

Living with severe food allergy

Kathryn Evans and Khadj Rouf look at the psychological challenges for children and parents

The prevalence of food allergy has increased with growing numbers of children being diagnosed with allergies to foods such as peanuts, milk, egg and fish. Whilst many children grow out of these allergies, some people will have this condition for the rest of their lives. Severe food allergy can have catastrophic health consequences, and so has to be managed carefully.

Much of the management of allergy focuses on the medical aspects. However, the implications of having severe allergy are wider than this. There is a modest literature on the psychosocial impact of living with allergy, but relatively little has been published about how allergies impact on parents and the wider family network.

Food is central to our lives. Our survival depends on what we eat and our nutrition is inextricably linked with our overall health and well-being. Our communities use food to mark celebrations, rites of passage and religious festivals. Birthday parties, weddings, funerals, holy days: there is always food in there somewhere, and it is the social glue that can bind us together.

So what is the impact on social and family life, when a child is diagnosed with severe food allergy?

We write from a professional and personal perspective on this issue. We are both clinical psychologists and mums of children with severe food allergies. We'd like to raise the profile of this issue, and to suggest that psychologists have a key role in helping children, young people and their families cope with the challenges that can be posed by living with food allergy.

A problem on the rise

The profile of food allergy has increased in the last few years. There is better awareness of food allergy now, though the day-to-day use of the term 'allergy' is often unclear; sometimes people think they have an allergy, when they are actually talking about food intolerance (which is a milder reaction to food substances). It's important to be clear what a severe allergy can mean as it can have potentially devastating health consequences, and can be life-threatening for some. Allergic response involves a heightened and exaggerated immune response to a substance that for most

people is not an allergen. Severe allergic reactions can be life-threatening in several different ways (e.g. in asthma, there is marked bronchoconstriction), and even if not life-threatening can trigger problems, such as a flare-up of eczema leading to infection.

Severe or true food allergy affects around 6 to 8 per cent of young children (Cummings et al., 2010; Teufel et al., 2007) and 1 to 4 per cent in adults (Teufel et al., 2007). The common food allergens in the UK are peanut and tree nuts, cow's milk, sesame, shellfish, fish and eggs. There has been an increase in diagnosed food allergies in recent years and an increase in admissions to A&E with severe reactions to food (De Blok et al., 2007; Sheikh & Alves, 2000). This can lead to anaphylactic shock: a severe and rapid onset allergic response, which can result in circulatory collapse, coma and death (Mandell et al., 2005). Signs of severe reaction can include rashing or hives anywhere on the body, a sense of impending doom, swelling of throat and mouth, vomiting, difficulty breathing, a drop in blood pressure and loss of consciousness.

The reason why there has been such an increase in allergies is unclear. Different theories abound, such as lifestyle changes, and environmental factors, but there is no conclusive answer. Neither is there currently a cure for food allergy, so avoidance of allergens is recommended. Treatment for allergic reactions is needed quickly, and involves the use of anti-histamines and adrenaline (EpiPens). Many children will grow out of allergy, but for some the condition will be life-long. There is some promising research around developing tolerance to known allergens through graded exposure, but this research is still in its infancy. The psychological and social impact of living with a severe food allergy is not fully embedded into allergy care; hospital clinics usually solely focus on the physical aspects of managing this condition – for example, assessing levels of histamine reactivity, training on how to use the EpiPen.

question

What are parents' experiences of having a young child with severe allergies to food?

resources

www.anaphylaxis.org.uk
www.allergyUK.org
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In the meantime, many people with severe allergies and their families are forced to adapt quickly to living with this chronic condition. Having food allergy involves being well most of the time if certain restrictions are adhered to, but there is the potential to become very seriously ill. A crisis such as an anaphylactic reaction or a significant allergic reaction is traumatic for everyone and can bring additional challenges. Parents and children can be left feeling anxious and traumatised by the allergic reaction, by the memories of it and the fear of it happening again; in more severe cases, a parent may have seen their child nearly die.

Such trauma can mean an enormous shift in many aspects of normal life involving food. So does psychological research offer anything in the way of comfort and support?

Impact on quality of life

Food allergy has been repeatedly shown to have a significant and continuing impact on the daily activities and quality of life of children and their families (Marklund et al., 2007). This review concluded that several domains of quality of life were affected including emotional issues, family and social activities and the family economy (as a high percentage of food allergic young adults do not work).

Another review also found that food allergy can impact upon quality of life for sufferers and their families. Cummings et al. (2010) said that there is poorer quality of life for people who have a larger number of food allergies combined with other atopic diseases, like asthma, and have suffered a large number of previous reactions. Bollinger et al. (2006) found that many caregivers said that the impact of a child's food allergy meant there were challenges around family



'My allergy will still be there'

When I was younger, I felt it wasn't fair to have an allergy and it made me cry. Now I'm older, I realise that crying doesn't help anything because my allergy will still be there. It won't go away if I complain, so I might as well get on with my life. Hopefully, one day there will be a cure.

Sometimes at school, if the teachers give out sweets or other kids bring food in, then I feel left out. Sometimes when you meet new people, they don't understand how important

my allergy is, and they might joke about it. I feel more OK about having an allergy now. When you think about it everybody is unique, so you can't compare yourself to everybody else all the time.

Sometimes I feel annoyed with companies for adding milk into foods when they don't need to, or if there aren't proper ingredients (labels) on foods.

Sometimes it feels like parents are overreacting with the whole allergy, 'life on the line' part. But I can see if you are too lax then

something is more likely to happen, but it is better not to be too protective. I feel OK about carrying my medical kit with me – it's not a big deal now.

It can be good that I get sweets that other people like too. There are times when we have eaten at vegan restaurants and the food was amazing. I know my allergy has affected what everyone in my family eats. I wonder if we eat more healthily because of it. I can't imagine my life without allergies. *Khalil, aged 12*

social events, field trips, parties, sleepovers and socialising with friends. Many parents found ways to participate, but it was anxiety-provoking, and some parents avoided some activities.

Impact on mental health

Researchers have highlighted a lack of focus on the psychosocial implications of allergy and impacts on mental well-being, such as risk for becoming over-anxious (Teufel et al., 2007).

When parents experience a more intense, persistent anxiety this could lead to unhelpful responses to perceived risks; for example, modelling avoidance or inadvertently reinforcing the child's anxious behaviour, which increases the child's vulnerability to develop anxiety (Le Bovidge et al., 2009). However, James (2001) and Mandell et al. (2005) point out

that a certain level of anxiety is adaptive as it can lead people to take precautionary measures and motivate them to carry their EpiPens.

An American study of food allergic young adults found that young people who had experienced anaphylactic reactions were more worried, and their parents were more protective, than allergic people who had not had severe reactions. Other than this, there were no differences between the allergic and non-allergic young people in their mental health (Herbert & Dahlquist, 2008).

Impact of developmental stage

How the sufferer and family adjust will change over time, as people become more confident about adaptations and as children reach different developmental stages (Cumming et al., 2010). Living with risk means that developmental milestones may well pose additional challenges (such as a child managing their own medical kit, the young person feeling confident enough to be assertive about asking about food preparation, taking protective measures when out at parties, etc.). Attitudes towards the allergy can affect psychological adjustment as with other chronic health conditions (Le Bovidge et al., 2009), and it is important that this is assessed over time as it is not a static process. Allergic incidents do happen, which naturally raise anxiety for all.

Impact on parents

There may also be gender differences in how parents manage their child's allergy.

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Cummings et al. (2010) suggest that the burden of responsibility for allergy management falls mainly on mums. There is mixed evidence about whether this can lead to marital strain or actually help greater family cohesion, but certainly the psychosocial well-being for mums may be more heavily affected. Mums may feel responsible for controlling triggers and for vigilance, having to carry the idea that they may have to deal with unexpected reactions.

We supervised Dr Loretta White's study for her clinical doctorate looking at what it's like to live with a young child with severe food allergy. We were interested in how this impacted on family relationships and managing the challenges associated with severe food allergy (Rouf et al., 2012). We had hoped that both mums and dads would take part, but only mums came forward. All of their allergic children were five-years-old or under, and diagnosed with a severe allergy. Three major issues emerged from the interviews:

- l Adjusting and re-establishing an 'even keel'
- l 'It's a big responsibility': Living with risk
- l 'Try to keep things normal': Identity and relationships

Mothers in this study shared similar concerns to mothers of children with other chronic illnesses. We recommended that the experience of allergy should be viewed in the wider family context, with specific consideration given to parental coping and anxiety

Day-to-day life with food allergy

Of course, our interest in this area sprang from personal experience. As psychologists, we observed the gap between empirical research and our own lived experience as parents of children with allergies. We feel fortunate that our clinical training, and experience of qualitative research, gave us grounding in reflexive practice. This means owning one's position (rather than claiming that there is absolute neutrality) and carefully observing and reflecting upon experience (e.g. Smith & Osborn, 2003). We believe this can lead to helpful and humane clinical practice. This section moves from empirical data, to observations and reflections on what it means to live daily life with allergy. It is based on research,

anecdote and observations, to illuminate the lived experience of having a child with food allergy.

Friendships

Living with food allergy impacts on social life, and part of this is likely to be mediated by how confident allergy sufferers and their families feel about allergy being taken seriously and managed carefully. It's common for parents to worry about their child feeling different, or being ostracised. One parent's child was made to sit on a different table at lunchtime, away from other children, because of school concerns that the child would have a reaction. This certainly echoed our qualitative findings that parents were trying to keep things as

normal as possible for their children.



Identity and self-confidence

For the child themselves, living with a severe allergy can impact upon their identity and how others view them.

Children may have to deal with unhelpful and hurtful comments, such as being the child who is 'allergic to everything', and not being invited to parties

because of other people's worries about managing risk. Children may feel upset about feeling different, or excluded from peer-group activities, which can be corrosive to self-confidence. As one parent commented, 'He's a normal boy that can't eat nuts, he's not a walking nut allergy that happens to be a boy.'

Accidental reactions and unpredictable triggers

Exposure to food allergens is a common risk for people with food allergy, and accidental ingestion of critical foods can occur, especially if others do not realise the severity of the potential reaction. Sufferers have to adapt through avoidance of allergens; taking care to avoid cross contaminations of foods; carefully and consistently reading food labels; and often facing limits on social activities where food is involved (or sometimes not going at all).

The unpredictability of reactions can lead parents to feel anxious about how to help and support their child.

Unpredictability of what is safe to eat can be distressing for the child. Again, this echoes the theme of living with risk, and how managing that risk can feel like a weighty responsibility.

Trust and safety

The most common times for accidental exposures are when people are out of their familiar environment or routine, when people are unaware that a person has allergies, being abroad where there are potential language barriers to checking that food is safe, or eating out when others have prepared food. Negotiating these challenges can be hard, both for the sufferer and their family. As parents, there are negotiations to be had with pre-school, child-carers and school, not to mention wider family and friends. It's important to have trusted places to eat with adults who understand and take responsibility.

It is a common observation, that even having explained which allergens are dangerous, others may prepare or buy foods that are still unsafe. For instance, the well-meaning person who buys a gluten-free cake, when actually the dangerous allergen is milk.

Letting go

There are also challenges in handing over more information about the allergy and responsibility to the child in a developmentally appropriate way. This also has to be done sensitively, to promote a sensible way of managing risks, whilst bearing in mind that accidental exposure to allergens could lead to potentially catastrophic health consequences. Letting go can be complicated by previous experiences of witnessing frightening reactions, and it can be hard to establish that even keel again.

Our reflection is that children often tell their parents when it's time to hand on more responsibility to them. One child went to a school event, having been briefed not to eat anything offered to him. However, he triumphantly came out of school with a bag of half-eaten jelly babies, having read the ingredients, patch tested his own skin and taken a nibble to make sure it was safe.

Having to persistently communicate There is a common misconception that the reason a severe reaction may not have happened recently is because the allergy is improving. The reality is that behind the scenes, confident and persistent communication is required, ongoing dialogue and anxiety management for oneself and for people involved in the child's life, together with a high level of

vigilance. If a serious incident has not occurred in a while, it can lull a child's wider network (e.g. grandparents, teachers, friends, etc.) into a false sense of security about needing to be so vigilant. This can lead to higher anxiety in the child's parents and carers, who may feel they have to shoulder all the responsibility for ensuring sustained attention to allergy management.

What psychology can offer

It is our view that psychology has some potential solutions for the day-to-day challenges of living with allergy. Services could be developed to better meet the psychological and social needs of those affected by allergy. There appears to be a gap in services for families living with severe food allergy: it is a relatively recent specialisation in medicine, and specialist advice can be hard to access. Allergy clinics naturally have a medical model, with a focus on the child's physiological reactions to certain allergens and on training in medical management. The psychological needs of allergy sufferers may not always be addressed; even though NICE guidance on the management of allergy refers to patient-centred care, there is not an explicit acknowledgment of the emotional and psychological needs of the patient, or their carers (see NICE, 2011). Allergy can be lifelong, and developing psychological services for this population would fit well with the proposed expansion of IAPT services to help people with long-term medical conditions.

This could help to improve current provision; the psychological and social impacts of allergy are not normally part of the care package. Families can be left feeling unsupported or that they are being overly anxious. Yet, research has shown that parental coping is critical in the young child's risk perceptions of allergy, anxiety and coping over time (DunnGalvin et al., 2009). Psychologists can help to think about allergy not just as a medical issue, but as a family and social issue. It's important to create supports for parents and to develop positive coping strategies across the family network.

An assessment of the child and family's attitudes towards the allergy would help to identify factors that could benefit from psychological intervention as well as building on strengths and resilience. Psychologists are well placed to support families in teaching children the skills they need to manage life with a potentially long-term condition. Such skills form important scaffolding for confidence and good self-esteem. This could include

learning assertiveness skills through role play, to help children to politely turn down unsafe foods, feel confident about asking about ingredients and saying 'no' to unsafe situations (e.g. some alcohols may contain traces of allergens such as sulphites, fish, casein or egg). Developing one's own resources and resilience is a crucial life skill, whether it is creating personalised cookbooks, learning to recognise safe and unsafe foods, taking a positive view of the condition or learning how to manage social activities.

Psychoeducation can address some of the problems around identity development for children, and also help others understand and manage risks for allergic children in developmentally appropriate and proportionate ways. For instance, teaching children about what allergy is and is not, so that it is taken seriously. Helping children and families understand that it is no one's 'fault' that it has happened. It is helpful to discuss the meaning of having an allergy, and again focus on resilience skills. A fear of being negatively labelled is an important theme for children and their families. Again, learning to accept and adjust to having a medical condition is key to feeling okay about being different to others in that respect. Learning to 'spot the difference' can help children and young people understand that most people feel different in some way, and that difference can have its strengths.

Psychological interventions can also support children and their families across developmental stages. Letting go is a theme that has emerged from research, and from our own experience. This is a complicated negotiation based on a child's age, understanding, level of risk and the ability to feel confident in others. There is a gradual shift towards the child taking more responsibility for self-management. Children need to learn to prepare for new challenges, such as managing their own medical kit and knowing how to use an EpiPen. They may need to carry a safety card or medical alert bracelet. Children need to feel they can carry their medical kit without embarrassment. There may also be social dilemmas, such as telling friends about the allergy, and training those peers to recognise signs of a severe reaction

and administer the EpiPen if needed.

This handing over of responsibility is crucial for a child's healthy emotional development, but it also rests on having a supportive network of wider family, friends, peers and professionals. This is what can lend parents the confidence to rely on others to carefully manage the child's allergy, especially when they are very young. Parents can experience anxiety that can potentially impact upon attachment relationships. Some feel traumatised by having witnessed severe reactions. Offering space to talk, and evidence-based help, can be very important to help the family keep on 'an even keel'.

Psychological approaches can consider and involve the wider system, including grandparents, friends and schools so that there is a holistic understanding of the impact for the young person and their family and the domains in which they live, work and play.

Psychology can play a role in training other professionals to be psychologically aware of issues facing children with food allergy at school. Ensuring that there are clear school plans in place is critical, and schools have a massive role to play in making sure that children do not feel socially excluded because of their health. Linking with positive networks is vital, such as those offered by the Anaphylaxis Campaign, who offer support to parents, children and teenagers. These strategies can lead to the kinds of good understanding, communication and relationships that allow children and their families to adjust well in the face of this health condition.

In sum, serious food allergy poses challenges to children and their families. These are not insurmountable problems, with the right balance between medical advice, treatment and recognition of the psychosocial impacts of living with this condition. There is a rich seam here for research, and for the psychological aspects of care to be developed. The government's agenda on improving psychological help for people suffering with chronic health conditions would be an opportune time to make sure help for allergy sufferers is placed firmly on the agenda.



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