

Part I

# **Risk Assessment**

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# **1 The reality of food allergy: the patients' perspective**

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## **1.1 BACKGROUND**

Most of us take our food for granted. We know where the next meal is coming from and we can be fairly confident that it is going to be safe to eat. But people who deal every day with a life-threatening food allergy do not have that confidence. They can find mealtimes a source of enormous stress.

For what is nutritious to the majority can be an extreme danger to a minority. Anyone who has been rushed to casualty suffering a life-threatening allergic reaction to a food, or has seen that happen to his or her child, knows how life changing that experience is.

One mother wrote to us saying: 'My seven-year-old daughter is allergic to nuts, milk, eggs and fish. Our lives are pretty much ruled around food. I worry terribly about the future.' That is typical of the messages we receive from families dealing with this problem every day of their lives.

The fact that food allergy can be deadly serious has been well known for decades to the medical profession, but it was not until the early 1990s that the public at large, the media and the food industry began to understand that it can kill a small but significant number of people. And for many, food allergy can be lifelong.

Before the 1990s, allergy was generally regarded as a minor inconvenience, if it existed at all. It was out there on the fringes of medicine, affecting (so it was thought) people who let their imaginations run riot. At the most, it was generally considered that food allergy amounted to no more than a bit of indigestion or an itchy rash. Then in late 1993, the UK media reported that four people had died suddenly in a short space of time from allergic reactions to nuts. They included my 17-year-old daughter, Sarah, who died after eating a dessert-containing peanut in a town centre restaurant. She had an inkling that she was allergic to peanuts but had no idea how serious it could be. The condition from which she died is called anaphylaxis. Her throat swelled and closed up, she suffered a severe asthma attack and her blood pressure plummeted.

The resulting media publicity spread alarm throughout the food industry and placed immense pressure on the government to take action. For if people's lives were at risk from a common, everyday food that was nutritious for the majority, what were the implications for food production and labelling?

The author is shown with his daughter, Sarah, who died from her allergy, in Figure 1.1.

As a result of those four tragic deaths, and others that came to light, the Anaphylaxis Campaign was formed in January 1994 with me as its co-founder and chairman. A small core group of a dozen of us (people with food allergy and the parents of children with food allergy) met in a flat near Baker Street, London, in January of that year. We had never met

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**Fig. 1.1** David Reading with his 17-year-old daughter, Sarah, who died in 1993 from an allergic reaction to peanuts.

before, but made contact as a result of the huge wave of media coverage that occurred. That informal London get together was the inaugural meeting of the Anaphylaxis Campaign, which began its life as a small pressure group run from people's homes. Our clear objective was to save lives, and in those early months we set out to be a focal point for the spread of information. This proved to be more straightforward than we had dared to hope. After the Campaign's launch, and the resulting media publicity, I was receiving 60–70 letters a day through my letterbox, many of them telling heart-rending stories of children who had been rushed to casualty suffering from extreme allergic reactions to food. Along with the information provided to us by medical professionals, this influx of case histories from people with allergies provided a comprehensive file from which to develop guidance for patients and the industry alike. We met the Food Minister, Nicholas Soames, in February of 1994, a few of the major retailers and manufacturers in March and the Department of Health in April.

We told Soames that more than 1000 people had contacted the Campaign in less than 2 months; 700 had signed up, and more were joining daily; 85% of those were allergic to peanuts; 80% of the total were the parents of allergic children younger than 15 years. Soames said that he was 'staggered' by the scale of the food allergy problem. He said that the food labelling issue had to be fought in Europe, but agreed to launch an awareness drive throughout the UK food industry. The Ministry of Agriculture, Fisheries and Food (MAFF) began that year to commission allergy-related research, and this has grown into a formidable programme in the hands of the Food Standards Agency (FSA).

See Tables 1.1 and 1.2 for a breakdown of the current membership profile of the Anaphylaxis Campaign.

## 1.2 CONSUMER REACTION

Several facts became apparent from that flood of letters to the Campaign: nut allergy was far more common than had been recognised; it was causing terrible anxiety and disruption to

**Table 1.1** Anaphylaxis Campaign membership profile by age (March 2008).

Number of members with recorded allergies	7566
Number of members aged 0–11	2738
Number of members aged 12–20	2995
Number of members aged 21–30	660
Number of members aged 31 and older	1173

people's lives; and many had been labouring under the mistaken impression that they were among only a handful of families affected.

One mother of a nut-allergic 13-year-old boy said: 'Until we found your organisation, we were forced to cope on our own. We felt we were playing Russian roulette every mealtime. The future looked very bleak.'

We learned that teenagers and young adults seemed to be those most vulnerable to potentially fatal reactions; a range of foods seemed to be implicated (not just nuts); and people were reacting to tiny amounts of the offending allergen. On the face of it, it was a nightmare scenario for the food industry.

Since that time, the Campaign has remained in the forefront of efforts to raise the level of debate. With our membership of almost 8000 people (Spring 2008), we have been able to comprehend quite clearly what people with food allergies want. Primarily, they want to be understood. Many believe their needs have been bypassed. Those who are allergic to foods other than peanuts, for example, will often complain that industry (and indeed the Campaign itself) is fixated on peanut allergy and that other foods are played down. It is important to understand that any food that contains protein could potentially cause anaphylaxis for someone, somewhere.

To the outsider, the degree of anxiety expressed by families who care for a food-allergic child can appear out of all proportion. The level of apprehension becomes understandable when you realise that there is a frightening unpredictability to severe food allergy and very often inadequate medical guidance. Many of those affected have experienced sudden life-threatening episodes requiring an emergency dash to hospital. One parent of an

**Table 1.2** Anaphylaxis Campaign membership profile by allergens (March 2008).

Peanuts and tree nuts	6680
Egg	1554
Sesame	905
Milk	845
Fish	546
Shellfish	508
Wheat/gluten	195
Kiwi	427
Soya	192
Lupin	22
Mollusc	21
Mustard	19
Celery	14

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allergic child answered one of our surveys with a bullet point list of food allergy's 'side effects':

- Holidays are limited to within 10 miles of a large hospital that can speak English.
- None of the family likes my son being out of our direct care.
- We can't go anywhere without medicine of some sort being administered, i.e. antihistamine daily.
- We pay for private education in a small school that is nut free and allows no packed lunches.
- Many parents will not have my son for tea let alone sleepovers.
- Pub food or restaurant visits involve a long and embarrassing plough through lists of food sheets to be told my son can have pasta – without sauce. That's if they have a food list.
- Many leisure facilities are not keen to let me leave him in their care.
- Schoolwork is sporadic at best for my son, and he suffered hair loss from a virus recently. His self-confidence is low.

Although the proportion of the population at risk of anaphylaxis is relatively small, the impact is felt much wider. If it is a child who has the allergy, the burden is carried by parents, siblings, grandparents, aunts and uncles, friends and their parents (particularly if a party is planned) and the local school.

### 1.3 SUPPORTING CONSUMERS

Over the years, it has become apparent that most food allergy problems are manageable – both for the patient and for the industry. But both parties need comprehensive, reliable information, and sometimes that is lacking. Furthermore, there are many allergy myths that have to be dispelled.

The most destructive of these myths relates to levels of risk. From the early days, it has been common to hear the comment that 'even the smell of a peanut will kill my child' or 'my child is unlikely to reach adulthood'. This is an understandable fear, because the media will always focus on the worst-case scenario of death.

Many of the headlines were sensational from the start: 'The deadly allergy we should all fear' was how one magazine put it. Others were equally alarmist – with peanuts described as 'the hidden killer' and another announcing that 'allergies can kill in seconds'. Instead of playing up the risks to gain attention, the Campaign found itself having to keep a cool head and dampen down the hysteria (see Figure 1.2).

In order to address this alarm and despondency, the Campaign instigated a programme of support and education to help both those affected by life-threatening allergies and the food industry. Thanks to a National Lottery grant, we opened an office in Farnborough, Hampshire; we developed information tools including fact sheets and training videos; we set up a helpline; we began a series of interactive workshops for allergic teenagers; and we continued to inform and encourage industry.

The picture emerging from calls to our helpline showed that many people were receiving woefully inadequate medical guidance, and therefore they were unable to cope with what is fundamentally a manageable condition. Patients need an accurate diagnosis, they need to understand exactly what foods to avoid and where they might encounter those foods, and



Fig. 1.2 Newspaper cuttings related to food allergies.

they need to know how to treat themselves when things go wrong. But it was common to hear it reported that a general physician (GP) faced with a young allergic patient had told the child's parents: 'If you think he's allergic to nuts, the solution is simple – don't give them to him.' This is easier said than done, and frequent close calls and occasional deaths occur.

Crucially, those at risk need to carry their own medication for self-treatment, should they inadvertently encounter an allergen that causes them harm. The front-line treatment is an injection of adrenaline, to be administered as soon as a serious reaction is suspected. People at risk are prescribed their own self-treatment kits (e.g. EpiPen or Anapen), and these must be carried at all times, with no exceptions.

## 1.4 ALLERGY SERVICES

But first the patient needs a good diagnosis, and as several influential reports have pointed out, allergy services in most parts of the United Kingdom are poor and many patients are unable to obtain the advice they need.

In the early days, there were promising developments. During the Campaign's first few months, the Chief Medical Officer gave the nation's GPs some clear guidance in one of his regular bulletins (CMO's Update, May 1994). He told doctors never to advise a peanut-allergic patient to test his or her reaction by eating peanuts, stressed the importance of prescribing adrenaline, and asked them to note that repeat injections were often needed.

But although we attended several meetings with ministers and civil servants at the Department of Health, allergy services have been painfully slow to improve. A report by the

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Royal College of Physicians (2003) declared that 18 million people suffered from allergy at some time in their lives, but there were only six full-time allergy clinics run by an allergy specialist. Other clinics existed, the report said, but most of these were run by specialists in other fields (such as ear, nose and throat) and were a part-time 'add-on'.

People told us frequently that their GP was unable to help. They were floundering with food labelling that confused them, restaurant staff who were reluctant to serve them and (in the case of children) school staff who had received little or no guidance on how to manage what is sometimes a life-threatening condition. The Royal College report said that hospital admissions due to anaphylaxis had increased sevenfold from 1993 to 2003 and doubled from 1999 to 2003.

Comments we received during a 2005 survey of our members included the following:

The wait to see a specialist is two years. We have known about our son's allergy since he was nine months and have never been seen.

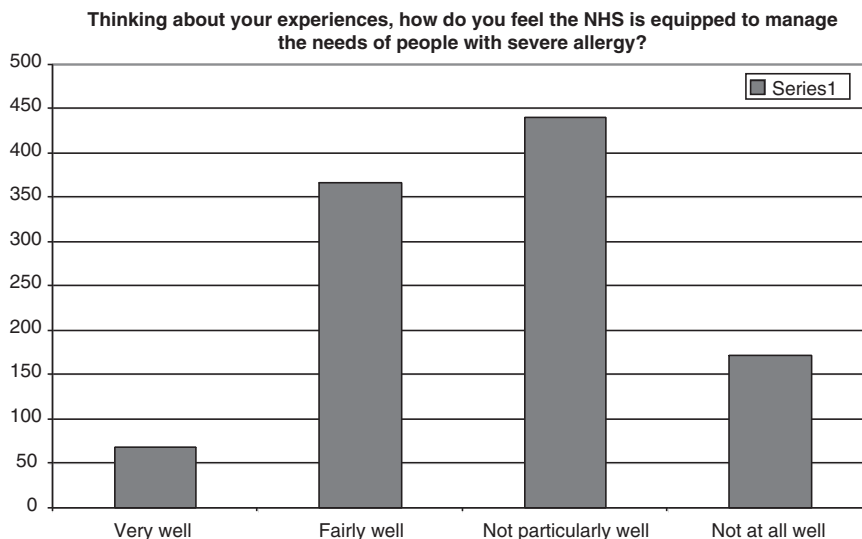
The GP said he had no training in allergies and a slow reintroduction of nut traces may be the way to go.

Without the Anaphylaxis Campaign our lives would be much poorer. We would have many more hospital visits.

After she suffered a reaction after eating banana, we took her to A&E. We were told it couldn't have been the banana. We gave it to her again, and she had another reaction.

Our son spent months visiting skin and eye specialists, who failed to diagnose his allergy.

Figure 1.3 shows a graph of survey results.



**Fig. 1.3** Results of a 2005 Anaphylaxis Campaign Survey looking at people's perception of allergy services. (Reproduced with permission.)

In 2005, the House of Commons Select Committee on Health reported categorically that Britain is in the grip of an allergy epidemic and the present NHS services cannot cope (House of Commons Health Committee, 2004). The committee's report said that 1 in 50 children in England is now allergic to nuts – almost a quarter of a million children – and there has also been an alarming rise in other allergies, including sesame and latex. The committee documented a huge amount of evidence of unmet need.

In 2007, the House of Lords Science and Technology Select Committee again emphasised the scale of the problem after it carried out its own inquiry into allergy (House of Lords Science and Technology Committee, 2007). The committee's recommendations included the following:

- At least one allergy centre should be established in each Strategic Health Authority. This should be run by a full-time allergy specialist.
- These allergy centres should encourage and coordinate the training of local GPs and other health care workers in allergy.
- The allergy centre should act as a lead in providing public information and advice.
- The lead allergist in each allergy centre should be responsible for maintaining a patient database to support clinical research.

We are still waiting for a firm commitment to allergy from the Department of Health. Government reports and statements have proved deeply disappointing. A campaign for change is being led by the National Allergy Strategy Group, a partnership of medical professionals and allergy charities. Early in 2008, a hopeful sign emerged when it was revealed that an All Party Parliamentary Working Group had been formed to ensure allergy maintains a high profile.

Deep concern over the lack of activity displayed by the Department of Health is demonstrated by a letter that appeared in *The Times* on 31 January 2008. Signed by some of the leading allergy experts of the United Kingdom, the letter stated:

We are in the midst of an allergy epidemic with about 20 million children and adult allergy sufferers in the UK. Indeed, we have one of the highest prevalences of allergic diseases worldwide – diseases such as asthma, anaphylaxis, drug and food allergy, eczema, rhinitis and insect-sting allergy. There is an enormous burden on patients and their families, and costs to the NHS are rising.

The letter stated that many problems could be eased or prevented by expert diagnosis and management. The Department of Health had acknowledged the need for improvement, but nothing had been done to implement the key requirements. Instead, responsibility had been passed to local agencies, which could not solve the problem because it required a national solution.

The letter ended by urging the Health Minister to adopt the Lords' recommendations without further delay.

## 1.5 TEENAGERS AND YOUNG ADULTS

Although people of all ages have food allergy, teenagers and young adults are at most risk from fatal reactions. This has been demonstrated by published studies (Pumphrey, 2000; Pumphrey and Gowland, 2007) and our own experience. Many in this age group find it hard to cope. Time and time again, we hear reports of problems faced by teenagers and so this age group became a particular focal point. The experience gained from our 1-day workshops for allergic teenagers is that the participants are often poorly informed and lack confidence in managing their allergies. Many admit they take risks. They know they should carry their adrenaline, but choose to leave it at home, particularly if they do not anticipate that they are going to eat anything. And they are so fed up with defensive labelling (e.g. 'may contain nuts') that they just choose to ignore it.

The first of our workshops for teenagers took place in London in 1999 and since then we have held almost 100 across the United Kingdom. We found early on that teenagers respond well to the interactive format, in which they share ideas, discuss best practice and act out challenging situations (such as confrontations with difficult restaurant staff).

Reporting on one of our early workshops, a young participant wrote in the Campaign's newsletter:

We gained a lot of useful information from each other during the day. We shared experiences and shared ways of dealing with situations and how to tell people about our allergies. We used role play to help devise ways of telling people we have allergies. For example, how do you ask someone you're going to kiss whether they've been eating peanuts? And how do you tell someone who thinks allergies are a joke that it's a very serious condition.

Another wrote:

It was a great feeling to know I'm not on my own out there and there are many other people just the same as me. Also I think people should be more aware of other allergies such as dairy products, eggs, fruit and non-food causes of allergy, as most publicity seems to be given to nut allergy.

## 1.6 FOOD LABELLING

From the early days, it became clear that one of the burning issues for the consumer was food labelling – in particular, the use of 'may contain' warning statements. These warning labels are believed to have originated in the confectionery industry in 1994 when it became clear that production methods carried a risk that small quantities of nut could potentially be picked up in the factory by products that were not intended to contain nut. To warn the allergic consumer, food companies began to adopt advisory statements on their packaging. This practice spread like wildfire, and within a few years customers were complaining that 'just about everything carries a warning these days'.

In 2005 and 2006, the Campaign organised two surveys of people with food allergy with the objective of providing evidence to the Department of Health on people's concerns and needs. One question asked online was: 'How well or badly does the current system of food labelling work for people with severe allergy?'

The results were:

- Very well 0.8%
- Fairly well 32.5%
- Fairly badly 39.1%
- Very badly 26.3%
- Don't know 1.3%

This online survey, and another survey in which we wrote to every one of our 7695 members, drew many comments about food labelling. Allergic consumers rely on the accuracy of labelling and one respondent expressed the views of many others when she said:

'A weekly shop takes ages as checking all ingredients is a must.'

The most frequent complaint focused on the increasing use of 'may contain' statements:

'We were looking for a birthday cake in (supermarket X) and all cakes said "may contain traces of nuts". In a sponge cake with buttercream and jam filling, where would the nuts be? What do I do, take a chance or trail around until I find one that's OK?'

'So many products sold by (supermarket Y) "cannot guarantee nut free" – nearly all the products I once used now say this. What am I supposed to do?'

'What's the difference between "may contain nuts" and "made in a factory that handles nuts"?''

'I went through every item in (an in-store) bakery and did not find one which I could eat.'

'Recently I saw a bag of peanuts labelled "may contain traces of nuts" – what were they trying to convey?'

'At the end of the day the "may contain" label is all down to cleanliness of production lines. (Manufacturer X) have got it sorted, they are fantastic.'

Many respondents had formed the view that 'may contain' was simply a defensive device with no substance and some said they disregarded the warnings believing the risk was not genuine.

One person wrote:

'We ignore all "may contain traces of nuts" warnings since we found one of these warnings on a cabbage.'

And another wrote:

'(My son) eats many things that are made in factories where nuts are handled and a couple of times has had a reaction. But he has to eat!'

Sometimes, labelling proves to be confusing, inaccurate and even dangerous. Respondents ranged from having an understanding attitude, even though life was difficult, to displaying anger. There was a strong feeling that information should be more consistent.

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Accuracy of information proved to be a serious concern. Some respondents reported mistakes and discrepancies that they believed to be extremely hazardous. People said they were constantly telephoning manufacturers and retailers to obtain clarity. A few became aware that manufacturers sometimes moved production to different sites, where there were different allergen issues. They had become used to eating a 'safe' product only to find that it was now out of bounds.

People offered criticism or praise of specific food outlets, depending on their experiences. There were those who felt neglected, such as the respondent who wrote: 'Some supermarkets are very helpful, but a lot are terrible. The attitude seems to be that "we have enough customers so why bother to improve product safety or choice of food for a minority".'

Industry has pointed out that 'may contain' warnings are usually adopted for good reason – and only after all possible measures have been taken to minimise or eliminated cross-contamination. In our experience, many members of the public are sceptical, especially when they encounter nut warnings in the most unlikely places, such as a bag of mixed salad or even on a packet of nuts. In the two examples given, there may be good reason why the warnings appear, but the average shopper is baffled. The Campaign's view is that 'may contain' warnings are a necessary short-term solution to a difficult problem, but we hope that eventually they will become unnecessary. One possible solution – the Campaign's certification programme – will be explored later.

A study we carried out for the FSA on 'may contain labelling' (FSA, 2002) indicated that it takes 39% longer to shop for a nut-allergic person and costs 11% more than for someone without food allergy in the family. Alarmingly, the study also revealed that one in ten 'may contain' labels was missed by shoppers reading food packets.

Frustration over advisory labelling is just one of many issues that consumers raise with our helpline staff. We are often the first port of call when a reaction occurs. If you can imagine what it can be like for you, or your child, to be rushed to casualty suffering from anaphylaxis, you will probably understand that there is confusion as well as distress. What was it that caused the reaction? People will often jump to conclusions, and these may be the wrong ones. They may blame allergen contamination or – if they are fish allergic – they may think the company has added omega-3 without declaring it. A whole range of scenarios are presented to our helpline. As a first step, if a particular product is believed to be responsible for the reaction, we encourage the consumer to have a full and open dialogue with the manufacturer or retailer, and try to get to the bottom of the problem. We may also contact the company ourselves and explore whether there was indeed allergen contamination or a mistake during production. Or has the consumer become newly sensitised to an allergen? We urge food companies to be honest and open, and consumers not to play the blame game. But if a serious mistake appears to have been made, we will expect local enforcement officers to become involved. Occasionally, a sample of a suspect product is sent off for analysis.

Reactions sometimes occur when a food product contains an ingredient that is properly declared but unexpected. We urge people to read the label every time they shop, but people lead busy lives and want short cuts. Consumers have failed to notice egg present in Edam cheese, kiwi extract in an Easter egg moulding kit and casein in a wide variety of pre-packed goods where you might not expect to find milk.

Often consumers make mistakes, but on occasions they can be forgiven for being confused. The average person has never been inside a food factory and will have no concept about risk levels. Does 'made in a factory that handles nuts' signify a real risk or can the statement be disregarded? Sometimes the packaging tells a contradictory story. The consumer may expect different-sized but similar products to carry the same allergen risk but it may be wrong to

make this assumption. In other cases, you find an allergen statement on the outer wrapper but not on the inner wrapper, or vice versa. Confusion may also occur where one brand of pesto sauce contains pine nuts but another is made with cashews. Some Bakewell tarts may be made with almonds, others with apricot kernel. All of this serves to make life difficult for the consumer.

Some people's demands are unrealistic. They expect to see a 'contains nuts' warning if coconut is present (when in fact coconut is not strictly speaking a nut); they want front-of-pack allergen information that will save them the trouble of going to the ingredient list (we advise people to read the list of ingredients every time); in extreme cases, they may want an allergen banned from the environment, such as in schools. This last point may sound unreasonable if you are not affected by allergy – and the Campaign itself has serious reservations about allergen bans – but such demands demonstrate the understandable anxiety that people feel.

Other consumer demands are more reasonable. If a new allergen has been introduced into a product, they are right to expect to see some indication on pack (such as a 'new recipe' flash). A company's information should be consistent. For example, people should see the same information on pack that appears on the company's website, which does not always happen. And food companies should be as scrupulous with their 'free from' lists as they are with their product labelling.

There are occasions when someone makes a mistake for which the manufacturer is partially responsible. This happened with tragic consequences in the case of a 20-year-old mother. She died from an allergic reaction to peanuts following a terrible mistake that involved a 'may contain' label.

The young woman regularly ate products that carried 'may contain' warnings because she had never reacted to them and believed she was fine with them. In October 2003, she prepared a pack of vegetarian sausages for herself and her son. She saw that the pack carried a warning, 'may contain traces of nuts', and looked no further. Had she gone next to the ingredient list, she would have seen peanuts listed as an intentional ingredient.

As she ate her meal, the young woman immediately realised she was having an allergic reaction. She was treated with adrenaline at her local surgery but by then too much time had elapsed. An inquest recorded a verdict of misadventure. At the time of her death, the young woman had not renewed her EpiPens. It was suggested at the inquest that she might have been frightened of having them.

The Campaign's food adviser, Hazel Gowland, who was an expert witness at the inquest, commented at the time:

This was a shocking example of what can happen out there in the real world. We all hope that people with food allergy will always read food labels thoroughly and have adrenaline to hand at all times, but life in the real world is often different. It's a fact that some people will eat a product carrying a warning label, find they don't react and believe this means they can eat other similar products. In this young woman's case, there was an additional factor that led her to making a mistake: the vegetarian sausages carried a 'may contain' warning plus the word 'peanuts' among the ingredients. She made a wrong assumption that 'may contain traces of nuts' was the only reference to nuts.

However, it is important to strike a positive note, as well as to list the problems. Industry has made huge strides since 1994. There is a genuine concern for people with food allergies

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and even if this is only partially altruistic, it is a fact that you can walk into a shop and see comprehensive allergen labelling that would have been unheard of just over a decade ago. Some companies have acknowledged the needs of the allergic public by developing products 'free from' certain allergenic ingredients and although this has sometimes brought its own problems (there have been recalls of products in 'free from' ranges), nevertheless this is one more sign that food allergy is well and truly on the industry's agenda.

### 1.7 ALLERGEN THRESHOLDS

In the tragic case outlined above, peanut was an intentional ingredient that was present as a significant amount. But a question frequently asked by industry and consumers alike is: When do unintentional traces of an allergen constitute a real risk? Is there a limit below which people won't react?

Scientists around the world are working to develop an understanding of threshold doses for food allergens – the lowest amount that can trigger an allergic reaction. The big questions are: How much is too much? Is there a measurable level below which people wouldn't react? If so, this would offer much-needed reassurance. Industry could make efforts to reduce cross-contamination to below these levels and consumers might feel safer.

However, not everyone is happy with this approach. Some consumers tell our helpline that they want to see every possibility of cross-contamination removed. They know that minuscule traces can trigger reactions and want zero risk.

The perception that microscopic traces can kill may be founded largely on scare stories and extreme cases, but it is true that reactions can be triggered by small quantities of allergen. They may not be life threatening but any symptoms requiring treatment are unpleasant and alarming. Furthermore, an allergic person's own threshold can vary from day to day. How much they react to at any given time may depend on factors such as their general state of health, how well their asthma is controlled, whether they have been exercising strenuously or drinking alcohol, and other factors. Even if industry works to agreed thresholds, would these limits be misleading if a person can react to lower amounts at certain times?

People question whether any industry action based on agreed thresholds will protect 100% of the allergic population all of the time. The answer is that there may be a very small minority who are so susceptible that they could react to an amount below the threshold. It is highly unlikely that this would be a life-threatening reaction – but do we know that for sure? Establishing thresholds will not totally remove uncertainty.

On the other hand, many consumers agree that establishing thresholds would hold benefits both for them and for the food industry. Total elimination of risk is impossible in any area of life, but risk minimisation is achievable. The most severe allergic reactions are normally caused not by traces, but by significant quantities of allergen, intentionally added to the food. In such cases, there is usually a major error made somewhere along the way, either by the person supplying the food or the person eating it, or both. Food industry action based on agreed thresholds could lead to a reduction in 'may contain' labels. We suspect that many of these warnings are applied when a food company is hampered by a lack of knowledge about what constitutes a significant risk. Knowledge of thresholds will make industry's job easier and have a positive knock-on effect for the allergic consumer.

The Anaphylaxis Campaign leans towards the pro-threshold argument. We sympathise with those who want zero risk. They want to see separate factories, or at least segregated

production lines, to eliminate cross-contamination altogether, and this is something the Campaign supports wholeheartedly. But this will take some time to achieve and meanwhile risk minimisation is the goal. In our experience, most life-threatening reactions are caused by significant quantities of an allergen.

Anxiety is fuelled by the myth that even touching or smelling a peanut is likely to cause death. There is no doubt that unpleasant reactions do occur when an allergen such as peanut or milk gets on to the hands of an allergic person. However, these are more likely to be localised reactions where the contact occurred. The myth that a trace is likely to kill needs to be dispelled. In an attempt to offer practical advice to people, we point out that they can lower their own personal risk by managing their asthma and eczema, taking special care with food when they feel unwell, run down or stressed and ensuring they do not take any risks with food if they have been drinking alcohol, which can increase the severity of allergic reactions.

## 1.8 FOOD ALERTS

In order to protect its members, the Campaign operates an early alert system that warns people when a mistake has been made by industry and products are on sale that pose a risk. After investigating the circumstances, and becoming sure of the facts, we target our allergic members by first class mail. Our database of members can tell us specifically who we need to target. For example, if necessary, we could pull out all members aged 0–7 years in Bolton with milk allergy. Our first alerts occurred in the late 1990s and the number rose steeply when the European Union's regulations governing the mandatory labelling of allergens took effect. The Campaign sent out 36 product alerts to allergic members during 2006, compared with 17 in 2004. In 2007, the figure rose to 58.

The following incidents are examples of those that have occurred over the years.

A company specialising in food for babies and infants announced the recall of four batches of cheese and tomato bake for infants from 4 months. These batches contained milk ingredients but had been incorrectly labelled as milk and lactose free.

Table 1.3 shows food alerts during 2007.

Due to a packaging error, a batch of children's ham snacks was recalled because they contained the hot dog variety. The affected packs did not show the correct ingredients or allergy advisory statement and there was a risk of contamination with nuts, milk, soya,

**Table 1.3** Anaphylaxis Campaign food alerts by allergen during 2007.

Milk	26
Peanuts/nuts	7
Wheat/gluten	7
Soya	7
Sulphites	6
Egg	5
Seafood	2
Celery	1
Mustard	1
Sesame	1

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poppy, sesame and sunflower seeds. The error was said to be due to an isolated manufacturing incident at a factory on the Continent.

Muesli products marketed by two separate companies were found to contain undeclared nuts – in one case pecan, hazelnut and flaked almond and in the other case whole hazelnuts and Brazils.

A retailer's chicken product containing couscous was labelled 'gluten free', but couscous is derived from wheat.

Bags of yoghurt-coated raisins were found to contain a number of yoghurt-coated peanuts. The packaging carried a warning statement: 'This product may contain traces of nuts.' In a separate incident, the mother of a peanut-allergic child found 13 chocolate-covered peanuts in a bag of chocolate raisins. The product was withdrawn after the company was contacted by environmental health officers. And there was yet another case involving a different company's yoghurt raisins. These were withdrawn from the shops after a customer found ten containing peanuts in the packet.

A major retailer withdrew stocks of fresh shortcrust pastry because, although butter was clearly listed among the ingredients, the words 'contains milk' were inadvertently omitted from the allergen box. The product contained a small quantity of milk protein. The message here is that if an allergen advice box is used, it should be comprehensive.

In the vast majority of cases, the company with the problem agrees to pay for the mail alert to our members. In a small number of cases, the Campaign has to pay for the alert out of its own funds. The FSA also runs an alert system, based on SMS text messages sent to subscribers. The Campaign welcomes this scheme but decided to remain with its own system after a postal survey among members came out overwhelmingly in favour of alerts by post.

## 1.9 OUR WORK WITH INDUSTRY

Industry faces significant challenges in ensuring that food is safe and properly labelled for people with allergies. What food companies require is information and guidance based on good science. In March 2003, we set up a membership scheme for the food industry in which we offer our subscribers regular, high-quality news bulletins and the opportunity to attend seminars, where problems can be discussed and analysed. Eighty companies had joined this scheme by the end of 2007. Bulletins contain important information on subjects such as peanut allergy research, the need for thresholds, allergy to individual foods such as lupin, poppy seeds and pine nuts, and European legislation.

However, we concluded early on in the Campaign's history that fundamentally what consumers really need is the knowledge that there are consistent, high-quality standards in place for the control of food allergens. Primarily people want to know that they can eat safely and they wish to see a significant reduction in 'may contain' warnings.

Progress was made in 2007 when the Campaign became the first organisation in the United Kingdom to develop a standard that specifically aims to promote good allergen management and labelling (Anaphylaxis Campaign, 2007). The standard had been developed thanks to a grant from the FSA in 2006. The work was done by recognised experts from within the industry and a rigorous consultation exercise was launched in the autumn of that year. Pilot audits were held and the standard was revised in line with the findings and with the comments that emerged during the consultation. The United Kingdom Accreditation Service (UKAS) completed a technical review of the standard in August 2007 and it became available for sale



**Fig. 1.4** The logo that food companies will be invited to use on products that have been certified against the Anaphylaxis Campaign Standard. The logo denotes good allergen control during the food production process. (Reproduced with permission.)

in November of that year. In developing the scheme, the Campaign had always intended that companies adopting the standard would have the option of participating in a certification scheme to show compliance with the requirements of the standard. With that in mind, a logo was designed for use on food packets to show the product had been independently certified.

The Campaign is working with Doncaster-based Highfield.co.uk Ltd. to seek to ensure that the standard is widely adopted, thus bringing a high quality of allergen control to food production. Highfield was given the task of marketing and selling the standard, and also took on the crucial role of training those people who are required to carry out audits against the standard as well as the staff of food companies that participate in the scheme. Highfield have now launched the Anaphylaxis Campaign allergen training courses for manufacturers, retailers, auditors and trainers (see Figure 1.4).

However, it would be completely wrong to infer that all of the good news relating to food allergy has been generated by consumer groups. Specific food companies, trade bodies and the FSA have been in the forefront of numerous positive developments. For example, the British Retail Consortium and Food and Drink Federation have both written realistic and constructive guidance documents for their members on issues such as the handling of nuts and the practical requirements of European allergen legislation. Both organisations have also provided positive input into important FSA initiatives relating to food allergens.

## 1.10 THE WORK OF THE FSA

Since our 1994 meeting with Nicholas Soames, a succession of government ministers and civil servants have shown a strong commitment to food allergy.

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In 1997, the Ministry of Agriculture, Fisheries and Foods (MAFF) instigated a poster and leaflet campaign aimed at the catering industry. This was re-branded by the FSA and became the popular 'Be Allergy Aware' pack.

The FSA produced web guidance for caterers and for newly diagnosed patients, commissioned work on catering, shopping and consumer attitudes, and worked with the Anaphylaxis Campaign to produce a poster aimed at allergic students and leaflets translated into Asian languages. The FSA also published a guidance document for retailers and manufacturers on allergen management, focusing largely on the 'may contain' issue (FSA, 2006). At the same time, the FSA developed training for enforcement officers and added food allergy to the curriculum for caterers. In early 2007, the FSA published its allergen guidance for caterers and businesses that sell food loose (FSA, 2008). Furthermore, the FSA's allergy research programme now funds projects to the tune of more than one million pounds a year.

### 1.11 SCHOOLS

Food allergy has a disconcerting effect on schools and playgroups. Saying goodbye to your severely allergic child at the school gate can be a stressful experience. Parents may be accused of being overprotective, but anyone who has first-hand knowledge of anaphylaxis will understand why a high degree of anxiety exists.

Our surveys have found many examples of good practice in schools. As one head teacher stated, it is possible to have excellent policies:

All children have to be registered with the school as having an allergy. We have to hold two EpiPens (the expiry dates are noted and parents reminded). The 'pens' are held in the office in a secure cupboard with easy access. Each child has the box clearly marked with photos on the box, also consent forms with medication to be given by school from parent, plus a pencil and checklist in each box. The teachers/staff are encouraged to attend annual courses for anaphylaxis training.

But there have been many other cases where understanding and awareness were poor.

'At playgroup, I had to organise the EpiPen training myself, and had to sit in the car outside the school in case of emergency as staff were not confident.'

'Our daughter with severe nut allergy was excluded from playgroup for 2 weeks until they could investigate their insurance cover.'

Our surveys showed up inconsistencies with regard to training of school and preschool staff in the procedures necessary to care for allergic children. Where teachers have not been trained, or have forgotten the training, there can be serious issues to deal with:

'He cannot have school dinners because they feel unable to take the risk . . . this has been hard for a 4-year-old to understand.'

'My son was rejected by his nursery school when he was prescribed an EpiPen, which now has a "no EpiPen" policy.'

We ask schools to be aware of the dangers of bullying, as everyone who is different is a potential target. The parent of a nut-allergic boy told us:

‘One pupil even tried to make him eat something containing nuts.’

Most schools have at least one child who carries adrenaline, and most will have several. School staff cannot be compelled to administer a child's injection in the event of a reaction occurring, but in most cases there are enough volunteers to give reassurance to the parents and their child. Educating the school staff is crucial. To meet this need, the Anaphylaxis Campaign has launched a major programme of training. Thanks to the receipt of several grants, including substantial amounts from the American Peanut Council and several food companies, the Campaign devised a comprehensive training package for school nurses. The project was piloted in five areas of the United Kingdom in 2006 and was so successful that a countrywide launch began in 2007 and will continue at least until 2009. The aim is to train all school nurses in the country so that they are able to pass down their knowledge to school staff. Subjects covered in the training packs and seminars include avoidance of allergens, symptom recognition and treatment of reactions, as well as a wide expanse of background knowledge. Even within the first few months, 12 newly trained nurses had led 44 training sessions in schools and reached no fewer than 630 members of school staff.

In a separate programme, the Campaign has launched an awareness drive to provide information and guidance for allergic students and for caterers in colleges and universities. This high-risk group forms an important part of the Campaign's work.

The attempt to improve safety in schools and other educational settings may have been hampered by government guidance that actively encourages the sale of nuts and seeds in school tuck shops and vending machines.

Under 2007 rules formulated by the School Food Trust, snacks such as chocolate and crisps are banned from sale in schools, and instead they are being told to sell products that are considered healthy. Government guidelines promote nuts and seeds as healthy options. We believe this could lead to an increase in risk for allergic children. Good food labelling will help, but primarily the major risks are likely to be through cross-contamination. Nut proteins tend to become transferred easily from children's sticky hands to desks, chairs, computer keyboards and other surfaces. The danger is that through 'casual contact' with these allergens, susceptible children may suffer reactions. Whilst these reactions may not necessarily be severe, they will certainly be unpleasant and disruptive.

The potential risk was demonstrated in a paper published by a German medical team (Lepp *et al.*, 2002). They reported the case of a 32-year-old man with peanut allergy who suffered a serious allergic reaction during a card game. His friends were eating peanuts and peanut protein from their fingers found its way on to the playing cards. As the cards often stuck together, the player with the allergy licked his thumb to separate them. It was this that caused his serious reaction.

In an attempt to assess whether our fears are founded, we launched an online survey in which we encouraged families to report whether there was an increase in nuts and seeds in individual schools around the country and whether they perceived the risks to have risen. We are encouraged by the initial findings. Although these are early days, results suggest that there has not been the expected rush by schools to introduce nut products. However, the exercise will have to be repeated to establish whether snack trends in schools will change to the advantage or disadvantage of children with allergies.

## 1.12 EATING OUT

Our more general online survey in 2006 asked respondents about the degree to which they were affected by everyday situations. A high level of concern was given to eating out as a family, with 78% mentioning this as having a great effect on them. In our experience, supported by published studies, people with serious food allergies face significant risks when they eat out. Clearly because this is, in part, due to the fact that the usual food labelling rules do not apply and people are relying on menu statements and verbal assurances by staff.

Pumphrey (2000) and Pumphrey and Gowland (2007) have shown that a significant proportion of the reported deaths occurred when food was bought in catering establishments, such as restaurants, hotels and takeaways. Peanuts or tree nuts were frequently implicated. In some cases where the victim had asked for a meal without nuts, the person serving (and in several cases even the caterer) had not been aware that the food contained nuts. In other cases, the request for nut-free food had either been misunderstood or forgotten. This shows that some highly allergic patients know that they need to be extremely vigilant at mealtimes, but mistakes still occur. In our view, most documented cases highlight the importance of prescribing adrenaline for 'at risk' allergy patients and educating them about their use.

Our surveys showed that eating out ranges from difficult to impossible for people with severe food allergies and their families. People complained about a lack of understanding and said catering staff were frequently unable to offer accurate advice.

One person told us:

'Most waiters just say, "You should be OK." One waitress said to me: "Please don't die here."'

Respondents noted that some national chains had put in place good systems of allergen control and communication with allergic customers. Implicit in these comments was the idea that if it could be done by one or two companies, why could not others do it? People complained of a lack of consistency among restaurants, hotels and takeaways:

'Some chefs are brilliant, making special meals, but otherwise you get a lethargic response.'

'Restaurants and cafes refuse to serve you.'

'We get very embarrassed. People think we are just being fussy if we ask for the ingredients.'

Respondents reported widespread lack of understanding and a need for training and education:

'Restaurants have no understanding of how life threatening it is to eat a food with nuts.'

'(My daughter) had a reaction due to nut-containing foods in a restaurant where two different waiters had assured us there were no nuts.'

'There is a widespread belief that only peanuts cause allergies. One restaurant owner guaranteed there were no allergy-causing nuts in a dish, but it arrived with cashew nuts.'

'In a café, I bought chocolate chip cookies labelled "may contain traces of nuts" but found white bits in them which turned out to be peanuts.'

Deaths are rare, but when they occur they generate dramatic media publicity which has a demoralising effect on people affected. My own daughter's death in 1993 is one of many that have been well publicised.

A 13-year-old girl died after eating a small amount of curry sauce made with peanut butter. There was some mention in her doctor's notes about peanut allergy, but there had been no proper diagnosis and no prescribing of adrenaline. Her family had no idea that she was at risk of a fatal reaction.

Another teenage girl collapsed and died during a formal dinner at university after she ate a dessert that – unknown to her – contained nuts. She knew she had nut allergy and had asked her GP for help. Her GP had led her to believe that nothing could be done. There had been no proper allergy diagnosis or advice and no prescribing of adrenaline.

Fatalities are thankfully rare but near misses are probably more common than most people realise. A young woman reported a severe reaction requiring hospitalisation following a meal in a cafe. The dessert menu had nut logos on some dishes and she asked about the tiramisu, which did not have a logo. The staff checked and checked again and she was served the tiramisu. She began to have a reaction, which became severe, and was taken to hospital. The restaurant double checked the box and found that the tiramisu she had eaten contained hazelnut crumb.

A young London man reported a severe reaction from a meal in his local curry house, where he ate regularly. He said that the staff had told him twice that his menu choice did not contain nuts. He was taken by ambulance to hospital, spent the weekend there and then a week recovering.

One must never forget that the onus is on each allergic diner to be clear with catering staff about what he or she cannot eat. This is an important message for people with food allergy. Despite the problems outlined above, many catering businesses now have excellent allergen management systems and effective controls in place. Furthermore, the FSA's guidance (2008) offers caterers a useful reference point if they wish to take allergy seriously. People with food allergy can be assured that things are improving. But here, as ever, we return to the problem of inadequate allergy advice under the NHS. How can people protect themselves adequately if they do not have an expert diagnosis and high-quality guidance in the first place?

### **1.13 DAILY LIFE WITH A FOOD ALLERGY**

People's lives are affected in many other ways, some of which are demonstrated by these comments that arose from our surveys:

'No woodland walks, house plants, or fresh flowers, no holding my grandchildren's cuddly toys.'

'I am smell-sensitive to nuts. This makes it impossible for me to go to the cinema.'

'I can't spontaneously embrace my husband in case he has eaten anything I'm allergic to.'

'My husband has had to give up his job to look after my daughter during school holidays.'

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‘We had problems booking flights with one airline. They wanted a form completed by the doctor before letting our son fly, so we booked with another airline which just asked for a doctor’s letter.’

‘If airlines provide nut-free meals, this is usually reliable on the outbound journey but frequently forgotten on the inbound.’

‘I was made to feel like a second-class citizen. Why should I be denied the social pleasures everyone else enjoys because of ignorance?’

‘When my son leaves home for university, he is likely to eat out more. Because of the years that have passed without an anaphylactic reaction, he may become less inclined to carry his EpiPen and less careful about reading ingredients labels.’

However, there are positive experiences among the negatives:

‘Whilst on holiday with (travel company A) recently, it was fantastic to hear the captain announce the need for all passengers to avoid all nuts as there were two passengers on board with severe nut allergies.’

### 1.14 HOPES FOR THE FUTURE

What does the future hold for people with food allergy?

There is some cause for concern. Pumphrey and Gowland (2007) showed that almost a third of the people who die from food allergy are not actively avoiding the particular food allergen. Some may have had minor symptoms in the past, but they were not expecting symptoms to become so severe so quickly. This presents a challenge to GPs, specialists and all those who diagnose allergy. It is also the job of researchers to devise ways of identifying the patients who are most at risk: something that cannot be done with any certainty yet.

The quality of life of people with food allergy is also a burning issue. One study (Avery *et al.*, 2003) showed that quality of life was more severely impaired in peanut allergy than insulin-dependent diabetes. The great challenge for the future is to improve the lives of allergic people by developing the clinical services and information systems, but also by better food manufacturing procedures and labelling to allow people to make accurate and appropriate risk assessments.

Clearly there is the chance, too, that further allergens will be identified as causing problems. When the Campaign first began its work, just a few food allergens were considered worthy of attention. Then kiwi fruit appeared on the radar. And others, such as lupin flour, began to emerge as potential problems. A young man with peanut allergy suffered a severe allergic reaction in 2002 after eating a chicken and ham pie in his office canteen. He suspected there were peanuts in the meal, but laboratory tests proved negative. Then it was pointed out that the pastry – imported from France – contained lupin flour. He saw an allergist and skin prick tests showed him to be extremely allergic to lupin. Until these emerging allergens are better understood, GPs cannot be expected to know about them, let alone know how to offer advice. There is some cause for unease.

However, there is also much cause for optimism.

The Campaign’s standard promoting consistent allergen control provides a real opportunity for food companies to get to grips with allergens for the benefit of the allergic public. We hope

to see more and more companies opting for certification, but even without it, the standard will improve life considerably for industry and consumers alike.

On the schools front, the Campaign's national training programme will inevitably lower risks for allergic pupils.

The present commitment by the FSA to allergy is to be applauded and we hope the good work will continue.

The campaign to achieve an improvement in allergy services will continue, despite the lack of attention given to allergy so far by the Department of Health. The National Allergy Strategy Group will continue campaigning until the point is reached where everyone with an allergy gets optimum diagnosis, treatment and guidance.

But what people really want for the future is a cure. Can the effects of a severe allergic reaction be reduced by drugs, and can allergy even be switched off altogether? Many parents who face the grim prospect of their allergic child remaining severely allergic for life – with the fear of death never far away – ask us passionately about the likelihood of medical science finding the elusive cure. Only this will end their anxiety.

The answer is that there is good work going on worldwide with this objective in mind.

Oral immunotherapy offers the possibility that people with food allergy can become desensitised by eating increasing amounts of the culprit food over a long period. Their immune systems would eventually become tolerant to the food. There are several research teams, in the United Kingdom and elsewhere, hoping to demonstrate that this can be done. The US researchers have had success with egg (Buchanan *et al.*, 2007) and are trying to do the same with peanut. Children in their study had reduced symptoms to egg when the team increased the amount they ate over a 2-year period. After the 2 years of desensitisation, all the children tolerated a higher dose of egg than at the outset of the study, and this was more than would typically be encountered in an accidental exposure. Most of the children could tolerate two scrambled eggs with no adverse reaction by the end of the study. In those who did react, the reactions were less severe. Eventually, the study team hopes to induce lasting tolerance to egg.

Anti-IgE therapy is intended to block the action of IgE, the antibody responsible for triggering the cascade of symptoms in patients with allergies. The drug could be delivered by injection once or twice a month indefinitely to people at risk of severe allergic reactions. People might still react, but the severity of reactions would be diminished. People would still be advised to avoid eating peanuts, but they might not have to worry about having a life-threatening reaction if they eat a small amount by mistake.

Researchers in the United States are experimenting with a vaccine based on *Escherichia coli* bacteria (Li *et al.*, 2003). These are killed and then used as a carrier for modified peanut proteins. These would be administered to the allergic person by suppository. The treatment seems to activate the immune system to turn off the IgE response.

Canadian researchers believe a protective enzyme found in the blood decreases the severity of allergic reactions (Vadas *et al.*, 2008). The enzyme acetylhydrolase breaks down PAF (platelet-activating factor), a chemical produced by the body as part of a severe allergic response. People with low levels of acetylhydrolase appear to have more severe reactions than those with higher levels of the enzyme. If the findings are verified, drugs might be developed that would treat life-threatening allergic reactions when they occur and possibly even protect people from experiencing severe responses in the first place.

Furthermore, scientists are also working on the question of what makes people allergic in the first place – and can this trend be reversed? Since 1994, the government has wrestled with the problem of why peanut and other food allergies are on the increase. The famous Isle of

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Wight studies showed initially that 1 in 200 children was peanut allergic and a decade later that the figure had risen to 1 in 70 (Grundy *et al.*, 2002). Parents of a peanut-allergic child have their own theory about how their child became sensitised. Many mothers become convinced it was because they ate peanuts while pregnant or breastfeeding, and are consumed by guilt. Although such anecdotal evidence is unreliable, the Department of Health gave credence to this hypothesis in 1998. Drawing on evidence provided by the Committee on Toxicity, the Department of Health issued guidelines to women suggesting that they 'may wish' to avoid nuts and peanuts during pregnancy and while breastfeeding if there is allergy in the immediate family (i.e. if they or their partners are allergic, or if they have an allergic child, e.g. with asthma, eczema, hay fever or food allergy). The guidelines also state that peanuts and tree nuts should not be introduced to children until after 3 years of age (Committee on Toxicity, 1998).

Recently, serious doubts have been expressed about this advice. A team of London-based researchers believe that they may demonstrate that introducing peanut-containing foods early into children's diets will actually prevent peanut allergy from developing. The team has been recruiting infants (aged 4–10 months) with severe eczema and/or egg allergy from the London area. Half the children are receiving peanut-containing snacks and the other half are advised on the avoidance of peanuts (as per the Department of Health recommendations). When the children have reached 5 years of age, a determination of the relative rates of peanut allergy will be made. It is a case of 'watch this space'. There are many experts who believe this study offers hope that the apparent rise in food allergy can be reversed.

In this chapter, I have tried to demonstrate that whilst there is much good work taking place to improve life for people with food allergy, the level of anxiety that some experience is unbearable. That is summed up poignantly in this final quotation:

Our daughter suffered from an allergy to peanuts. There was no specialist support system in place to help her. In particular, we had no knowledge of the fact that peanut allergy sufferers may also be allergic to lupin flour – an ingredient in high grade pastry. At the age of 15 she had this potentially fatal anaphylactic reaction to lupin flour following the consumption of school food. The paramedic responded well but the local hospital was lamentable following the first attack. The doctor dealing with our daughter had never before seen an EpiPen. He succeeded in squirting it up a wall and suggested we find a pharmacy to replace it since the hospital did not have any.

We have no doubt that the cavalier treatment Alice received affected her psychologically. She took her own life on the eve of starting at university and having just completed her Duke of Edinburgh Award Gold.

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