

STOLEN LIVES 7

Food Allergy & Intolerance Report

How difficult is it to live with Food Allergy or Intolerance?



Published January 2010



This report has been conducted in association with **Sainsbury's**

Introduction

Christmas may be over and for many we are more than happy to go back to eating a 'normal' diet. However, for people with a food allergy or intolerance, the grind of trying to find specialist foods will continue every day of the year.

In this the most recent of our Stolen Lives Reports we highlight how Food Allergy and Food Intolerance affects people's lives, from obtaining diagnosis of their condition to coping with everyday occurrences such as shopping or eating out.

Knowing what you are allergic or intolerant to is the key in managing your condition and getting your health back on track, in our survey we found that an amazing 88% of respondents have suffered from their symptoms for years. Luckily, there are kits available now, via the Allergy UK website www.allergyuk.org to test for food intolerance that is both affordable and easy to use.

For those that have had a medical diagnosis, many are given good advice on understanding the cause of their reactions, but it is the advice on more basic everyday needs such as cooking family meals or making up packed lunches that can be overlooked. Most of us rely on supermarkets to do our weekly shop, and having to find specialist food shops can be frustrating and time consuming let alone the cost involved.

"My food bill has trebled but my health has dramatically improved, so it has been worth it."

Thank goodness, we are now starting to see more allergy friendly foods available in the high street, Allergy UK is working with Sainsbury's who will be bringing out their revamped range of freefrom foods with many new and improved products available soon.

Support is also vitally important, our survey shows that most people need more than a selection of food on the supermarket shelves; they need practical help such as recipe ideas and tips on how to shop with a food allergy or intolerance something that is not provided by the medical profession. Allergy UK have recognised this need and can give just this type of ongoing support and advice via their helpline.

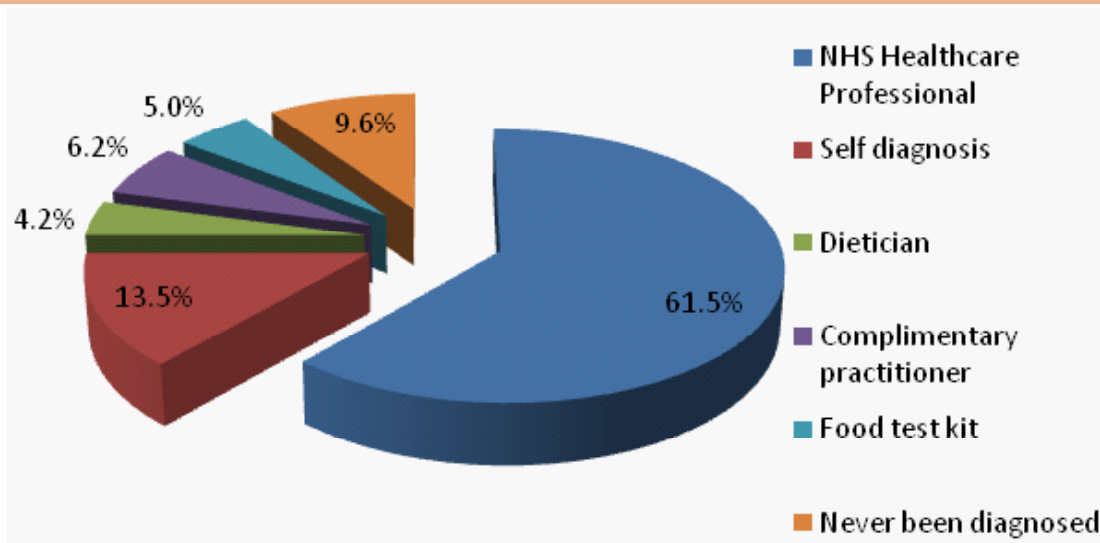
"My child is only two, but we are worried about when he becomes more independent. We have already explained to him that some things make him poorly and he accepts that, but it is heart breaking watching him miss out, yet be so good about it. It affects our family a lot. I am actually terrified of him dying, which sounds extreme, but it's the worse fear of any parent; yet when a tiny mistake like food especially when he is with other people, can be fatal. The risk is a reality we face every day."



Alan Bolton
Executive Director of
Allergy UK

In our survey we asked:-

At any point in your life have you or an immediate member of your family been diagnosed with a food allergy or intolerance, if so by whom?

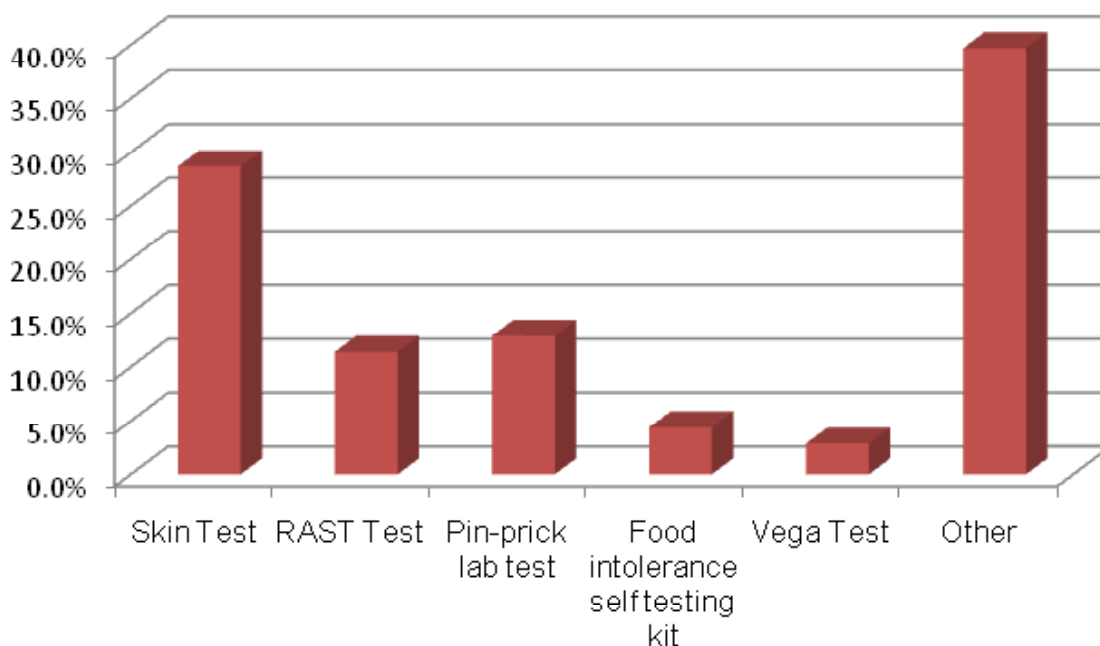


“My Health Visitor helped diagnose my son as he started vomitting at 3 months when trying formula milks, she suggested trying a fully hydrolysed formula - haven’t looked back since.”

“Seeking medical advice WAS a huge problem.”

We asked:-

How was the diagnosis carried out?



“Cut out gluten and dairy from diet, re-introduction caused very unpleasant side effects, however this is not recognised by the NHS who require 4 weeks of eating slices of toast per day to diagnose gluten allergy - which is basically not possible without becoming seriously ill.”

“Elimination diet combined with single blind challenges. Note that this was done in Australia, not here in the Third World!”

We asked:-

At the point of diagnosis of your allergy or intolerance, which of the following types of guidance/practical help were you given by your medical professional on how to manage your allergy?

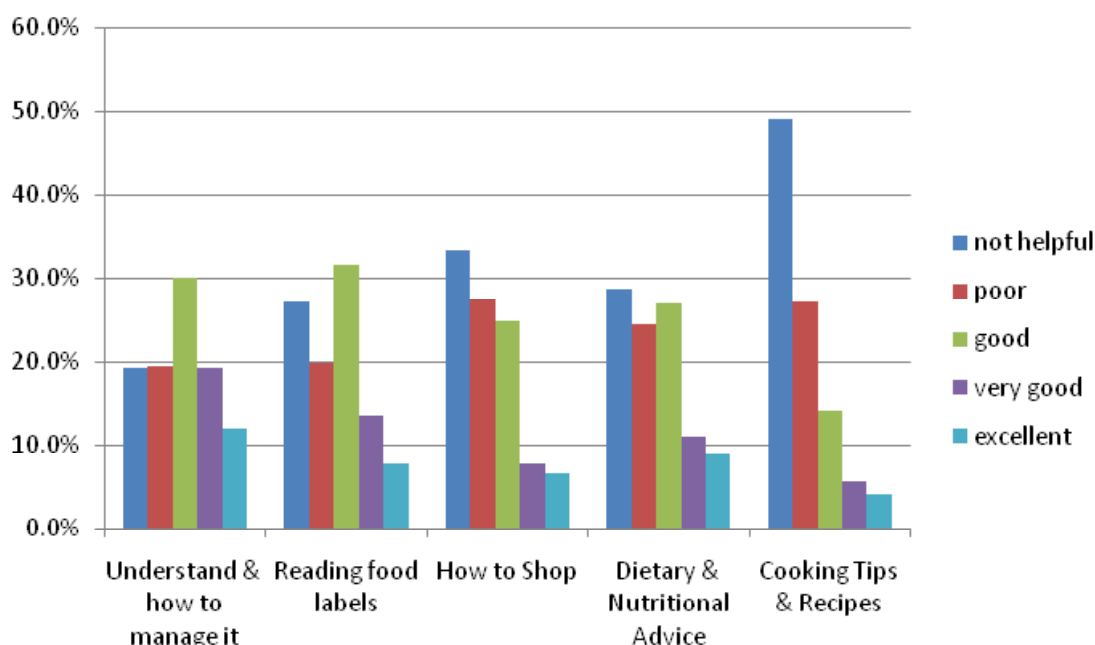


“Trial and error. I was told by my GP to keep a log of what I was eating to try to identify the trigger.”

“I was advised to read labels on the food that I buy, but was advised to cook fresh foods.”

We asked:-

How would you rate the quality of the guidance you received from your medical professional?



“I have found the NHS unhelpful and only interested in treating the symptoms with steroids, it has been a long and exhausting battle.”

“Presented at hospital with breathing difficulties after eating shellfish. I was advised to carry an epi-pen.”

“Exclusion diet followed by controlled re-introduction of foods. I was not given any advice on how to shop or cooking recipes.”

We asked:-

What are/were your main symptoms?

SKIN PROBLEMS



"I suffer from severe allergic reaction that can lead to anaphylaxis."

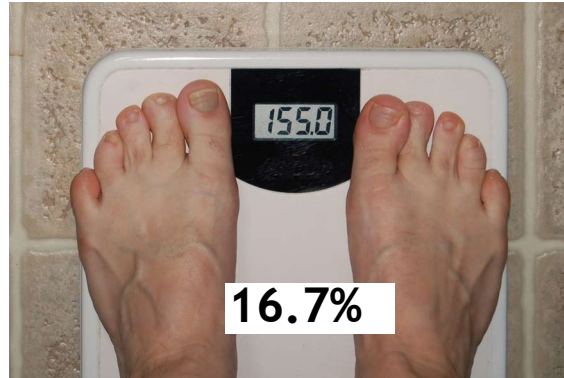
"Some foods make me very sleepy, almost immediately, others make me hyper - unable to switch off and relax."

"Extreme cases of hot & cold sweats, stomach cramps, severe bloating in the stomach, inability to leave the bathroom."



GUT PROBLEMS

WEIGHT PROBLEMS



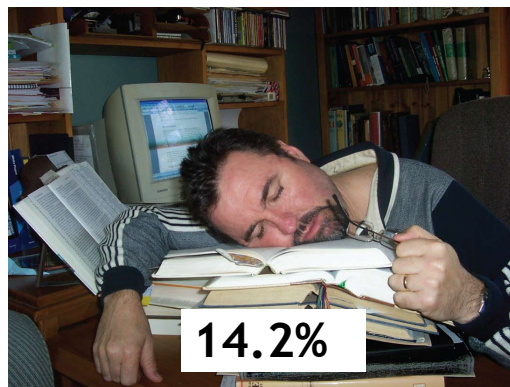
"I have lost about two stone in weight, my bones hurt and I have very little energy."

"Skin and gut problems are heavily linked, so that one is likely to be accompanied by the other."

"Depression and mood swings."

"Brain fog, cognitive difficulties & lethargy."

"I have to cope with lips swelling and difficulty in breathing."



SLEEP DISTURBANCES

HEADACHES/ MIGRAINES



"Persistent nausea, chronic acid reflux, extreme tiredness and weakness. Malabsorptions of vitamins and minerals."

"I have sinus problems and extreme fatigue."

"Blisters on my daughter's face and red blobs and very lethargic, and right eye closing. Sometimes sickness & diarrhoea."



OTHER

We asked:-

How long have you suffered from your symptoms?

- 1.7% of respondents reported that they have suffered from their symptoms for 1 week.
- 0.4% of respondents reported that they have suffered from their symptoms for 1 month.
- 9.1% of respondents reported that they have suffered several months.
- A staggering **88.8%** of respondents reported that they have suffered for years!

"It took ten years of trying to find out what was wrong, and only finally got resolved when I paid privately to see a GP with a special interest in allergy and intolerances."

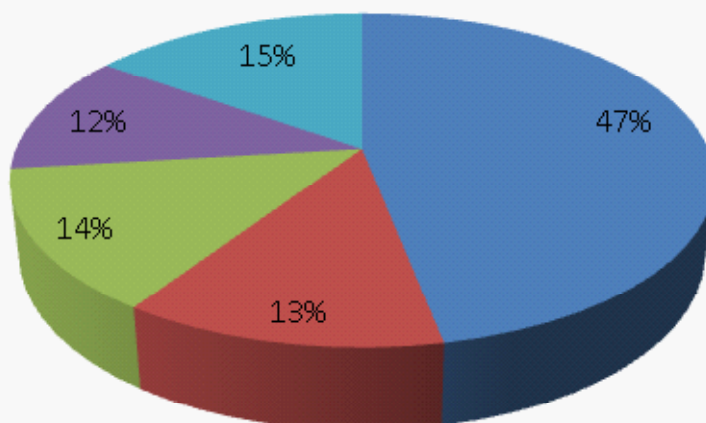
"Ongoing!!!!!!"

"I have suffered for years and once I had seen my GP who referred me to a Dietician it took 6 months overall - to identify my intolerances!"

We asked:-

How soon did you notice an improvement in symptoms once you avoided the food or foods that you reacted to?

■ Almost Immediately ■ After 1 Week ■ After 2-3 Weeks
■ After 1 Month ■ Other



"I noticed improvement to my symptoms varied between 1 week and 3 months, for instance, the quickest improvement was in my asthma the slowest was in my skin."

"Depends on which food - some were within days, others took a month before noticing any improvements."

"When I have sorted one problem another food problem raises its head."

"I still experience problems but not as bad as I used to be."

"I have a severe nut allergy, so total avoidance is necessary."

"Im OK as long as nut products are avoided, but just occasionally something will not be clearly labelled - holidays are a particular problem even with warning cards."

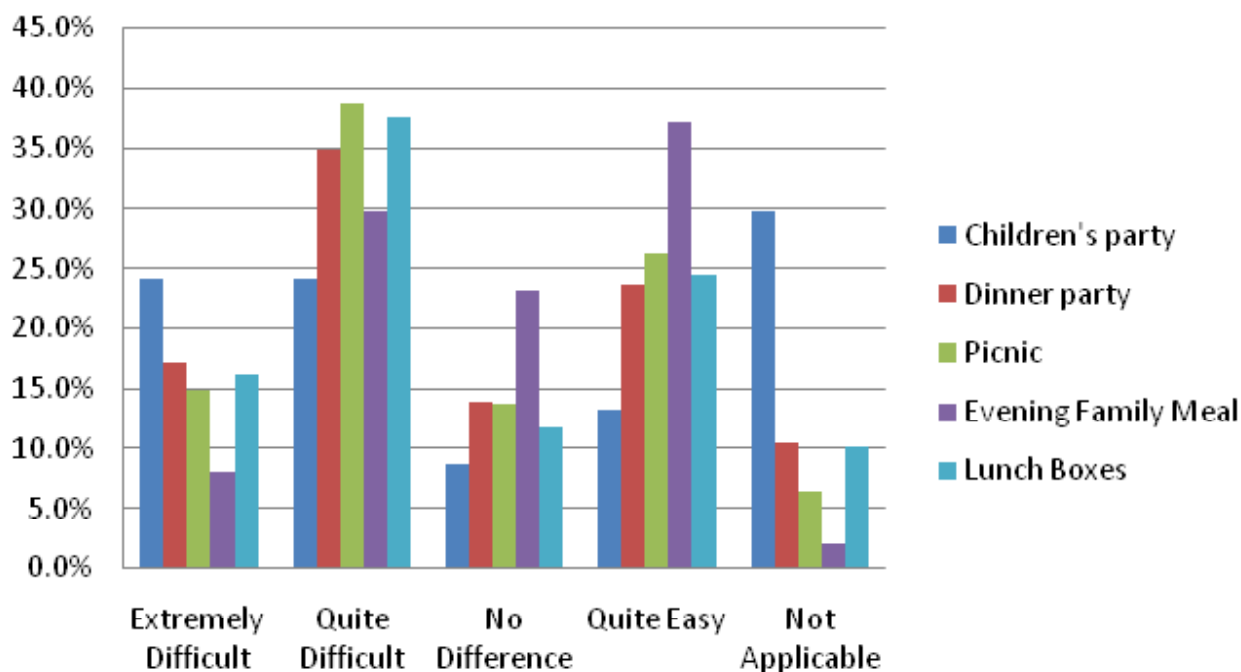
"It's a very slow process to eliminate enough food to make my symptoms settle down."

"It has taken years to identify all the allergens that I have an allergy to. It's very scary. I'm still struggling."

"No improvement as such, but no more life threatening reactions."

We asked:-

How difficult do you find the following events to cater for?



"It's a pain cooking for the family as a whole. I often eat separately."

"I think ahead and carry my own food, Business lunches are the worst as sandwiches are nearly always the staple menu."

"Cooking takes so much more time, which is hard if you work full time."



"It makes other people feel awkward and guilty when I eat with them. Has become a big issue within family and social life. Makes me feel bad."

"Eating out or at a family do is not enjoyable as people don't understand how serious it is if the food ingredient is not correct."



"Lunch boxes are a nightmare! Especially now there is healthy eating campaigns in schools."

"It's emotionally challenging for school age starters at lunch time without having to worry about their lunch."



"It is awful having to deny your children so many things that need not contain the allergen or trace of the allergen."

"I have three sons, two of which have severe anaphalaxis. I believe this is harder on them mentally than we could ever imagine!!!!."

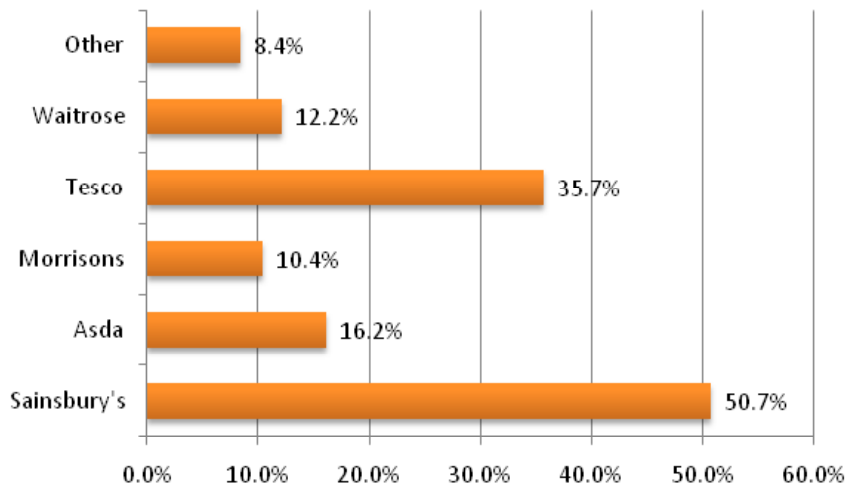


"My son feels left out as he cannot eat the same things as his friends and family. No one else can or will cook for him."

"Children have fads too - even allergic children."

We asked:-

Which supermarket do you shop in most frequently?



"I shop equally at Morrisons, Sainsbury's, Coop and Asda's."

"I do not use supermarkets. I shop at the local organic butchers, deli. Borough Market and Abel & Cole."

"I travel to Sainsbury's to buy lots of Wheat Free foods."

"I use local shops with fresh produce."

"I have to use Tesco's as I am waiting for Sainsbury's to open. Sainsbury's have a better variety of foods and better labelling."

We asked:-

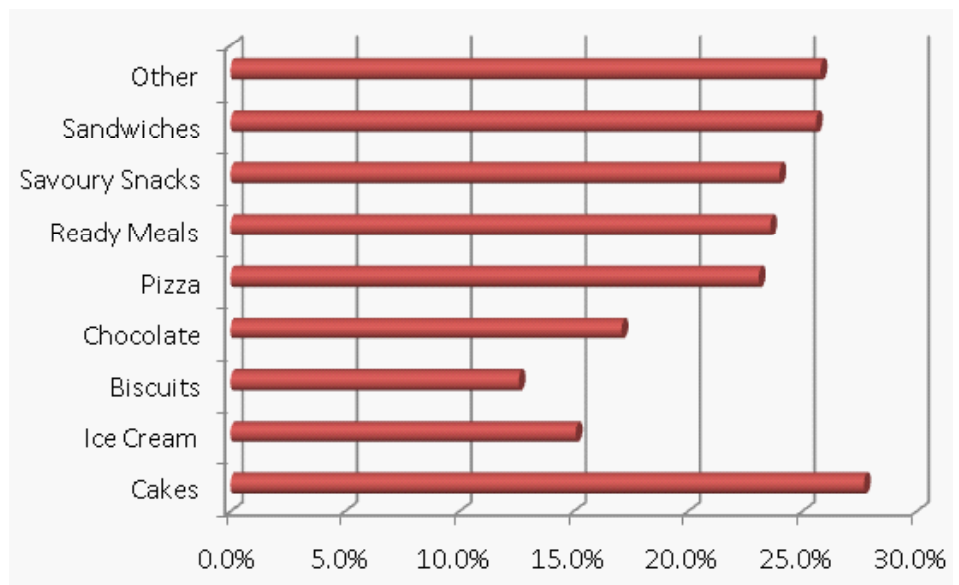
If there were two food items you would want to be able to buy, what would they be?

"Anything that can be eaten on the go!"

"Mayonnaise, coleslaw and quiche - I can only dream of having these."

"If labelling was better and less vague (may contain) life would improve immensely and could eat without feeling anxious all the time."

"Bread and cheese."



"Desserts that are non dairy and non egg. Bread and savoury snacks."

"Convenience foods, such as frozen roast potatoes."

"Birthday cakes for children and adults."

"Lactose-free yoghurt. Lactose-free cream - Soya substitute is not up to scratch."

"Things that are easy to grab for lunch and don't taste like cardboard."

"Bits and pieces for Christmas, decent biscuits, soups that don't have wheat flour in them."

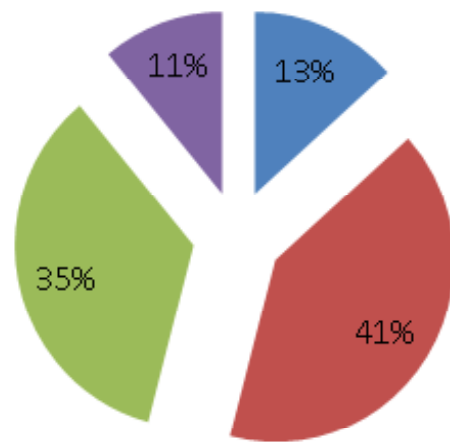
How confident are you that your supermarket can provide you with fresh, tasty and healthy products and helpful advice that are suitable for your allergy or intolerance?

“Grateful that we can buy a variation of most things at Sainsbury’s. When we travel to Turkey labelling is not very reliable. I totally appreciate our supermarkets here in the UK. It is vital that the impetus is kept up and improved yearly.”

“There are too many ‘may contain’ warnings, which put you off previously purchased food items.”

“The growing awareness of food allergy and intolerance amongst food manufacturers and the general public has actually made my life easier and safer.”

Very confident Quite confident
Not very confident Not at all confident



We asked:-

If you see the words ‘free from’ on the packaging of a product, what does it mean to you?

“This means different things in different shops, ideally this should be the same standard across the board.”

“Sometimes food that says free from are free from artificial flavourings, so you have to be careful to read the labels.”



“Overpriced, sterile and tasteless!!”

“No gluten.”

“Bad labelling - saying something that it’s not can be fatal to my daughter.”



“Hope! It’s free from the allergens or trace of the allergen and is therefore safe for my son to eat.”

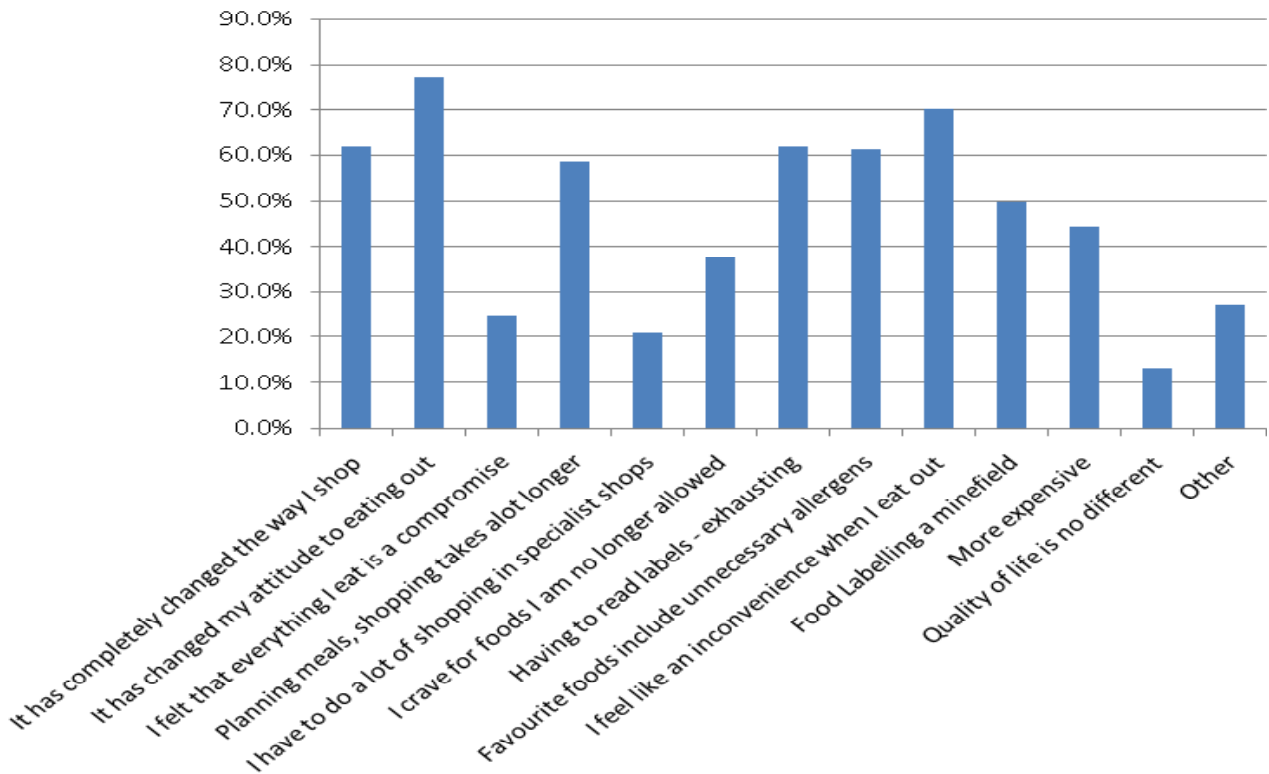
“Should be free from certain ingredients although you should read the labels thoroughly.”

“Experience has taught me that these words mean very little. We have seen ‘free from’ and believed the product to be free from gluten, wheat and dairy, only to find there is dairy in the product.”



We asked:-

If you have a food allergy or intolerance, how has it affected your personal quality of life?



“Restaurants are not interested and you feel like a social outcast.”

“I didn’t choose to have an allergy, supermarkets never seem to have offers when buying free from products.”

“I don’t feel like I socialise because of other people’s fear of a reaction makes life difficult.”

“Natural rubber latex should be listed on pre-prepared foods when the makers are using latex gloves or equipment - otherwise you have to get the bar code and enquire on each product and this often is ignored or unknown by producers.”

“My conditions affects my social life, my relationship and ways of spending time together.”

“I find it difficult to do online shopping when you have an intolerance.”

“It becomes a way of life, you have to adapt.”

“I have found travelling abroad is very difficult and complicated. Can’t get insurance!”

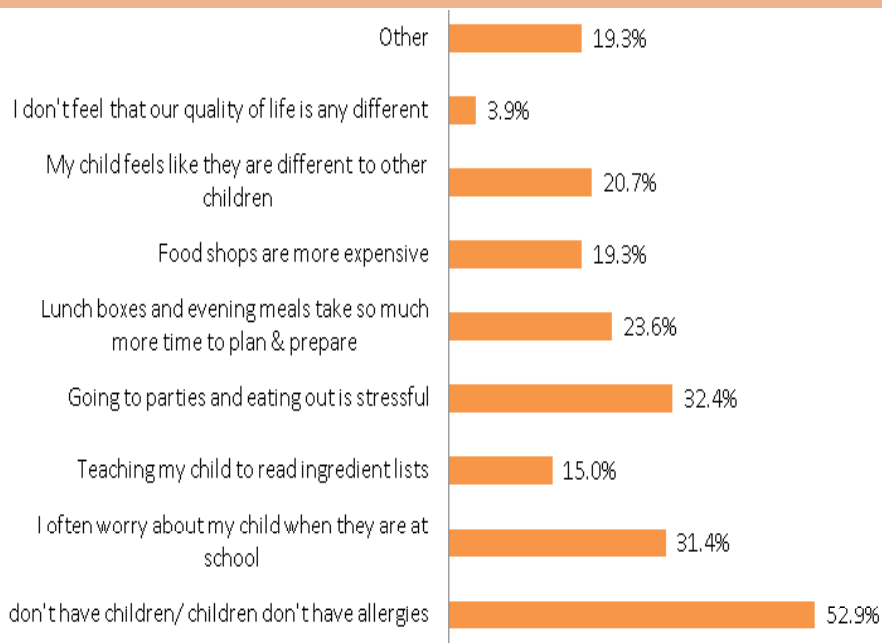
“Everything has to be planned in advance, and this can be very frustrating at times because I do like to do things at the last minute, and it often feels that our wings have been clipped.”

“I have no children as I would not put them through what has happened to me.”



Finally we asked:-

If your child has a food allergy or intolerance, how has it affected the quality of your family's life?



“My son is only 4, but has to be aware his allergy could kill him.”

“My child misses out on friends sleepovers, as their parent’s find it too stressful to provide safe food.”

Conclusion

This report highlights the need for not only better services to diagnose food allergy and food intolerance but also the need to find specialist foods easily at local supermarkets and at comparable prices to normal foods.

Particularly in the case of food intolerance sufferers, because of the lack of understanding in the medical profession around food intolerance, identifying what is causing their symptoms can be frustratingly difficult. Reliable, easy to use tests would be a way forward for sufferers. Thankfully there is now more choice available, Cambridge Nutritional Services Ltd have launched a new food intolerance kit called Food Detective™; which detects foods specific IgG antibodies, a simple to use food testing kit at a reasonable price. Information can be found on our website www.allergyuk.org

Everyday foods such as breads, pasta’s and sauces, party foods for children or even birthday cakes should be available for everyone, so that something as simple as preparing an evening meal should be an easy affair rather than what can be a nightmare.

The report has also highlighted the need for clear and easy to understand labelling; it was apparent from the report that many people believed the wording ‘Free From’ to mean various things; this could be a major cause for concern if people do not read the labels thoroughly. It was also clear that allergy and intolerance sufferers would like guidance on how to shop, as to the newly diagnosed this can be a minefield. Sainsbury’s came out on top for shopping with a food allergy or intolerance thanks to their excellent labelling and continued expansion of products.

Allergy UK and Sainsbury’s have listened to the needs of the allergy and intolerance sufferer and will be working together to address those needs.

Food Allergy & Food Intolerance Week 2010 and Stolen Lives 7 report has been supported by
Sainsbury's

Allergy UK is a national medical charity established to increase understanding and awareness of allergy and intolerances, to help people manage their allergies and to provide training in allergy for healthcare professionals including Doctors, Nurses, Dieticians and Pharmacists.



For further copies of this report contact Allergy UK on 01322 619898

Allergy UK Helpline Number (9am-5pm Monday - Friday) 01322 619898

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