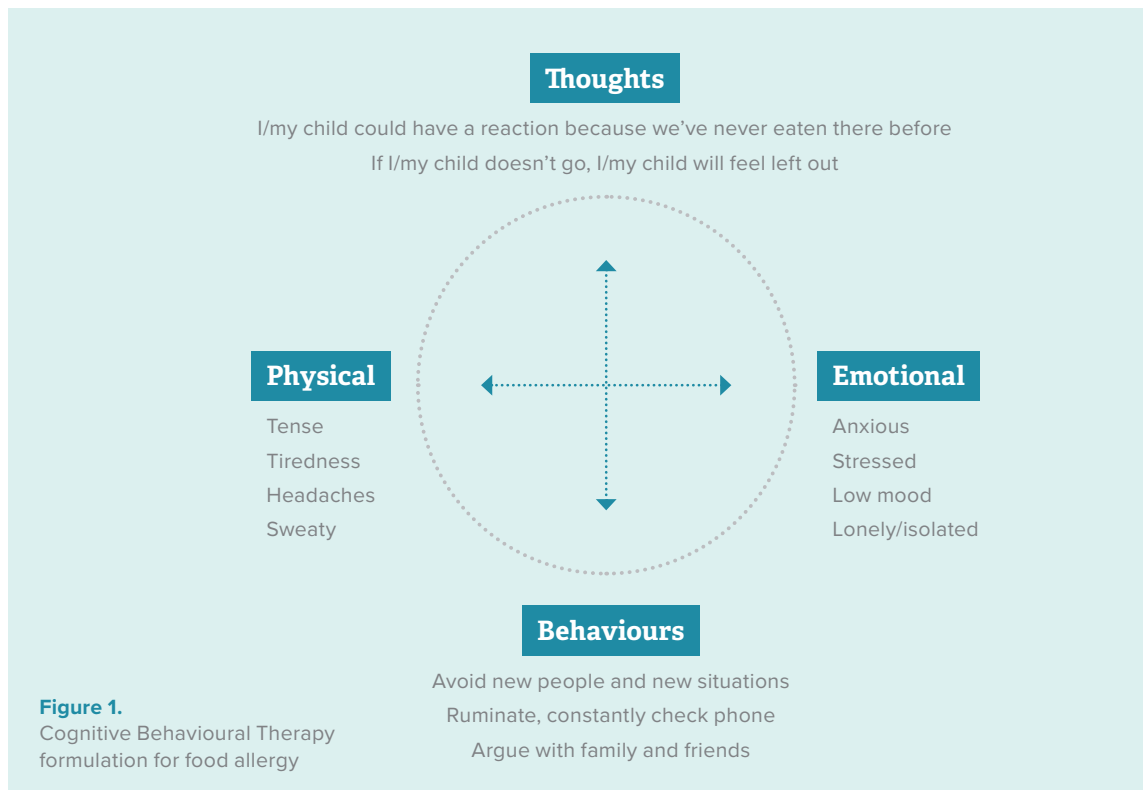


# Psychological interventions for patients, and their parents, with food allergy

## What are the psychological needs of individuals with food allergy and their families?

Living with food allergy (FA) is well documented to impair quality of life in childhood, adulthood and parenthood.<sup>1</sup> There are critical times throughout the FA life course which are likely to lead to greater psychological needs such as pre-diagnosis, during FA challenges, at time of diagnosis, throughout self-care regarding management and medication with transition periods (such as moving schools, going to university, changing hospitals and desensitisation), again leading to piqued emotional distress and subsequent need for support. These needs are observed in parents, with almost a third reporting anxiety and 17.5% depression prior to diagnosis,<sup>2</sup> which is unsurprising given the fact that the process for allergy diagnostics can be lengthy and challenging, often requiring multiple tests.<sup>3</sup> For the individuals experiencing the diagnostic journey first-hand, it can lead to distress in terms of facing fears even though this is within a secure environment, as well as the anticipation of having a reaction.<sup>4</sup> Furthermore a negative challenge was not always associated with reintroduction of the food showing the complexity of the experience for individuals with FA.

For some parents and individuals, this emotional distress is seen to subside after food challenges regardless of whether the outcome to the challenge was positive or negative.<sup>5-6</sup> We also see a greater impairment of quality of life in the adolescents who are allergic to multiple or ubiquitous foods,<sup>7</sup> in addition to higher levels of stress for these parents,<sup>8-11</sup> likely due to the increased responsibility, burden, guilt and worry in being able to competently care for their child's allergic needs.<sup>12-13</sup> Given the nature of allergy →



**Figure 1.**  
Cognitive Behavioural Therapy  
formulation for food allergy

management and a parent’s natural sense of responsibility for the wellbeing of their child, the ever present threat of anaphylaxis means that parents may feel safer managing the burden alone, with fears of “handing over” care to others further inhibiting their quality of life.<sup>14-16</sup> Parents who are instructed to maintain a high level of vigilance as a part of FA management may also experience anxiety and impose excessive restrictions on their child,<sup>17</sup> which causes concerns for parents when the child transitions towards independence as they experience a loss of control.<sup>18</sup> This has subsequent impacts on the child or young person leading to feelings of isolation,<sup>19</sup> with reports of exclusion and bullying not uncommon.<sup>20-21</sup>

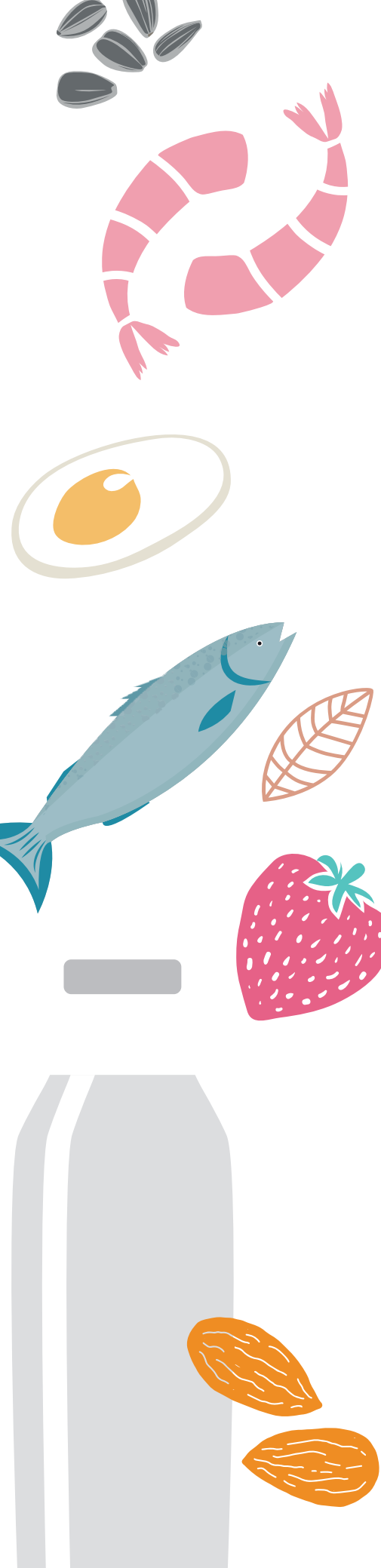
### What’s the current evidence-based for psychological interventions in food allergy?

Despite the above evidence, access to specialist psychological support is recognised as lacking<sup>1</sup>, as are evidenced-based psychological interventions for FA more generally.<sup>22</sup> Current evidence predominantly utilises Cognitive Behavioural Therapy (CBT) approaches, which is unsurprising given CBT is the recommended treatment in the UK for people experiencing low mood or anxiety,<sup>23-24</sup> and anxiety being one of the most common difficulties given the uncertain and unpredictable nature of FA. CBT approaches are almost exclusively focused on parents of children with FA, particularly mothers,<sup>17,25-26</sup> possibly given the fact that most FA is diagnosed

before the child turns five meaning FA management rests primarily with the caregiver. As parental anxiety has been identified as one of the risk factors of children developing anxiety disorders, it makes sense that recommendations have been made to address excessive parental anxiety and associated restrictive behaviours specifically for children with FAs in a bid to reduce transmission.<sup>27</sup> Current evidence shows some support for individualised and group CBT approaches utilising brief and intensive session contact for mothers.<sup>17,25-26,28</sup> At the time of writing, three further randomised controlled trials of manualised, online, group CBT for children aged 11-17 years with FA, adults and parents are currently being analysed.

### Why focus on Cognitive Behavioural Therapy for food allergy?

CBT aims to help individuals look at the different situations that they find themselves in, and enable these individuals to understand how their thoughts, physical sensations, feelings and behaviours interact. In CBT, the goal is not to never experience anxiety again, but to learn to manage distressing symptoms, have a more balanced perspective and to not let anxiety impair quality of life. With FAs, as with most long-term conditions, a certain level of anxiety, vigilance, and avoidance is adaptive as attuning to these keeps individuals safe. However, as demonstrated in some of the research documented above, that level of anxiety can become excessive leading to



impaired quality of life and unnecessary avoidance. People who experience anxiety are more likely to be hypervigilant meaning that they are constantly on the lookout for threat and danger. When both the psychological (such as feeling scared, worried or frightened) and the physical symptoms (such as increased heart rate, butterflies or sweating) are noticed, individuals find themselves questioning their ability to cope, and can make them feel more anxious. This is usually referred to as the vicious cycle of anxiety (Figure 1).

Whilst avoiding things (such as certain social situations), might help individuals cope in the short-term and lead to less anxiety in the moment, this doesn’t improve general feelings of anxiety and may contribute to longer term feelings of isolation, regret and sadness. By not challenging those anxious thoughts, individuals are unable to disprove their negative or catastrophic predictions. Safety behaviours also serve to keep anxiety going; individuals depend on them to make themselves feel better so they do not learn that distressing emotions (such as anxiety, worry and fear) will reduce and go away on their own.

### How does the current evidence meet the psychological needs of individuals with FA and their families?

In addition to the research on CBT approaches for parents of children with FA, other educational interventions were found to improve FA knowledge and management, though the impact of this on psychological wellbeing was not explored.<sup>29</sup> Given the lack of specialist psychological care available to those with FA or their parents, and the fact that the majority of people seek health information online, a review of freely available websites for coping with emotional distress related to food allergies has also been conducted.<sup>22</sup> This review identified 25 websites (less than half were aimed at children and young people or adults) and all targeted ameliorating anxiety and stress. Multiple strategies were recommended within the websites which were broadly categorised as problem focussed (e.g., managing or altering the person-environment relationship at the source of stress such as reading food labels, carrying adrenaline auto-injectors and making an emergency management plan) and emotion-focussed coping (e.g., regulating the stressful emotion such as normalising, thought challenging, positive self-talk). Possession of a written anaphylaxis management plan has been associated with a reduced number of reactions<sup>30</sup> and better self-care behaviours in adolescents<sup>31</sup>, but given the cross-sectional nature of these

studies, causation cannot be determined. Despite most of the problem solving suggestions making sense from a FA management perspective and unlikely to lead to harm, there is little evidence to support their impact on psychological well-being.

There is more evidence for the benefits of the recommended emotion-focussed coping approaches on well-being. Research suggests that nurturing helpful thinking, positive self-talk, and talking about food allergy as “manageable” rather than “deathly allergic” is associated with better emotional well-being.<sup>32</sup> Again, none of these approaches have been explored using experimental methods. Other websites promoted elements from CBT, which we see from the above have some benefit in reducing anxiety in mothers of children with food allergy; however, there remains a current lack of evidence in adult patients or fathers.<sup>17</sup> Other emotion-focussed suggestions included membership of patient support groups, for which there is some encouraging evidence in both young people<sup>31</sup> and parents<sup>17</sup>, but again results are associative. Whilst these websites are freely available to access and could be a starting point in which to signpost individuals or their families who may be struggling with distress related to their FA, a recent trial of a self-help website for improving parent outcomes showed no benefit though subgroup analysis showed some evidence of effect for those with highest levels of depression at baseline.<sup>33</sup>

### What needs to change to better support the psychological needs of individuals affected by food allergy?

As demonstrated, evidenced-based psychological interventions do exist for parents of children with FA and show some benefit; however, services are under-resourced to deliver these. Research has shown that therapists with no previous experience of delivering CBT can be trained in specific interventions and reach acceptable levels of competence quickly.<sup>34</sup> Models of service provision should be evaluated where allied health professionals working with individuals with allergy are trained in these interventions before subsequent pragmatic evaluation of effectiveness on both psychological wellbeing and cost are carried out.

Whilst CBT is the predominant approach for anxiety and provides the greatest evidence-based treatment related to those with FA, the original assumptions of CBT might not →

fit the needs of all clients and so alternative psychological approaches should be considered. At the time of writing, a randomised controlled trial of mindfulness for parents of children with FA is currently in preparation for publication. Diverse interventions are likely to be required to ensure suitability for specific subgroups of individuals with FA and their families. Whilst there are a number of freely available online resources which individuals who are struggling with the emotional aspect of FA may find useful, and could be signposted to, there is no robust evidence to support their effectiveness on psychological well-being. These resources may prove normalising to some, reduce feelings of isolation and improve self-care behaviours, and are unlikely to cause harm in the absence of more intensive support.

In conclusion, the detrimental impact of FA on various aspects of daily living and subsequent psychological well-being is well recognised. However, there is a paucity of access to specialist psychological care and high-quality research evaluating interventions to support all individuals affected by FA and their families. Although limited, the evidence provides an indication that further support in the form of CBT could offer parents, especially mothers, some benefits. The reviewed research suffers from methodologic constraints, which limit the validity of reported outcomes. Future research needs to develop and evaluate a range of accessible, psychologically-informed resources which utilise existing staff within allergy care teams. Research should be holistic in nature, whereby educational and practical information together with psychological awareness of FA is assessed in order to determine the overall impact on well-being. 🙌



**DR CHRISTINA JONES**  
Associate Professor in  
Clinical Health Psychology,  
University of Surrey



## References

1. Knibb RC, et al. Psychological services for food allergy: the unmet need for patients and families in the United Kingdom. *Clin Exp Allergy*. 2019;49(11):1390-1394.
2. Knibb RC & Semper H. Impact of suspected food allergy on emotional distress and family life of parents prior to allergy diagnosis. *Pediatr Allergy Immunol*. 2013;24(8):798-803.
3. Akeson N, et al. The psychosocial impact of anaphylaxis on young people and their parents. *Clin Exp Allergy*. 2007;37(8):1213-20.
4. Strinnholm Å, et al. Reintroduction failure is common among adolescents after double-blind placebo-controlled food challenges. *Acta Paediatr*. 2017;106(2):282-287.
5. Zijlstra WT, et al. Parental anxiety before and after food challenges in children with suspected peanut and hazelnut allergy. *Pediatr Allergy Immunol*. 2010;21(2 Pt 2):e439-45.
6. Knibb RC, et al. The psychological impact of diagnostic food challenges to confirm the resolution of peanut or tree nut allergy. *Clin Exp Allergy*. 2012;42(3):451-9.
7. Protudjer JL, et al. Impaired health-related quality of life in adolescents with allergy to staple foods. *Clin Transl Allergy*. 2016;30;6:37.
8. Warren CM, et al. Quality of Life Among Food Allergic Patients and Their Caregivers. *Curr Allergy Asthma Rep*. 2016;16(5):38.
9. Howe L, et al. What affects quality of life among caregivers of food-allergic children? *Ann Allergy Asthma Immunol*. 2014;113(1):69-74.e2.
10. Ravid NL, et al. Mental health and quality-of-life concerns related to the burden of food allergy. *Immunol Allergy Clin North Am*. 2012;32(1):83-95.
11. Springston EE, et al. Variations in quality of life among caregivers of food allergic children. *Ann Allergy Asthma Immunol*. 2010;105(4):287-294.
12. Aika S, et al. Food allergy response capabilities of mothers and related factors. *Nurs Health Sci*. 2017;19(3):340-350.
13. Klinnert MD & Robinson JL. Addressing the psychological needs of families of food-allergic children. *Curr Allergy Asthma Rep*. 2008 May;8(3):195-200
14. Knibb RC, et al. Parental self-efficacy in managing food allergy and mental health predicts food allergy-related quality of life. *Pediatr Allergy Immunol*. 2016;27(5):459-64.
15. Williams NA & Hankey M. Support and negativity in interpersonal relationships impact caregivers' quality of life in pediatric food allergy. *Qual Life Res*. 2015;24(6):1369-78.
16. Gupta RS, et al. Food allergy knowledge, attitudes and beliefs: focus groups of parents, physicians and the general public. *BMC Pediatr*. 2008;19:8-36.
17. Sugunasingha N, et al. Interventions for caregivers of children with food allergy: A systematic review. *Pediatr Allergy Immunol*. 2020;31(7):805-812.
18. Stensgaard A, et al. Peanut allergy as a family project: social relations and transitions in adolescence. *J Clin Nurs*. 2017;26(21-22):3371-3381.
19. Jones CJ, et al. Exploring what motivates and sustains support group engagement amongst young people with allergies: A qualitative study. *Clin Exp Allergy*. 2018;48(9):1195-1205.
20. Dean J, et al. Disclosing food allergy status in schools: health-related stigma among school children in Ontario. *Health Soc Care Community*. 2016;24(5):e43-52.
21. Fong AT, et al. Bullying in Australian children and adolescents with food allergies. *Pediatr Allergy Immunol*. 2018;29(7):740-746.
22. Vreeken-Ross SC, et al. A review of freely available online support for food allergy-related emotional well-being. *Clin Exp Allergy*. 2021;51(7):942-946.

23. National Institute for Health and Clinical Excellence (NICE). Depression in adults: recognition and management [CG90]. 2009. <https://www.nice.org.uk/guidance/cg90> Accessed July 2022.
24. National Institute for Health and Clinical Excellence (NICE). Generalised anxiety disorder and panic disorder in adults: management. [CG113]. 2011. <https://www.nice.org.uk/guidance/cg113> Accessed July 2022.
25. Vreeken-Ross SC, et al. Feasibility of an online CBT group intervention for parents of children with food allergy. *Clin Exp Allergy*. 2021;52:171-175.
26. Boyle RJ, et al. A brief psychological intervention for mothers of children with food allergy can change risk perception and reduce anxiety: outcomes of a randomized controlled trial. *Clin Exp Allergy*. 2017;47(10):1309-1317.
27. Manassis K. Managing anxiety related to anaphylaxis in childhood: a systematic review. *J Allergy (Cairo)*. 2012;2012:316296
28. Knibb R. Effectiveness of cognitive behaviour therapy for mothers of children with food allergy: a case series. *Healthcare*. 2015;3(4):1194-1211.
29. Wahl A, et al. The evaluation of a food allergy and epinephrine autoinjector training program for personnel who care for children in schools and community settings. *J Sch Nurs*. 2015;31(2):91-98.
30. Ewan PW & Clark AT. Efficacy of a management plan based on severity assessment in longitudinal and case-controlled studies of 747 children with nut allergy: proposal for good practice. *Clin Exp Allergy*. 2005;35(6):751-756.
31. Jones CJ, et al. Factors associated with good adherence to self-care behaviours amongst adolescents with food allergy. *Pediatr Allergy Immunol*. 2015;26(2):111-118.
32. Knibb RC & Horton SL. Can illness perceptions and coping predict psychological distress amongst allergy sufferers? *Br J Health Psychol*. 2008;13(1):103-119.
33. Sugunasingha N, et al. Evaluating an online self-help intervention for parents of children with food allergies. *Pediatr Allergy Immunol*. 2022;33(2):e13731.
34. Vickers B, et al. Therapy competence in delivering a brief cognitive behavioural therapy intervention to reduce maternal anxiety associated with child food allergy. *J Child Health Care*. 2019;23(3):446-457.

## Continued Professional Development

- What resources are you aware of that might support the psychological needs of patients and their parents with food allergy?
- How can you ensure better signposting to psychological support in your day-to-day practice?
- What simple strategies might you be able to put in place to ensure the psychological needs of patients and their parents with food allergy are acknowledged?

