

The psychological impact of anaphylaxis: advice and coping strategies for people affected

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Background

Anaphylaxis is a severe and potentially life-threatening allergic reaction. Symptoms can start within seconds or minutes of exposure to the food or substance you are allergic to and usually will progress quickly. The fact that anaphylaxis can be serious and unpredictable can place a heavy burden on those affected, and on their families and friends. The constant vigilance required and the possibility of being in a life-threatening situation means there is often intense anxiety associated with many daily activities.

This factsheet aims to outline the potential psychological effects of anaphylaxis and offer advice and coping strategies to individuals and families. We also hope it will be useful to clinicians and healthcare professionals in their work with people at risk of anaphylaxis.

Getting advice and information

In our experience, the extreme anxiety that some people with allergies feel is caused by the lack of reliable, high-quality information. Once they have a clear understanding of the symptoms of anaphylaxis, and know how to treat them, they find themselves in control and this can reduce anxiety. Where the allergy is triggered by food, learning how to avoid the culprit allergen also helps them manage their condition successfully and stay safe.

Therefore, it is important to obtain high-quality guidance from a medical professional. Seeing your GP is a first step. You may be referred to an allergy clinic and/or a dietitian.

You can also find a wealth of information on the Anaphylaxis UK website, including fact sheets that will help you understand allergies to various foods and other allergy triggers. Follow the links

near the end of this factsheet.

Remember, if someone in your family has a severe allergy, the other people around them also need accurate, reliable information about it – such as friends and people at school or in the workplace.

Contents

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Psychological impact of anaphylaxis on young children

When a young child suffers the trauma of anaphylaxis, life is never quite the same again for the whole family. This is particularly true if the allergy is triggered by food, as eating is an essential daily activity and finding safe food becomes a regular challenge.

Unfortunately, anxiety felt by the child's parents and other family members may be communicated to the child, and that child may grow up with a fearful disposition.

This section has been written primarily to help parents and other family members to support their allergic child to manage their allergies with confidence.

Keeping calm

Your child may be quick to pick up on any anxiety you feel. To reduce your own anxiety, become well-informed on the subject of allergies. Find reliable sources and be suspicious about

information you see on social media sites.

You can help to guard against your own anxiety being passed on to your child. When you tell others about your child's allergies:

- Be matter-of-fact. Keep calm and be aware of the tone of your voice and the unspoken messages you are sending your child when you talk about allergies.
- Be careful of the language you use when you talk about the risks. Although it's important to convey the seriousness of the situation, constant references to death will not help.
- Involve your child when passing on information to others. Avoid talking about your child's allergies as if he or she is not present.
- Remember that the aim is to help your child to feel able to handle people and situations. Be careful not to instill panic or fear, which may stifle and overwhelm your child.

Handing over responsibility

Although it may be tempting for you to ask questions and read food labels on behalf of your child, remember that you are building for the future. Patience is important. Helping your child to avoid their problem allergen from an early age (for example, by teaching them how to read food labels) will prepare them for the months and years ahead. Furthermore, letting them know they have a say in decisions will give them the confidence to speak up and ask questions.

Try to encourage a gradual shift towards your child taking more responsibility for management of their allergy. Involve them in discussing their allergy appointments and encourage them to prepare any questions they have for the doctors, nurses and dieticians in advance. Children need to learn to prepare for new challenges, such as managing their own medical kit and knowing how to use an adrenaline auto-injector. Children need to feel they can carry their medical kit without embarrassment.

When you are planning to eat out, involve your child by researching menus online together and discussing options available on the menu and what questions to ask at the restaurant. You could call ahead to the restaurant and let your child know you have done this.

You could invent 'role play' games for your child by practising communication with others – for example, how to order food safely when you eat out or how to talk about allergies at a friend's house or a party.

Creating a written care plan together with your child can be a great way to help them understand their allergy and have more confidence. The care plan could include what they are allergic to, recognising the symptoms that may occur, and what they should do if a reaction happens.

Education is essential to empower your child to have the confidence to tell others what they are allergic to and to discourage sharing of food. Ideally you want to raise a child who asks questions and makes independent decisions, regardless of pressure from friends and acquaintances. A child with a positive attitude will have fewer problems. To achieve that, it is important to begin early to lay the groundwork.

Social occasions

In our experience, some parents are unwilling to allow their allergic child to attend social events, school trips and parties because of concerns about the risks. But if a child's social life is restricted unnecessarily, they may grow up feeling isolated and different to other children. This may affect their healthy development.

Social occasions and school trips simply need planning and forethought. Communication is essential among all those concerned. Sensible steps can be taken to ensure that your child only eats food that is safe. At children's parties, for example, this may mean that your child should take their own party food.

Be patient with yourself about handing over control to other family members and friends. It can feel like a huge and overwhelming step to trust another person to look after your child. It is important to do it in a way that helps you feel confident and assured. This can be done by firstly explaining your child's allergies to friends and family, then supervising them with regards to food for your child. Eventually, when you feel at ease, you can leave your child with them for dinner. In our experience, many parents who have made these steps are surprised at how accepting and willing others have been to accommodate their child's needs.

It is important to be proactive when educating your friends and family about your child's allergies. It is best to face this early on in your child's diagnosis to ensure that you feel supported, and that your child doesn't miss out on important social opportunities.

School and preschool issues

The first day of preschool or school can be a daunting time but it can really help you to face your

fears. Through it you can learn that other people can understand about good allergy management and keep your child safe.

Once again, the key factors to consider are information and communication. School staff need to be well-informed about what your child is allergic to, the signs of an allergic reaction, and how to treat it. Arranging a meeting with key staff to pass on all the relevant information is vital. This will help you to remain calm and confident when your child is at school or preschool.

The following Anaphylaxis UK factsheets may be helpful to you:

- Frequently asked questions in schools
- Guidance for parents and carers of children in early years settings

See the links near the end of this factsheet.

Bullying

Bullying – in or out of school – can result in emotional distress, isolation, reduced self-esteem, anxiety and depression. We receive occasional reports via our Helpline of bullying towards children with allergies, particularly in schools. This may be due to other children having a lack of awareness or understanding of allergies.

We recommend that schools educate all pupils about allergies and take a serious view of ‘allergy bullying’ as they would with all bullying. All state schools must have a behaviour policy in place that includes measures to prevent bullying. This policy is decided by the school. All teachers, pupils and parents must be told what it is.

As a parent, it is important to encourage your child to include their friends in their allergy management. This will help if someone tries to tease them, pick on them, or bully them about their allergy.

There are occasions when adults set the scene for bullying by excluding children with allergies from activities enjoyed by everyone else. They are sending a message to all the children that it is okay to exclude children with allergies. And it sends a message to the child with allergies that they are not worth including. We believe many children with food allergies are bullied at school because of this behaviour. Children with allergies deserve to feel safe and that their well-being is important to the adults in charge. They deserve to have their basic needs for safety and inclusion met.

Communication is important. Ask your child's class teacher if there are any activities planned which might be risky for your child and ask if it is possible to find alternatives to ensure they can still join in. If treats are given out at school, you could give your child's teacher their own treats that are safe.

If you do suspect your child is being bullied but they don't feel ready to talk about their worries, there are strategies that could help. Making a "worry box" is one idea. Encourage your child to write down what they are worried about on small pieces of paper throughout the day and then post them into the box. Schedule in a regular time each week to sit down with your child and discuss the worries. If the talking helps, the worries can be taken out of the box and thrown away. If not, it needs to go back in the box for you to look after. The worry box may help your child to reach the point where they find sharing their worries much easier.

Role playing with your child can also be helpful. You could act out scenarios that may occur at school or clubs involving food and practising what your child might say if someone teases them about their food or their allergies. You could also discuss steps to take if bullying occurs: that is, who they should speak to and how to handle the challenging situation. This helps children feel more prepared and in control.

Handling difficult people

Your child will have to face difficult people and challenging situations from time to time. Teach them how to cope with this. For example, they may need to handle situations that arise in restaurants or at a friend's house. Calmly discuss how to manage these problems.

When a difficult situation arises, your priority is to give your child a sense of accomplishment and control but be ready to step in if necessary. Don't wait until the child feels defeated before helping out. Do so discreetly and give control back to your child once the situation is cleared up. Make sure they know you will back up their decision to say 'no' to eating a new food or something they are not confident about.

Difficult situations will arise when you are not present. Teach your child how to politely but firmly refuse certain foods. Explain that there will always be people that don't "get it," so it's up to your child to take responsibility for avoiding risky foods. Again, role playing challenging situations at home is a great way to practise what to say and how to say it.

Other tips

- You could consider writing down any questions your child has, discuss them together, and fill in the answers using their own words. You could even draw pictures.
- Consider writing down your experiences together – “My Allergy Journey”. Starting from when they were first diagnosed, draw pictures on a timeline to help them see how the allergies have changed and developed over time.
- Encourage your child to be interested in their food by doing cooking together.

Getting further help

Speak to your GP or allergy specialist if your child seems to be particularly affected by anxiety or worry. They can refer you to any specialist services for children in your area that might be able to provide some support and reassurance.

Psychological impact on teenagers and young adults

If you are the parent of a teenager or young adult with a severe allergy, you may face a different set of problems to those that arise with younger children.

In our experience, many teenagers and young adults lack confidence in managing their allergies and find it difficult to speak up for themselves for fear of embarrassment (e.g. in restaurants). For others, the anxiety about having a severe reaction leads them to avoid social situations unnecessarily. Some restrict their food beyond what is healthy, adversely affecting their weight and nutrition. Some people with allergy to insect stings avoid all outdoor activities.

On the other hand, some admit they take risks. They know they should carry their prescribed medication but forget it when they go out or choose to leave it at home, particularly if they don't expect to eat anything. Adjusting to a diagnosis of allergies is understandably difficult and feelings of unfairness may lead them to eat food they are allergic to. Some are so frustrated with “may contain” labelling that they choose to ignore it.

Allergic children who are supported to cope in their early years will reap rich rewards when they become teenagers. However, there are bound to be some for whom the problems of having an allergy are difficult, even overwhelming in some cases.

Talking to others in the same situation is likely to help. Anaphylaxis UK has set up a closed

Facebook page, where 18-25 year olds can chat about allergy issues. This is regularly monitored to ensure the posts are helpful and accurate. Follow this link and then click on “Join group”:
<https://www.facebook.com/groups/acyoungsupportgroup/>

In our view, teenagers and young adults should be shown respect in their need to make their own decisions. For example, they should have the opportunity to attend their medical appointments without you.

If you have a teenager who is afraid of social situations, or restricts their food intake unnecessarily, you could help them to gradually expose themselves to the feared situation. In this way they will learn that nothing dangerous is likely to happen. Anxiety reactions can mimic allergic reactions, so it is important for your child to know which is which.

If social situations are a problem for your teenager, you could invite a best friend around to your house for tea as a first step. After a while their confidence may increase, so that eventually they will be ready to stay at a friend’s house. Although this may trigger anxiety initially, it may lead to your child gaining in confidence and their anxiety may recede.

Tips on how to support children after a severe reaction

A serious allergic reaction is traumatic for everyone. Parents and children can be left feeling very anxious by the memories of the incident. Such trauma can mean an enormous shift in many aspects of normal life involving food.

Neither children nor adults will benefit from repressing the memories of an event. In the case of children, their fears and fantasies can be more frightening and disturbing than the truth. Young children often make false assumptions about the causes of anaphylaxis. Unfortunately, these assumptions may include some sense that they were somehow at fault. Correct and clarify as you see false reasoning develop.

Encourage your child to express how they feel and show them understanding and acceptance. Answer questions and provide comfort and support. Reassure them whenever you can (although you cannot assure them that they will never have a reaction again). For example, you could say; “Things will get better”, “I will be there for you”, “you can ask questions anytime”, “you are safe now and so are the people you care about.” For further reassurance, you can point out some of the safety measures that are routinely carried out. You could explain to them what their

medication does exactly.

It is fine to tell children that you don't know why something happened. And it is fine to tell them that you too get confused and upset – for example, in cases where the allergen or cross-contamination was unexpected. In the end, listening and comforting a child without avoiding the issue or overreacting will have long-lasting positive effects on the child's ability to cope with trauma. Honesty and openness will help your child develop trust.

Focus on the good – for example, point out that the medication worked, people were there to help and lessons have been learned from the experience. Positive interpretation of the trauma can be helpful. The good news is that children are very resilient, and they can even inspire adults with their feats of inner strength and optimism.

Be a role model of emotions. When they are ready, share how you feel, both positive and negative.

Psychological impact on adults with allergies

So far, this information sheet has concentrated on the problems of children and teenagers with allergies and their parents. But of course, anxiety may also be a problem for some adults with allergies. We hope the sections that follow will be helpful for children and adults alike.

Daily coping strategies

You may find one or more of the following strategies helpful.

Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) is a talking therapy that can help people manage their problems by changing the way they think and behave. It is most commonly used to treat anxiety and depression. You can find out more about CBT here: <https://www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt/>

A 2016 UK study found evidence that CBT, combined with accurate information about risk, was helpful in easing the anxiety of mothers of food-allergic children. Importantly, the study showed that the mothers were left with a more realistic understanding of the actual risks their children faced.

CBT can also be helpful in developing a risk strategy. All allergies bring an element of risk for the person, and it is therefore important that they find a way to assess how much risk they feel is acceptable for them. For example, some patients feel eating out would be too risky, whereas others feel this is a risk they want to take and develop strategies to manage the situation.

Although we acknowledge that CBT may not be effective in all cases, we believe it is worthy of consideration if anxiety impacts everyday life and restricts ordinary activities.

In many areas of the country you can get psychological therapies, including CBT, on the NHS. You don't need a referral from your GP. You can refer yourself directly to a psychological therapies service. A CBT therapist should be accredited by The British Association for Behavioural and Cognitive Psychotherapies. The register of accredited therapists in your area can be found here: www.cbtregisteruk.com/

However, in Scotland it is not possible to self-refer and we understand the waiting time for CBT in Edinburgh following a GP referral can be 12 months.

An alternative in all areas of the UK is the website Headspace, which offers mindful exercises, breathing and relaxation techniques. Go to <https://www.headspace.com/>

Deep breathing

Deep breathing is a useful technique for easing stress, anxiety and panic. It takes just a few minutes and can be done anywhere. Adults and children alike get the most benefit by doing it regularly, as part of a daily routine. You can do it standing up, sitting in a chair that supports your back, or lying on a bed or yoga mat on the floor.

Here's an example of a helpful breathing exercise:

1. Put one hand on your stomach and one on your chest.
2. Slowly draw in a deep breath while you count to four. This deep breath should fill the bottom part of your lungs and makes your stomach move outwards – try to get the air into this lower part of your lungs.
3. Hold your breath for the count of five.
4. Slowly breathe out while you count to seven.
5. Repeat this a few times to help you take control of your body and feel calmer.

Visualisation

Visualisation is another useful strategy – thinking about the things you find restful or pleasant can help you to relax. The technique can be used by adults or children. The idea is that you think about a dream place – it could be somewhere you have been, something you have seen in a film or an imaginary place. Imagine a picture of it and make the picture as restful and peaceful as possible... all the little details. Imagine how it would feel to be there. Is it warm? Is there a gentle breeze? Is it sunny? Try to imagine you are really there in that peaceful scene. Some people like to think about lying on a beach or walking in the countryside.

Physical relaxation

This technique is particularly good for people who are constantly tense. Ideally it should be done while lying down comfortably. All the major muscle groups in your body are tensed for about five seconds, then released. You may find it useful to do this before bed if you have sleep difficulties.

Yoga

By practicing yoga poses, children and adults alike can learn how to exercise, develop confidence and concentrate better. By becoming aware of your body and aware of your breathing, yoga provides the ability to cope when you start to feel anxious or upset. Many yoga classes can be found online throughout the country.

The Triple P Programme

The Triple P Positive Parenting Programme® is a parenting and family support system designed to prevent – as well as treat – behavioural and emotional problems in children and teenagers. It aims to prevent problems in the family, school and community before they arise and to create family environments that encourage children to realise their potential. There are Triple P parenting groups in many London boroughs and UK cities, funded by local authorities.

Going on holiday

Families sometimes tell us they feel particularly vulnerable when going on holiday, particularly overseas. Air travel is often regarded as particularly risky.

Once again, getting reliable, accurate information is crucial. Find out what foods are customary in

particular countries and learn what ingredients are commonly used. Translation cards can be useful – you can either take them with you or save the files on your phone. Examples can be found on Dr Hazel Gowland’s “Allergy Action” website – <https://allergyaction.org/translations/> (Please note that we have not verified the information on the above site. If you have any queries, call the number on Dr Gowland’s home page).

Some people with peanut allergy report that they experience symptoms during air travel when peanut snacks are handed around to passengers with their drinks. In our view, the most likely cause of these reactions is skin contact. If you touch a fold-down tray table or some other surface that has previously been touched by a passenger eating peanuts, and then touch your eyes or mouth, you could have a reaction. To minimise the risk, you could carry wet wipes to clean surfaces as soon as you get on the plane.

Reactions caused by inhalation of peanut dust are thought to be less likely. A study presented to the 2012 annual meeting of the British Society for Allergy and Clinical Immunology found that peanut protein does not easily become airborne. Therefore, significant exposure to peanut protein via inhalation is unlikely. However, you must be guided by your doctor or consultant, and your allergy history. If you know you are at the high end of the risk scale (for example, you have reacted after inhaling peanut dust in the past), contact the airline well in advance to request that peanuts are not distributed on your flight.

Debunking the myths

There is a lot of false information, particularly on social media. For example, the level of risk faced by someone with a food allergy is often exaggerated in the media. Whilst anaphylaxis can be life-threatening and must be taken very seriously, the majority of reactions do not result in catastrophic outcomes. Fortunately, fatal anaphylaxis is a rare event. You can check any information you pick up by calling our Helpline (01252 542029) or emailing info@anaphylaxis.org.uk

Allergens other than foods

Although this article has focused to a large extent on food, other allergens can also cause anxiety for those affected. Once again, getting reliable information is crucial. We have fact sheets on allergy to insect stings, animals, natural rubber latex (NRL), drugs and exercise. You can view our factsheets here: <https://www.anaphylaxis.org.uk/factsheets/>

The positives of having an allergy

In our experience, many families find there are positive aspects of having a food allergy, and it may be helpful to bear these in mind. People with food allergies become more knowledgeable about food and food labelling, which can result in a healthy lifestyle and may also lead to the development of skills in cooking.

And remember – anaphylaxis is serious but manageable. If you obtain accurate information, take care at all times to avoid the problem allergens, and carry prescribed medication everywhere, the risks are significantly reduced.

Links

- Our fact sheets: <https://www.anaphylaxis.org.uk/factsheets/>
- Information relating to schools: <https://www.anaphylaxis.org.uk/education/>
- Information relating to early years settings: <https://www.anaphylaxis.org.uk/fact-sheet/guidance-for-parents-and-carers-of-children-in-early-years-settings/>
- Our AllergyWise training courses will improve your understanding of allergy: <https://www.allergywise.org.uk/>

Feedback

Please help us to improve our information resources by sending us your feedback at: -

<https://www.anaphylaxis.org.uk/information-resources-feedback/>

Sources

All the information we produce is evidence-based or follows expert opinion and is checked by our clinical and research reviewers. If you wish to know the sources we used in producing any of our information products, please contact info@anaphylaxis.org.uk and we will gladly supply details.

Reviewer

The content of this factsheet has been peer reviewed by Christina Raeburn, Cognitive Behavioural Psychotherapy and Counselling Consultant at The Edinburgh Clinic.

Disclosures

We are not aware of any conflicts of interest in relation to the review of this factsheet.

Disclaimer

This fact sheet draws on the expertise and experience of the two authors and expert reviewer. Other psychological points of view may exist. The information and advice we provide is given in good faith and every effort is taken to ensure accuracy. But all patients are different, and specific cases need specific advice. There is no substitute for good medical advice provided by a medical professional.

About Anaphylaxis UK

Anaphylaxis UK is the only UK-wide charity solely focused on supporting people at risk of serious, life-threatening allergic reactions. We provide information and support to people living with allergies through our free national helpline and local support groups. We also campaign and fundraise to achieve our ultimate aim, to create a safer environment for all people at risk of serious allergies. Visit our website www.anaphylaxis.org.uk and follow us to keep up-to-date with our latest news. We're on Facebook @anaphylaxixUK, LinkedIn, Instagram @anaphylaxisUK, Twitter @AnaphylaxisUK and YouTube.