

TOTAL FOOD ALLERGY/INTOLERANCE

“What is food to one man may be fierce poison to others.” Lucretius

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What is Total Food Allergy/Intolerance? by John Scott

Total food allergy/intolerance is a rare and largely unrecognised condition in which most or all normal foods cause an adverse reaction.

The effects of total food allergy/intolerance are devastating and frightening to those affected by it and medical support is minimal but, as more cases come to light, a clearer picture of the condition is emerging.

Total food allergy/intolerance appears to develop in those whose health is already compromised by some other illness, such as MS, Chronic Fatigue Syndrome/ME, or multiple chemical sensitivity (MCS), or as a direct result of an eosinophilic gastrointestinal disorder (EGID), in which eosinophils - a type of white blood cell - proliferate within the gut.

The reactions experienced by those with total food allergy/intolerance are possibly mostly due to intolerance - i.e. caused by some as yet unidentified mechanism - but some reactions may also be due to a true IgE-mediated allergy. The absence of a positive skin prick test result to a food challenge does not necessarily rule out the possibility of true allergy, because it is possible for allergic reactions to take place in the gut without producing positive skin prick test results, but these reactions can only be revealed by carrying out a COLAP test (<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1027199>). As COLAP tests do not appear to be used much, if at all, in the UK, nor food intolerance currently verifiable by any means, and as UK doctors will only accept the existence of a condition which they can validate via clinical tests, recognition and acceptance of total food allergy/intolerance is problematic.

The typical response of doctors, most of whom will rarely, if ever, see a case of total food allergy/intolerance, is to attribute any symptoms not verified by clinical tests to psychological causes - either in the patients themselves, in the case of adults, or perhaps in a parent when the patient is a child (fabricated or induced illness (FII), previously known as Munchausen's syndrome by proxy). However, when patients have had a psychological evaluation, this has invariably found no psychological problem.

The onset of total food allergy/intolerance can be rapid, but a creeping progression of symptoms over time appears to be more common. The exact nature of symptoms can vary with different foods and between different people. As ever more foods begin to cause reactions, finding anything to eat that does not cause an adverse effect becomes progressively more difficult and may eventually become impossible.

Although there is no known cure for total food allergy/intolerance at the present time, medicine does have the means to manage this disorder, and thereby to keep people alive, by using special medical feeds and other alternative methods of feeding which were developed to manage a variety of different conditions. However, expertise in using these approaches to treat total food allergy/intolerance is virtually non-existent.

Semi-elemental feeds have proved to be the best tolerated form of food - better even than fully elemental feeds such as Elemental 028. Best of all are the semi-elemental infant feeds - even for adult sufferers. Peptidite and Neocate (SHS International) and Nutramigen 1 (Mead Johnson) have all been found extremely helpful by some adult patients. (NB. Nutramigen 2 does not contain sufficient protein for adults.)

In 2009, it emerged that helminthic therapy can provide effective, long-term remission from the symptoms of total food allergy/intolerance. Since then, several patients with this disorder have found relief after infecting themselves with a safe dose of benign, therapeutic helminths, and lives have been saved as a result.

If helminthic therapy is used, it needs to be introduced VERY gradually in anyone with total food allergy/intolerance. For more information about helminthic therapy, see this blog post: <http://gut-buddies.com/wordpress/helminthic-therapy-2/>

Personal experiences

There is light at the end of the tunnel... by Isobel Bracewell (Foods Matter October 2006)

To all readers of Foods Matter - have hope - there is light at the end of the tunnel I have had, and still have, many problems relating to food - but at this time last year it was doubtful whether I would even see the year out.

I am 64, an ex-nursing sister, and have multiple sclerosis. I have always enjoyed life and over the past years have become very involved in caring, disability and Quaker issues.

Allergy onset

Three years ago, after being prescribed aspirin, statins and betablockers for high blood pressure/cholesterol levels, I began to have severe food and allergy problems. Previously I had only been allergic to fish and penicillin, although I did carry an EpiPen.

Doctors refused to believe that I could possibly be reacting to so many foods, despite an anaphylactic episode and an emergency hospital admission. I frequently had tingling or swollen lips and tongue, breathing difficulties and sometimes was unable even to swallow water. These were not panic attacks or hysterical reactions.

Ditching the drugs

Two years ago when in hospital for tests, a South African consultant, here as a locum, suggested I come off all medication to see what would happen. As a result, all heart problems, blood pressure and muscle pains cleared. By this time I was on daily antihistamine tablets but, after discharge from hospital, we were left to cope as best we could with the worsening food symptoms.

Left to cope alone

My husband and I felt totally alone - isolated and abandoned. What would the future bring? It was a very dark time indeed.

We do have wonderful GPs who would see us in emergencies but one could feel their frustration at not being able to help. They told us 'We can only be advised by specialists who don't know what to do themselves.' There is only one part-time allergy specialist in Scotland. He was in Glasgow and I was too ill to travel even if an appointment was available.

Starving to death

After losing 8 stones in weight, my muscle tone was poor and, physically, I was very weak and limp. My clothing was smaller by 12 sizes. My husband and I were at the end of our tether. I had no quality of life - I was just existing. My funeral service was planned, and death would have been most welcome.

It was at this point that the charity Action Against Allergy' gave me details of a state registered dietician in the local private hospital who had a special interest in people with food allergies and intolerance. When all hope had almost gone she threw us a lifeline.

Finding the formula

After a full consultation she said that I needed to start on elemental formula feeds immediately. The proteins in elemental formula, which are used mainly for ultra-allergic babies, have been broken down into their constituent amino acids so that there are no proteins left against which the system can react.

I had to stop the six foods which, by then, was all I was able to take, as she was uncertain as to which of them was still causing reactions. She wrote to my GP for a prescription and asked him to refer me to a gastroenterologist who had a special interest in nutrition. His private waiting list was even longer than his NHS list!

My body had been so malnourished for so long that it would only accept a very low dosage of the formula (I used the infant formula, Prejomin - unfortunately now discontinued) at a dilution greater than recommended. Very gradually I increased the quantity by two and a half grams each day, or according to tolerance.

There is an adult formula more familiar to doctors, and used by hospitals, called Elemental 028 Extra Original SHS. It nearly killed me after only 131/2 grams.

Hospitalisation

My 'urgent' appointment with the gastroenterologist for hospital admission took six months so, without Prejomin I would not have survived. My GP said, on one visit, "I hope we get you in in time." My husband and I just looked at each other.

When eventually I was admitted the consultant wanted me to receive hospital formula (to which I had already reacted badly) by nasogastric tube, then they would give me a percutaneous endoscopic gastrostomy (PEG).

I refused as by then I had gained almost one stone in weight, my muscle tone was good and life was looking more positive. Also my faith in modern drugs and treatment was shattered. As it was the drugs that had made me ill, I was very reluctant to accept more interference when healing was taking place.

After many tests, it was confirmed I had multiple food and drug allergies - as my husband and I had been trying to tell doctors for so long. The consultant said that my body appeared to have an adverse reaction to food and only appeared to tolerate nutrition in the elemental form. I was also salicylate sensitive but he didn't know why these reactions had occurred.

Getting better and better

Living almost entirely on the elemental diet for 18 months has allowed my digestive system to rest and gut healing to occur. I feel better now than I have felt for years. As a bonus, the multiple sclerosis has improved dramatically, and I now have full use of hands and arms, increased mobility indoors and better bladder control. The optician can't believe the visual improvement, my finger and toe nails are growing again and my hair is thickening.

In April I decided to try taking FOS fructooligosaccharide powder from Biocare (dosage one rounded teaspoonful a day). This has helped my body to accept a few foods again. It will be a slow process and I have been told that I will be on elemental formula for a very long time but I look forward to the day I will be able to enjoy the superb recipes which appear regularly in Foods Matter.

More formula please

Too many people are, I fear, struggling to exist on too few foods on a minimal rotation diet. As a result they end up malnourished and less able to handle food.

My consultant wrote (and other professionals would agree) "The number of patients who have to go on to elemental diets is extremely small. The vast majority of people can be managed by other methods and do not have to see an allergy specialist."

I disagree. It appears to me that many professionals are unaware of elemental diets and their value, even in the short term, for people with multiple food intolerances.

Do please contact me, on 01224 484957, if you wish to have a chat. I feel so fortunate.

Source: http://www.foodsmatter.com/allergy_intolerance/personal_histories/articles/isobel_b.html

Annabel's Story by Richard Senior (ME Essential Spring 2003, and Foods Matter Jan 2008)

She was born Annabel Robinson, on the 4th March 1942, eldest daughter of Squadron-Leader 'Robbie' Robinson, who had commanded 73 (Hurricane) squadron in the Battle of Britain. She died on 8th January 2003, two months short of her 61st birthday. Too young to die.

Sent to boarding school in her mid-teens, she began to notice how quickly she got tired, and how difficult it was to keep pace with her peers. In spite of this, she excelled at everything: athletics, gymnastics, games, drama, art, music, and above all, examinations. So much so, that she easily achieved a place at Oxford, and only narrowly missed a First - simply because by now she was unable to work more than two hours out of 24, sometimes taken in the middle of the night.

She realised she would need support, from whomsoever would give it, because she now knew that she would not be able to cope on her own. She therefore accepted the first offer made to her, and was married before she graduated.

For the next 30 years, she struggled with what was easy for most people, including raising a family of three, but was never able to hold down a job of any sort, because of her crippling lack of stamina. Her first husband died, and she and I were married in 1979. She disguised her condition so well that it was some time before I realised how ill she was.

Smells affected her very badly - they seemed almost to drive her to distraction. Noises terrified her, bright light blinded her. And, worst of all, she began to react violently to foods, one after another.

ME diagnosis

Not until 1990 did we realise what was wrong: ME/CFS. There was some treatment about by then, but limited, and we took what was on offer. Even if it had been the right treatment, by that time it was too late: so many years of neglect, disbelief, wrong medication, wrong diagnosis, so many referrals to psychiatrists who, to a man, sent her away because they couldn't find anything wrong - with a prescription for an anti-depressant just in case...

Dwindling diet

The foods that she could eat without becoming very ill dwindled in number. She coped with this situation for two to three years by going on a semi-fast, say four to five days, and then trying again. Bit by bit the 'good' days became

fewer, and by the autumn of 2002 there was virtually nothing left that she could eat with impunity, Her heart also began causing trouble around this time.

Forty-five years with such a condition, misunderstood and un-recognised for most of those years, is enough. Many people would have given up long before that. Annabel NEVER gave up; she simply found that there were no 'safe' options left - and stopped eating altogether.

She survived for 52 days - and died at home, with me by her side. Had she been born say, 20 years later, this need never have happened. Today there is palliative treatment for this appalling illness available, but no definite cure in sight yet. In her young days there was simply nothing around.

CFS/ME seems to bring out the best in people, Annabel was an outstanding example of this, in that she poured all her available efforts into helping people, particularly those distressed or in emotional trouble of some kind.

She helped many such people, who kept in touch with her till the end of her life, many years after she had 'rescued' them and restored their confidence in themselves, in some cases even preventing them taking their own lives. She touched many lives, even though so very many never even met her.

She will be greatly missed. She was greatly loved. This is a bald and inadequate account. There is so much more that I could say about this incredibly courageous and loving woman.

Source: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/annabel_senior.html

Total food intolerance - a medical black hole by John Scott (Adapted from articles originally written for Foods Matter 2004-2007, and updated.)

Twenty seven years ago I began to experience excruciating abdominal pain after eating sweetcorn. Then, one by one, other foods began to have the same effect, but my GP could find nothing wrong with me nor offer any constructive advice. Left to my own devices, I could only avoid those foods which caused the problem.

The pain I experienced after eating problem foods could be excruciating, would usually last for several hours and was always followed by several days of abdominal soreness - described by medics as gastritis. Once a food had begun to be a problem it would continue to cause a reaction whenever I ate it, even after avoiding it for a considerable length of time, and the list of offending foods grew steadily longer.

Doctors listened impassively to my accounts of these painful episodes and invariably prescribed antacids, which were of little help. Eventually, however, I found a solution of sorts myself, when I discovered that a large dose of Epsom salts, taken immediately the reaction began, could greatly shorten the period in pain, although it also inevitably resulted in diarrhoea.

Psychiatry, allergy and disbelief

With my GP insisting that there was nothing organically wrong with me, I asked to be referred to a psychiatrist.

I was offered a course of cognitive behavioural therapy but, after a few sessions, was told categorically by a psychotherapist that there was absolutely nothing wrong with my mind. I was advised that the problem was most likely due to allergy and was bounced back to the GP, who said that there was no specialist allergist locally to whom he could refer me.

A private allergist diagnosed multiple allergies, following skin prick tests, and introduced me to rotation diets and diet record keeping but, as more foods began to cause severe reactions, I was increasingly forced to rely on more unusual foods and, eventually, I became restricted to just a few rare foods, sourced, often at considerable expense, from obscure suppliers.

For several years, my life was dominated by my bizarre diet: the acquisition and preparation of special foods - purple yams, pumpkin seeds, tapioca and the rest! - and the necessity of always having to ensure that I had sufficient food to meet my needs, wherever I might be. I also had to be prepared for the development of new sensitivities to even these foods, and the episodes of intense pain that this always entailed.

A new GP diagnosed both anaemia and scurvy, due no doubt to my restricted diet, and referred me to a gastroenterologist. After carrying out an endoscopy, this specialist told me that there was nothing wrong with my gut, other than some inflammation. He dismissed my pain as imaginary and told me and that I should "go away and eat a normal diet". When I tried to discuss the possibility of allergy, he declared "I don't believe in allergy"!

ME and yet more specialists

Then, following a particularly debilitating viral infection, I became perpetually exhausted and began to react, with a variety of symptoms, to an even greater number of foods.

After seeing several more specialists, I was told that I had ME and, eventually, I had to retire, aged only 44. However, the interminable rest did little to reduce my exhaustion and the problems with food continued to escalate.

Soon after this, an emergency admission to a different hospital, during an acute reaction to a new vitamin tablet led, very belatedly, to a firm diagnosis of "long-standing food allergy associated with ME". I was given ranitidine to ease the gastritis, domperidone to improve my gut motility, and put on the sip-feed Ensure Plus.

It had taken the medical profession over ten years to acknowledge the serious nature of my illness and offer appropriate treatment for some of its consequences, though there was still no interest in further exploration with a view to identifying and possibly correcting the underlying problem.

I picked up quickly while taking the sip-feed but, all too soon, began to react to even this, and then to the alternatives suggested by the hospital dietitian. I consulted numerous other specialists, including more gastroenterologists and some of the best allergists in the country, and I tried every treatment that was offered, including desensitization to several foods, but none was successful.

My own best doctor

Finally, one eminent allergist admitted that there is no successful treatment for this problem, which he said is definitely organic and caused by some as yet unidentified mechanism, possibly enzyme-related. This specialist advised that avoidance of everything that upsets me was the only remaining treatment option, and he 'reassured' me with accounts of several other patients who were managing on extremely restricted diets, including one lady who could only eat potatoes.

When this consultant added that I would be my own best doctor, I took him at his word and personally contacted all the manufacturers of special medical feeds, in the hope of finding a tolerable alternative to Ensure Plus.

I discovered that there are a number of hypoallergenic 'elemental' and 'semi-elemental' formula feeds available, which no doctor or dietitian had ever mentioned to me. I began to try these, and my current GP, who has always been sympathetic and supportive, prescribed the ones that I found I could tolerate.

As there were, by this time, only a handful of normal foods which did not cause an adverse reaction, I was dependent on a special feed of some kind to maintain adequate nutrition and weight and, thus, to ensure my survival. However, all the adult versions of both the semi-elemental and elemental feeds eventually, if not immediately, caused an adverse reaction, which now included intestinal bleeding in addition to the usual pain. Fortunately, however, I found that I was able to tolerate powdered semi-elemental *infant* feeds surprisingly well!

For the next few years, I alternated the semi-elemental infant feeds Nutramigen and Prejomin but, eventually, even these began to produce symptoms, with some batches being more of a problem than others. Taking digestive enzymes helped somewhat, for a time, but I had to stop using Nutramigen when this was reformulated to meet new EU regulations. Then, in 2004, Prejomin also began to cause a continuous, nagging discomfort, which I could not find any way to prevent.

As it looked like I might finally be out of options, I asked my GP to refer me to an immunologist, to explore the possibility that an over-active immune system might be responsible for my reactions to food and that the use of medication to reduce my immune response might offer a way forward.

Dogmatic dismissal

When I met the immunologist in his allergy clinic, he promptly dismissed my reports of excruciating pain after eating normal foods, and declared, "Food is not the problem, YOU are the problem!" In other words, he thought it was all in my head!

He rubbished the advice of the previous allergist (a respected pioneer in the field of allergy research) to avoid anything which consistently causes pain, and told me, instead, to start eating a wide and balanced diet and, crucially, to change the way I think about how I will react to what I eat!

I was given no advice as to how I might accomplish this feat, nor offered a referral to someone who might help with this. Indeed, when I requested just such a referral, the suggestion was brusquely dismissed.

This, I realised, is the 'evidence based' approach to medicine, in which clinical tests are the only truth, and any evidence from the patient which appears to point in a different direction from established dogma is deemed heresy.

Without actual physical evidence, doctors will not consider the existence of a biological problem, and the only evidence that would have been admissible in my case is a positive skin prick test result proving the existence of a 'true allergy' to food - the only reaction to food which doctors will accept.

Practitioners of evidence based medicine appear not to recognize the fact that all medical tests have limitations, that tests only exist for conditions that are already understood, or that each patient is unique and, as a result of living inside his or her body 24/7 for many years, inevitably knows far more than any doctor about its individual reactions.

A step forward, 26 years late

Having been dismissed by the immunologist, without any constructive help whatsoever, I could only continue to live on the Prejomin, the effects of which continued to worsen during the next two years, particularly the pain and bleeding from my gut and, eventually, my GP referred me to yet another gastroenterologist.

This new specialist acknowledged that I had previously been passed around from pillar to post and agreed to carry out a full work-up of tests.

He was only the second of the fourteen consultants I had seen thus far to look any further into my intestines than the short reach of an endoscope, and he began by ordering a barium follow-through X-ray to examine my entire small intestine. This revealed two strictures, along with a grossly enlarged section which the surgeon said could have 'exploded' at any time, with potentially very serious consequences.

When the diseased sections were removed and analysed, it was confirmed that I have Crohn's disease. (So much for the assertion by an earlier gastroenterologist and the immunologist that the problem was all in my head!)

Although the removal of the strictures has meant that I no longer have any severe pain, I do still experience the same range of other symptoms after eating any normal food. However, the gastroenterologist who found the strictures can see no reason for the occurrence of any further symptoms.

So far as he is concerned, my gut had been restored to normality, so I should once more be able to eat anything and everything. Accordingly, he advised me that I have a choice between either continuing on what he called my 'self-selected' semi-elemental diet or being 'bold' and trying normal food again.

Just for him, I once again tried a selection of common foods, recording the unpleasant and debilitating reactions which I experienced on eating each of them, and gave him a written report of these, but he remained unconvinced.

In spite of the fact that my previously reported pain and bleeding had been proved to be the result of genuine organic disease, the specialist could still not bring himself to consider that my reports of continuing adverse reactions to food might also be genuine. Here was another dedicated follower of the cult of evidence based medicine!

I am, of course, immensely grateful to this consultant that the severe pain, which I had experienced for 26 years, is no longer on my list of symptoms, and I realise that he sincerely believes that he has now done all that he can.

However, I am now unable to find any local hospital consultant who will accept that I genuinely react to all normal foods, and I am left able to eat only two types of semi-elemental infant feed, both of which also now cause a number of symptoms, some of which are worsening progressively.

Through the back door

As has so often been the case in this saga, I was once again forced to rely on my own ingenuity and, still wondering whether immune modification might be an effective means of reducing my symptoms, I decided to cash in on my recent diagnosis of Crohn's disease. I used my newly acquired status to get myself into a clinical trial designed to test the possibility that the immune modulatory effects of infection with a particular species of hookworm might have a therapeutic effect on this condition.

I was undeterred by the fact that immune involvement in my case had been dismissed by a local immunologist - the one who said that *I* was the problem and not the food that I ate! It still seemed logical to me that a down-regulation of my immune system might prove beneficial for my food intolerance, and the truly scientific approach is surely to test all possibilities.

Quite suddenly, about four weeks after I was given either a hookworm infection or a placebo, my bowel habits normalised somewhat, abdominal discomfort decreased, sleep improved, itching at eczema sites eased, perennial rhinitis dried up completely, and a persistent nocturnal throat irritation was also much reduced - many of my chronic symptoms eased at a single stroke!

I began to try some normal foods and, after initially mixed results, began to have some real success towards the end of the trial. Foods which had previously caused a variety of symptoms, including bloating, nausea and abdominal soreness, increased malaise, headache and inappropriate shivering, now produced less severe symptoms and, in a few cases, no symptoms at all.

Following eradication treatment, at the end of the trial, all these positive changes were gradually reversed and I was forced to revert once more to a solely semi-elemental diet, but was buoyed by the possibility that I may have found at least a partial solution to my problem with food.

On the strength of these results, I managed to persuade my current specialist to authorise a long-term 'infection' with hookworms, ostensibly to help me control my Crohn's disease, but also to enable me to continue experimenting with normal foods. At the time of writing, I am awaiting an appointment to collect a new worm infection...

Source: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/tfa.html

Total food intolerance in 2008 by John Scott (Foods Matter Jan 2008)

Judging by my own experience, and that of a number of others, there has been no positive change in the medical attitude to total food intolerance since the death of Annabel Senior (see Annabel's Story, above). In fact, doctors appear to have hardened their attitude somewhat, as strict adherence to the principle of 'evidence-based' medicine has become more widespread.

Patients still being dismissed

One lady recently reported that she has developed a 'very strange intolerance to just about every kind of food', with a vast array of symptoms, all triggered solely by food or drink. These include tremors, dizziness, numbness, rapid heartbeat, tightening in throat, tingling in arms and legs (usually on one side only), shortness of breath, irritability, daily bouts of diarrhoea, feeling extremely cold and exhaustion.

The attacks of symptoms happen even at times when just sitting on the sofa relaxing - but always after putting food or drink in her mouth.

She has not lost her appetite, and in fact craves food, but is finding it increasingly difficult to find any foods that do not bring on the symptoms, and is having to get by on literally just a few tiny bites of food each day and a few mouthfuls of liquid.

Already extremely thin, with energy at an all-time low, she is now unable to lead a normal life, and has had to call on a relative to help care for her two small children.

When she presented this scenario to her GP, he sent her for blood tests for anaemia and thyroid function but, when these came back normal, she was given the clear impression that the GP believes the problem must be psychological.

At a further appointment, she tried to give her GP a print-out from the internet about total food intolerance but he just waved it away, saying "I don't believe anything off the internet!"

There was no offer of a referral to a specialist for further investigation, and the GP closed the discussion by telling his patient that she might want to find another doctor, because he didn't know what was wrong with her!

The ultimate question

The question remains as to how hospital doctors would respond if my condition was to worsen still further. Would they offer to feed me intravenously, as my ever-supportive GP has already suggested, and as is routinely done for patients with several conditions which affect their ability to ingest and absorb food in the normal way? Or would they turn me away on the grounds that the solution lies in my own hands?

According to the last few consultants I have seen, all I have to do is eat a 'normal, balanced diet' and think positive thoughts about how I will react to this, though none has given me any advice as to how I might accomplish this feat, nor offered to refer me to someone who might. (And the fact that an NHS psychotherapist has already determined that there is absolutely nothing wrong with my mind is completely disregarded!)

One would hope that no doctor would refuse treatment on these grounds, but I am not convinced that they would not and, in this respect, we are no further forward now than when Annabel Senior was allowed to die after running out of foods that she could eat without suffering severe reactions.

Annabel was never offered intravenous feeding, nor even told about hypoallergenic formula feeds, at what sadly became, but should never have been allowed to be, the end. And no-one at my local hospital has said anything to make me think that I would be treated any differently, if I was to lose what tolerance I still have left to the two remaining semi-elemental infant feeds.

The two-edged sword of evidence-based medicine

In the late eighties and early nineties, I had seen three allergists, all of whom recognized the reality of my reactions to food and tried valiantly to help, using every treatment option available to them. Now, however, the medics of the noughties, including an allergist (a professor of immunology), all dismiss my symptoms as psychological because they do not fit current medical theory.

Today's evidence-based approach to medical treatment has done much good in terms of discouraging the use of medical practices which have no evidential foundation of proof, but it has also encouraged doctors to dismiss some forms of evidence - such as that provided by patients - as inferior, and to consider this inadmissible in the absence of clinical corroboration. Consequently, patients with some conditions are routinely blamed for causing their own symptoms ("It's all in your mind!") and are turned away without appropriate help.

Guilty until proven innocent

If a patient has one of the conditions which doctors now cynically refer to as 'controversial' - food intolerance, multiple chemical sensitivity or electrical sensitivity, for example - no amount of reasoning is likely to be able to break through the hard line which doctors will present to them.

Although research is beginning to appear on the horizon which offers hope of evidence for a link between food intolerance and disease (see <http://www.medicalnewstoday.com/articles/76578.php> and http://www.foodsmatter.com/allergy_intolerance/miscellaneous/articles/igg_emmanuel.html), it will be some time before sufficient corroborative data is gathered to convince doctors, and it can take years, even decades, for new research insights to filter through to and be accepted by the majority of medics.

Meanwhile, those of us who have total food intolerance will no doubt continue to be held guilty of imagining or fabricating our own symptoms, because no means exist currently by which we might produce acceptable evidence to prove ourselves innocent. So, whilst the technology exists to manage this disorder, information about, and access to this are likely to continue to be denied by doctors.

Whilst understandable, in the context of twenty first century medical dogma, the current attitude of doctors to those with total food intolerance is nevertheless deplorable, and I consider it totally unacceptable for anyone working as a healthcare professional to dismiss as self inflicted my own two and a half decades of suffering from the effects of this condition. Yet, what is one to do? Doctors are their own judge and jury and there is no effective appeal against their judgements!

A solitary but welcome ray of hope

Although acceptance of total food intolerance by doctors appears to be as far off now as when Annabel Senior was alive, her death and the reporting of her story by her husband Richard, were the catalyst which eventually led to the mounting of the total food intolerance information section on the Foods Matter website.

Thanks to them, this unique repository of information, comprising articles and personal stories by sufferers and their carers, is now available worldwide to anyone who is affected by this devastating condition. Check it out at: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/index_total_food_intolerance.html

Source: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/tfi_2008.html

Clare's story by Clare Greasley (Foods Matter Oct 2012)

After a few stressful years things changed and life looked as though it couldn't have got better for us. I have a wonderful husband and two fantastic kids. My husband has his own business which is stressful for him at times. I don't have to work, which is great because it has given me the time to look after the family and take away any additional pressure from my husband. My job was to run the house, and life was busy with two teenage kids and a dog.

My day would start with breakfasts, packed lunches and the school run. I'd meet my friend and we'd walk our dogs for over an hour every day. Some days we'd take a drive out to the Derbyshire Dales and spend all day walking. I'd pick the kids up, make tea, help with homework, ferry kids around to various activities and do what mums do.

The start....

I've always had a good appetite, been able to eat anything and enjoyed cooking. I loved my life.

In the spring of 2011, I began getting abdomen pain, stomach and side pain. I went to my GP who arranged for a few tests to be done. I had an ultrasound, endoscopy and X-ray, which were all normal. Over the summer the pain began to get worse and I felt generally unwell. I also began to get cystitis regularly and I kept getting a hoarse throat.

I went to A&E a couple of times during the summer of 2011 as the pain was so bad, but they sent me away with Buscopan. By October, the pain was so bad that I returned to A&E. This time they kept me in for a week. I had a CT scan, which showed a narrowing of my colon, and a colonoscopy, which was normal. They sent me home and told me to forget about it and go on holiday - suggesting that it was all in my head.

Could it be something that I am eating?

It was after my stay in hospital that I began to wonder if it was something I was eating that was causing my pain. I knew I ate a lot of cereals and milk so I began a gluten-free diet and kept a food diary. After a couple of weeks, I began to feel slightly better but still not completely well.

I had further tests done at Christmas 2011, including another endoscopy with biopsy and a barium X-ray. These were again both normal. I continued my gluten-free diet over Christmas and had mostly good days with a few bad.

On the 26th January this year I had extremely bad abdominal pain that was caused by brown rice. I have never known pain like it, I was in agony for three days. A week after that I had another colonoscopy, and again it was normal. The doctors sent me away with no answers about my pain.

Pure Health Clinic tests

Ever since I had the brown rice in January, I have been extremely unwell. In desperation for some help with my pain and terrible malaise, I hunted the internet for some answers. I found a wonderful nutritionist, Micki Rose, who arranged for me to have some allergy testing done and a gene test.

I had blood taken on 20 February and sent to a laboratory in America. I had IgM, IgG and IgA tests done on 96 foods. When the results came back, they showed intolerances/allergies to lots of foods. My gene test came back positive for all four HLA-DQ gluten sensitive genes.

Gluten sensitivity

My nutritionist, having spent years studying the effect that gluten has on the gut in genetically pre-disposed people, explained that gluten causes the intestinal wall to become permeable, allowing food particles to enter the blood stream. These undigested particles are then attacked by the body's immune system (like a virus). The body then remembers the invader and every time you consume that food the body attacks it. That is how allergies and intolerances are created. I knew my gut had become 'leaky' from the gluten damage but if I followed my nutritionist's diet and gut repair plan, then I thought that, although very restricted, there were enough foods for me to live on. She also explained that there is gluten in corn and rice as well as wheat, barley, rye and oats. At last I thought there was a light at the end of my tunnel, but I couldn't have been more wrong!

But not just gluten - everything...

As the weeks went by during Spring 2012, the intolerances became far worse. I started reacting to many more of my 'safe' foods too. I began to realise the seriousness of my situation. I knew what was happening to my body and I became very scared. I had another gastroenterological appointment in March, where I saw a registrar. I told him that my body was reacting to all these foods and how frightened I was. To my horror, he laughed and told me it was not possible to be intolerant to everything!

A few more weeks passed. I suffered terrible malaise, pain all around my abdomen, headache and migraine, sore throat, cystitis and rashes, and my hair began falling out. I'd lost 4 stone in weight since October. Eventually I collapsed at home in April and was again admitted to hospital.

I was in hospital for four weeks, during which time I had every test going, including gastroscopy, CT scan, capsule camera, and various blood and urine tests. I was seen by an immunologist, a professor, several gastroenterologists, an allergist, dieticians and a dermatologist, but they could find no reason why I could not tolerate food. The only thing that has shown up so far is some inflammation of my stomach. I was fed on Elemental 028 for a few days via a nasal tube, but that made me extremely unwell. I was then put on intravenous TPN (Total Parenteral Nutrition) for 8 days, and I even reacted to that! My body was reacting to everything!

It's not IgE so it doesn't exist...

It's now October 2012. I have seen probably hundreds of NHS doctors, nurses, and dieticians, etc., over the past 18 months. I have spoken to every one of them about my severe food intolerance, but food intolerances are largely unrecognised by the medical profession. The problem is that they do not have a test that proves what I say is true. They would rather think it's in my head! The only allergy tests that they recognise are those that create an IgE reaction. They will not accept my IgG, IgM & IgA tests as evidence.

Another consultant gastroenterologist told me this week that IgG immune reactions are the type of reaction you get when the body finds a virus or foreign invader, which is my point exactly. My body has created antibodies to my food because it thinks I'm being invaded by a virus.

A couple of Doctors have admitted that science hasn't given them answers to everything, and that they still have a lot to learn about the immune system.

I am an extremely poorly lady. I cannot accept that 'Total Food Intolerance' is not a recognised condition and that I will have to 'go it alone'.

Fellow sufferers are the only ones who have any idea

The only people who seem to understand how I am suffering are other people like me; and, yes, there are other people like me - LOTS of them, in fact! The internet led me Foods Matter, where I found a man called John Scott. He had suffered from Total Food Intolerance for 20 years. He lived on semi-elemental infant formula for 15 years, and has heard from lots of other people suffering the same fate, none of whom have had any help from the NHS. I have tried the semi-elemental feeds but have yet to find one I can tolerate.

Sadly, John has also heard of people dying because they can no longer find any food to live on. As my intolerances and pain get worse every day, I am now beginning to wonder where will this end for me. Anyone who has food intolerance will know how desperately ill you are when you eat that food. Imagine if you had to eat something that was poisoning you everyday of your life. How much of that could you take?

I see my GP every week and he weighs me. He is at a loss to know how he can help. He has run out of specialists to refer me to. He cannot believe the change in me.

And mentally, I am just fine

I've even had a psychiatric assessment to prove that I do not have depression or any deep rooted psychiatric disorder. Mentally I am fine.

I was a bright, happy, energetic, slightly overweight 45 year old. Now I am a shadow of my former self. My husband and children are worried sick about me and I have to admit I think my days are numbered. I have made my Will and have spent a lot of time sorting stuff out to make things easier for my husband in case I die. We are now looking to re-home our beloved dog because I can no longer walk him. I am living on about six foods: venison, rhubarb, turnips, swede, dates, and dried cherries. These are the foods that give me the least reaction but they still make me feel awful. Week by week my reaction to these foods is getting worse.

However, there may still be just one glimmer of hope for me. I mentioned earlier about a man called John Scott. He too had Total Food Intolerance, but he has found help from a very unusual experimental therapy called Helminthic Therapy. (You can read John's story [here](#).)

Helminthic therapy

Helminthic Therapy is a type of immunotherapy. It involves patients inoculating themselves with a low dose of helminths - a type of parasite (actually a symbiont) that lives in the intestines. The theory behind it is that, over millions of years of living with mankind, these tiny worms have learned how to modify their host's immune response. Our immune systems have also got used to having the helminths around, and were constantly occupied with keeping the worms in check. The problem now is that we in the West have got rid of these creatures in the last few decades. Consequently, our immune system no longer has a legitimate target to attack, so it goes for other things, like food.

John, and a growing number of other people with Total Food Intolerance, have found that they have been able to tolerate foods again about three months after starting this treatment. You can read reports from over a dozen of these pioneers in this document.

As I can find no other way to treat my own food intolerance, I have decided to join the 'citizen scientists' who are experimenting with this therapy and have recently inoculated myself with 35 hookworms. I'm now waiting to see what happens.

Thank goodness that there is information about Helminthic Therapy on the internet and a Facebook group where you can chat about it with other users. Without this information and support, I dread to think what I would have done.

Why did I want to tell this story?

I decided that I wanted to write my story for two reasons. Firstly, the more people that hear about Total Food Intolerance the better. I need to get the message out there. Even some of my family and close friends are struggling to understand and accept what I am telling them. At times I can barely believe it myself! It's bad enough that doctors don't believe you but, when friends and family don't, then you are in a very lonely place. I wouldn't wish this on anyone.

Doctors need to hear that there are many people who are suffering terribly as a result of overwhelming food intolerance. Perhaps if more of these people told their stories, doctors would start to take this condition more seriously and stop dismissing patients who report symptoms like mine.

Mine is an extreme case, but there are other people struggling to survive on very limited diets with no help or advice from the medical profession. I will never accept that, in the 21st century, there are so many people suffering horrendously every day, yet being denied help by their doctors.

Scientific research is being done into the workings of the immune system but, sadly, I don't think it will come to fruition in time to help me. There are drugs currently available that are used to treat other auto-immune diseases that could potentially help me but no doctor will prescribe them unless there is clinical evidence to back up my claims.

I think it's appalling that doctors have not been able to help me, and unbelievable that so many of them have doubted what I have told them about my symptoms. They seem to have a set of diagnostic boxes into which they place people, and, if you don't fit into one of their boxes, there can't possibly be anything wrong with you! I also can't believe that they aren't taking Helminthic Therapy more seriously when it seems to be helping so many people with Total Food Intolerance. In fact, many doctors seem to dismiss this treatment without even looking at it in any detail.

The other reason I want my story to be told is for my children. So many times over the past 18 months it has been suggested that it might be 'all in my head', so I want my children to read my story in my own words. If I die, I don't want them to be told that their mother died from some kind of eating disorder or mental illness. There is nothing wrong with my head. The problem is that my immune system is attacking my food as if it were a virus.

I have since learnt that my grandfather had food intolerances and allergies. I never really knew him as he died when I was only 5. Apparently he was a baker in his younger days but had to give it up because he was allergic to the flour. My children may also be genetically pre-disposed to gluten sensitivity and may go on to develop intolerances themselves. If they know my story, then they may be able to do something about it before it becomes serious.

Source: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/tfi-clares-story-10-12.html

Managing Total Food Intolerance

Elemental and semi-elemental feeds By John Scott (Foods Matter March 2007, updated 2009)

A refined taste

Semi-elemental (oligomeric) feeds contain hydrolysed protein (partially pre-digested to form simple peptides), simple sugars, glucose polymers or starch and fat, along with essential vitamins and minerals. This combination provides complete nutrition in a very easily digestible form which is sufficiently modified to prevent the body from recognizing it and reacting adversely to it.

The protein in elemental (monomeric) feeds is even more fully refined, to the point at which only individual amino acids remain, making it virtually impossible for the body to react to the protein that has been used, whether this is derived from milk, soya or meat.

Both types of feed can be a valuable resource for someone with food allergy or intolerance. They can be used to supplement a restricted diet, to maintain a sound nutritional base while foods suspected of causing a reaction are tested one at a time, or they can become the sole source of nourishment when problems caused by normal foods are overwhelming.

An unlikely success

Unfortunately, some adults who are allergic or intolerant to a large number of foods also have problems with the elemental and semi-elemental feeds that are manufactured for adults, yet many have found that they are able to tolerate those feeds which are intended for use by infants - Neocate (SHS) and Nutramigen (Mead Johnson), for example. Pepdite (SHS) - the proteins in which are derived from pork and soy rather than milk - appears to be particularly well tolerated in its basic infant form ('Pepdite') but not always the 'Pepdite 1+' or 'Pepdite 1+ MCT' versions.

However, even with these feeds, several products may need to be tried before one is found that is suitable, and a feed which has proved to be well tolerated by one person may not necessarily be suitable for another. Each individual has a unique allergy/intolerance profile, so it is impossible to recommend any one particular feed. Only trial and error will reveal the best feed for each patient. (See below for a list of currently available infant feeds.)

Many medical professionals are opposed to adults consuming infant feeds under any circumstances, believing that the balance of nutrients contained in them is not suitable for an adult. Yet the differences between the adult and infant feeds are not large and the latter are arguably closer to the ideal balance of nutrients required by an adult than is the average British diet (only 8% of Britons eat a healthy diet). Moreover, an infant feed is undoubtedly preferable to a very restricted diet of just a few ordinary foods.

The protein requirements of adults who are using a hypoallergenic infant feed are, surprisingly, best met by feeds that are intended for children under six months old, as feeds formulated for children over 6 months now usually contain less protein because older children are expected to obtain protein from other food sources, as part of the weaning process.

'Neocate Infant', for example, contains 13 g protein per 100 g powder, whereas 'Neocate Nutra' contains only 8.2 g. However, the Pepdite feeds, by SHS, are an exception to this rule, with Pepdite+1 containing the same amount of protein as the infant version, Pepdite. The protein content of each feed is given in the list below.

Adults can, if necessary, live largely or even solely on elemental or semi-elemental infant feeds for many years. However, long-term exclusive use of one particular feed may eventually lead to a loss of tolerance to that feed, and, for this reason, it is preferable to alternate between two or more feeds, if possible. Certain batches of the same feed can sometimes also be less easy to tolerate than others, perhaps due to variations in ingredient sources.

Pharmacy hurdles

Elemental and semi-elemental infant feeds can be ordered through any pharmacy and no prescription is necessary, although they are expensive. Some GPs are willing to provide prescriptions for them, where they are persuaded of a medical need.

If obtaining an elemental or semi-elemental infant feed without a prescription, pharmacists may ask what purpose the buyer has in mind for it, and I am aware of cases where rather intense questioning on the part of a pharmacist has given a customer the impression that they would not be able to buy the feed if it was intended for adult consumption. This, however, is definitely not the case!

The information presented here should provide those wishing to purchase elemental or semi-elemental infant feeds for adult use with sufficient information to allow them to assure any concerned pharmacist that they know what they are doing and, hopefully, to educate the pharmacist about the place that hypoallergenic infant feeds can have in the treatment and management of food allergy and intolerance in adults.

Scoop of the day

Elemental and semi-elemental infant feeds are supplied in powder form, but the scoop provided in each tin of feed is too small for adult use, and a standard eighth-of-a-cup measure is much more appropriate. This is roughly equivalent to a heaped desert spoon, but provides a more accurate means of measurement.

One level 1/8 cup measure or heaped desert spoonful (13 grams) of feed will meet the nutritional needs of an adult for 20-30 minutes, depending on the level of activity, and 5 x 1/8 cup measures (66 grams) will provide approximately 2 hours of nourishment. A sedentary adult of average size, who is using an elemental or semi-elemental feed exclusively, will need slightly more than one 400 gram tin of powder (30 x 1/8 cup measures) per day to maintain normal body-weight.

The water used to mix up the feed should be filtered and, ideally, should not be warmed but used at room temperature or chilled, to prevent the loss of vitamins and improve taste.

With most feeds, three measures of water are needed for each measure of powdered feed, which means mixing almost 2 cups (400 ml) of water with 5 x 1/8 cup measures of powder. A hand-held mixer is ideal for this purpose and will quickly produce a liquid with the consistency of whole milk.

The amount of feed taken at any one time, and the frequency of feeds, are obviously a matter of individual need, capacity and preference, although, initially, it may be best to take only very small amounts and to dilute these even further than recommended above.

Supplementation

It can be argued that the levels of some of the vitamins and minerals in infant feeds are inadequate for adults, and it might be advisable to supplement these. It is perhaps particularly important to add extra trace minerals, from a product such as Ultra Trace, by Higher Nature (0800 458 4747 - http://www.highernature.co.uk/ShowProductFamily.aspx?ProductFamilyID=347#.U_oXM0s-Xeg). My own experience is that SpectraMin - another transparent, colourless liquid supplement - is the most easily tolerated of the mineral formulations, but this is only available directly from a limited number of alternative health-care practitioners, such as Turningpoint Natural Healthcare (0116 266 1962 - <http://www.turnaroundyourhealth.co.uk>)

Another important omission from many manufactured feeds is fibre and, whilst there are several forms of fibre available from chemists and health food outlets, most are likely to present tolerance problems for anyone who needs to use a hypoallergenic feed. The ideal product in this case may be pure Cellulose Powder from Allergy Research Group, available from the Nutri Centre (0845 602 6744 - http://www.amazon.co.uk/Nutricology-Allergy-Research-Group-Cellulose/dp/B00028P80M/ref=sr_1_1?ie=UTF8&qid=1408899139&sr=8-1&keywords=cellulose+powder) This will normalize bowel function, easing both diarrhoea and constipation. (Pale, greenish stools are to be expected while only taking a semi-elemental infant feed and this is not a cause for concern.)

Enjoyed by all

So far as taste is concerned, elemental and semi-elemental infant feeds are not unpleasant and are easily adapted to, especially if served chilled. They are certainly a lot more palatable than adult versions of the same types of feed, some of which are so unpleasant that people who need to use them may be willing to agree to the fitting of a feeding tube in order to avoid the taste.

Because of their very refined nature, hypoallergenic feeds are always eagerly welcomed by the bugs that inhabit our mouths! To prevent causing an oral population explosion, it is best to drink the feed through a straw placed as far towards the back of the mouth as possible, and always to clean one's teeth immediately after each feed.

Elemental and semi-elemental infant feeds available in the UK at July 2009

Mead Johnson Careline: 00800 8834 2568 <http://www.meadjohnson.com>

* **Nutramigen 1** An extensively hydrolysed, casein-based, semi-elemental infant formula. 14 g protein per 100 g powder. Supplied in 400 g cans.

* **Pregestimil** A hydrolysed, casein-based, semi-elemental infant formula containing medium chain triglyceride (MCT) oil for easy absorption. 14 g protein per 100 g powder. Supplied in 400 gm cans.

* **Nutramigen AA** Elemental (amino acid-based) formula. This contains Lipil and 13.9 g protein per 100 g powder. Supplied in 400 g cans.

Nutricia (Cow & Gate and Adaptamil) Resource Centre - 01225 751098
<http://www.nutricia.co.uk>

* **Pepti.** (Cow & Gate) An extensively hydrolysed, whey-based, semi-elemental formula for cow's milk-intolerant patients. The carbohydrate blend contains 40% lactose. Only 11.6 g protein per 100 g powder.

* **Pepti-Junior.** (Cow & Gate) An extensively hydrolysed, whey-based, lactose-free, semi-elemental formula. May not be hydrolysed quite as extensively as the casein-based feeds, but some find it tastes better than casein-based feeds. Formulated for children over 1, but actually used with all ages from birth to adulthood. 14 g protein per 100 g powder

SHS 0151 228 8161 <http://www.nutricia.co.uk/products/category/epilepsy>

* **Peptide.** An extensively hydrolysed, meat/soya-based, semi-elemental infant formula for infants under one. 13.8 g protein per 100 g powder. Supplied in 400 g cans. Fats per 100 g powder: 23.2 g total; 7.1 g saturated; 10.6 g mono-unsaturated; 4.4 g poly-unsaturated. 5% MCT. https://www.nutricia.co.uk/products/view/cystic_fibrosis/peptide

* **Peptide 1+**. An extensively hydrolysed, meat/soya-based, semi-elemental formula for children over one. 13.8 g protein per 100 g powder. Supplied in 400 g cans. Available in two versions, either with or without MCT oil. Fat content of the latter is, per 100 g powder: 17.3 g total; 6.7 g saturated; 7.6 g mono-unsaturated; 2.3 g poly-unsaturated. 35% MCT.

* **Neocate (Neocate Infant)**. An elemental (amino acid-based) infant formula. Contains 13 g protein per 100 g powder. (User comments range from "Palatable" to "Lousy taste") <http://www.shs-nutrition.com/products/neocate>

Abbot Nutrition (including Ross) Nutrition Helpline - 0800 252 882

<http://www.abbottnutritionuk.com/display.aspx>

Abbot currently have no hypoallergenic infant feeds available in the UK, although they do market such products in other countries.

Source: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/semi_elemental_feeds.html

Homemade Elemental/Semi-elemental food

If someone were to find that they react to all the manufactured feeds, they could try making a bespoke feed at home, using whatever carbohydrate, fat and protein sources they can tolerate best. Several people have already done this:

http://www.foodsmatter.com/foodsmatter_forums/showthread.php?t=433

Artificial Nutrition

By Pam Harris (Foods Matter Jan 2005)

I am sure that most of you who read John Scott's or Sam Bailey's stories were deeply shocked. (See Sam's story at http://www.foodsmatter.com/allergy_intolerance/egids/articles/samuel.html) I wish I had been too, but, sadly, I have seen many cases of total food allergy among both adults and children. I do understand that ambitious medical researchers are often reluctant to investigate what up until now has been, as John Scott describes it, an obscure medical backwater. This is partly because it is almost impossible to get funding for such research, and partly because it is unlikely to gain them the recognition they need if they are to advance their careers. Let us hope that the recent Health Committee finding that some 11 million people in this country are suffering health problems believed to be related to food or chemical allergy may raise awareness of the problem, encourage health practitioners to seek further allergy education and encourage the government to pay for it.

This would have the added benefit that patients would no longer need to seek help from unqualified practitioners whose findings and advice may not be in those patients' best interests. The medical procedures needed to identify allergies and intolerances accurately are time-consuming but safe, and subsequent treatment will avoid further complicating an existing health problem with an unbalanced or nutritionally inadequate diet.

OK - but where do we go from here?

To someone to whom John Scott, little Sam and possibly many others should have been referred a long time ago - a specialist who could consider them for Artificial Nutrition Support (ANS). Artificial Nutrition Support is used to correct undernutrition or to maintain nutritional status in patients who are unable to eat, swallow, digest or absorb sufficient nutrients to provide them with adequate nutrition for health.

Medical conditions in which either temporary or permanent ANS would be appropriate:

- Surgery (sometimes as a result of cancer) which has physically removed the oesophagus/stomach/small intestine or other essential part of the digestive tract.
- Motor Neurone Disease, stroke or a severe burn which prevent the patient swallowing.
- Physical malformation in babies. These children can be fed by ANS at least until they have reached an age at which surgery is possible to correct or create a non-functioning organ.
- Crohn's Disease, Ulcerative Colitis or other bowel conditions where ANS may be used for a period to allow the intestine/bowel to heal.
- After major oesophageal or gastric surgery until normal food/feeding can be reintroduced.
- Where intestinal failure of some kind prevents the absorption of nutrients from food.

- In patients with severe anorexia. ANS not only provides them with basic nutrition but also stimulates their appetites.

- In severely malnourished patients ANS can be used to boost their intake of nutrients.

Although ANS is often only a temporary measure until a satisfactory nutrient status is reached or a relevant digestive organ has healed, there is a substantial body of people for whom ANS is part of everyday life, as it is their only way of receiving the nutrition necessary for the normal functioning of their bodies.

ANS is normally delivered in one of two ways:

Enteral Feeding

- Via a nasal-gastric tube. This is a thin plastic tube which is inserted via the nose and runs down to the stomach or direct to the intestine, thus avoiding the mouth, throat and oesophagus.

- Via a small tube (known as a PEG - percutaneous endoscopic gastrostomy) which is inserted through the skin and feeds directly into the stomach or small intestine.

Enteral feeding is the preferred method as it is cheaper, safer and more physiological than parenteral feeding (see below). The intestine has an important immune and barrier function.

Parenteral Feeding

- Intravenous feeding through a catheter directly into a vein. This method is used when the stomach/intestine is unable to absorb sufficient, or indeed any, nutrients.

All forms of delivery are invasive and are not, therefore, risk-free. Infection is the greatest hazard (especially in patients whose immune functions are already impaired), so all procedures must be aseptic and the patient needs to be constantly and carefully monitored. Because of the 'unnatural' way in which nutrition is being delivered, the functions of other organs, such as the liver, also need to be carefully monitored. However, having said that, many people use these forms of nutrition at home, either to give them extra nutritional support or to provide their total nutrition. Indeed many have their nutrition fed to them during the night and are able to go to work and live perfectly normal lives during the day.

Exactly what goes into the feed (which comes as a thick liquid and has already been pre-digested so that it can be easily absorbed) will depend on the needs of each individual patient. Although there is a basic nutritional mix, it will normally be adjusted according to whether the patient can absorb any nutrients from normal foods and what their specific nutritional requirements may be.

So why are there so many people with severe food sensitivity difficulties suffering on, unaware that there may be help for them that could change their lives?

As you will realise, ANS is not only inherently somewhat risky, it is also very expensive. One day's worth of parenteral nutrition costs over £60 - and that is not including any of the substantial medical back-up service which is obviously essential. Funding is also complicated by the fact that hospital patients on ANS are paid for by the hospital, but as soon as they go home financial responsibility passes to their local health care trusts - which have to be persuaded to take it on. Moreover, this is a highly specialised technique only performed by a small number of gastroenterology units, so relatively few hospitals or trusts know very much about it.

In this country work has been pioneered at Ninewells Hospital in Scotland from where consultants have gradually been fanning out to other hospitals to set up specialist units. Ninewells sees itself as the hub at the centre of what it hopes will be spokes extending all over the country. Interestingly, while ANS remains an even more obscure branch of medicine than allergy in this country, in the USA there are well over half a million people, both children and adults, who are using it daily to substantially improve their quality of life.

We are, at the moment, in the process of setting up a charity, The Nightingale Trust for Nutritional Support, to promote the use and understanding of Artificial Nutrition. If you would like to know more about ANS or the charity, please e-mail or write to me about it: pjih1@tiscali.co.uk, or Pam Harris, 3 Ashfield, Deeping St James Road, Deeping Gate, Peterborough PE6 9AL

You could also consult PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy) at www.pinnt.co.uk or PO Box 3126, Christchurch, Dorset BH23 2XS, which has lots of support information - including support for children on NAS - the Half Pinnt!

You could also take a look at BAPEN (The British Association for Parenteral and Enteral Nutrition) - www.bapen.org.uk Although this is primarily a professional organisation they do have a helpful question and answer section on their site (click on 'Activities', then on 'Litre', then on 'Dear Litre').

Source: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/artificial_nutrition.html

Navigating through the UK's National Health Service By Pam Harris (Foods Matter Feb 2005)

Last month John Scott asked if anyone had any advice on how to gain access to the specialist forms of food and feeding that may become necessary if food intolerances reduce one's diet below a weight maintenance level. Pam Harris suggests a route you could follow.

Having read John Scott's plea in 'Navigating through the NHS' (FM January 04), I will try and explain the procedure you need to follow if you are to have any hope of obtaining any form of supplemental or artificial nutrition. I say 'any hope' as, sadly, there are no guarantees that everyone will get it. My own mail bag would suggest that you are in a post code lottery - even assuming that you have managed to be referred to a gastroenterologist who specialises in food allergies or intestinal management. There are very few specialists in either field.

Step 1. Food Diary

For anyone setting out on this path I would recommend that you keep a food diary.

This means listing everything that you eat and drink in detail, and the time that you eat or drink it. You need also to list your condition and symptoms 3-4 times during the day. The diary should be kept for 4-6 weeks and then repeated for another two weeks at least, omitting any foods to which you suspect you are allergic or intolerant, and noting any changes in your symptoms.

Step 2. Visit GP

Then book an appointment with your GP - and take your diary with you. Your GP will probably say that he/she hasn't got time to read it but may well give you a prescription for one of the drugs that can help - in some cases. I would suggest that you ask, at this first appointment, if you could be referred to a dietitian. She (or very occasionally he) will be more likely to read your diary and will probably suggest you continue to keep it. (I would advise you to do so anyway.)

If your symptoms persist, return, and return again. Repeated visits to your GP should result in your referral to either an allergy specialist or gastroenterologist at your local hospital.

Step 3. Referral to allergy specialist/gastroenterologist

Once you get a referral, skin prick tests will probably be carried out which will give an indication as to whether it is allergy or intolerance. If you have an allergic reaction when tested then you will be advised to completely avoid the food to prevent a serious reaction. If food intolerance is suspected you will be given advice, possibly medication and continuing guidance from your dietitian

If you are one of the unfortunate people who has multiple allergies and intolerances, you have severe weight loss, your intake of oral food is so limited that you are becoming malnourished and the ongoing care at your local hospital is not addressing your situation, then you are likely to be prescribed an elemental, peptide or other oral food supplement.

This type of food supplement feeding does give you the complete nourishment that your body needs and will also bring your weight up to a normal level. It does not restrict your lifestyle in any way other than denying you normal oral eating. Each tin of feed is expensive but it is the pleasantest way of maintaining dietary nutrition. It does not work for everyone as the nature of the underlying condition has to be taken into consideration.

Step 4. Referral to teaching hospital

However, an oral food supplement is probably the best that your local hospital will be able to offer, so, if you are one of those for whom elemental feeds do not work, you have the right to ask for referral to a consultant at a teaching hospital who specialises in intestinal malfunction and management. Under the care of such a specialist, you will be more likely to be assessed to see if you are suitable for an alternative form of feeding. Unfortunately, not everyone is.

Even if the result is in your favour, your local health authority has to accept the financial responsibility for your treatment and ongoing care after you have left the hospital. If they do, you will remain under the clinical care of the teaching hospital, but will also have the additional care of a home-care support team. They will be there for you at

all times and be responsible for delivering your food and ancillaries. It is the financial responsibility for this team and for the nutritional food itself which your local council has to assume. But the cost is extremely high and some local health councils have been unable to accept the responsibility.

Step 5. Trouble-shooting

Even if your GP or specialist is thoroughly unhelpful, do not forget that you do have rights. Under the Patient's Charter you can not only ask for a referral to an allergy specialist but, if you are not making progress with the consultant you are seeing, you can ask also for a second opinion from another consultant, or a referral to a teaching hospital.

If you find yourself facing a total brick wall, book an appointment at your MP's surgery and ask why, in view of the government's latest policies on choice of hospitals for treatment, you are being denied an appointment to see a specialist for diagnosis and treatment.

Source: http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/navigating_through.nhs.html

Homeopathic allergodes By John Scott

In my experience, desensitisation using an allergode appears to be as effective for food intolerances as it is for IgE-mediated food allergies and can be particularly valuable to anyone who is at the extreme end of the food sensitivity spectrum.

You can use homeopathy to increase tolerance to any food, and homeopathic pharmacies keep stocks of remedies made up to antidote a number of foods. Just phone round and ask them if they have a remedy made from whichever food you're interested in - carrot, apple, or whatever. They will only have what they have been asked to prepare previously, so each pharmacy has remedies for different foods, hence the need to phone around.

Helios - www.helios.co.uk - 01892 537254

Ainsworth's - www.ainsworths.com - 020 7935 5330

Freeman's Homeopathic Pharmacy - <http://www.freemans.uk.com/> - 0845 255 5155

Weleda - www.weleda.co.uk - 0115 944 8200

If none of them has what you want, you can send a sample of the item you would like to be able to tolerate to one of the above pharmacies for homeopathic potentisation, although this can be expensive, especially if you need the 200C potency (which will require 200 successive dilutions - very labour-intensive!). I have found that Helios is by far the cheapest for this service, if you need the highest potency, because they use a machine to carry out some of the work, though they can take several weeks to process an order. Once the food has been potentised, you will be able to have supplies of either tablets, pills, or liquid made up from this, as often as you require, for just a few pounds each time. It's just the initial potentisation which is very expensive.

Homeopathic tablets are usually 50% lactose and 50% sucrose; soft (quick dissolve) tablets are usually pure lactose; and pills (tiny balls) are pure sucrose. The liquid form (for use as drops) utilizes a mixture of distilled water and approximately 20% -30% alcohol but, if alcohol is a problem, the drops can be added to a little water and left to stand briefly until the alcohol evaporates.

Once you have the remedy, take this, as mentioned above, three times per day, starting about five days before you begin eating the related food, to build up your tolerance/ 'desensitise' you to the food, and continue to take the remedy for as long as you want to eat this food. If you want to use homeopathic antidotes for several foods, up to about twelve can be included together in the same remedy, for convenience.

In order to establish whether you need the 6C, 30C or 200C potency, I would recommend using a dowser or a kinesiologist, either of whom will be able to establish which dose you will require. A dowser (located by contacting the British Society of Dowzers on 01684 576969 for a list of experienced health dowzers) will even be able to tell you whether or not such a remedy will be effective in your case.

A dowser would also be able to tell you exactly which foods you are able, and not able to tolerate, so can be invaluable in managing food intolerances generally. And they can provide this service at a distance, so there is no need to select a dowser near to your home in order to be able to see them in person.

Alternatively, you could learn to dowse yourself, in which case, see the BSD website for books on the subject and simple dowsing tools:

http://www.britishdowzers.org/about/national_dowsing.shtml

and/or read the following article:

http://www.foodsmatter.com/natural_medicine_comp_therapies/dowsing/articles/dowsing_food_intol.htm

I have found the use of homeopathic 'specials', as described above, extremely helpful, and not just for food. I also use this method to desensitise myself to food supplements that I need to take but can't tolerate, and I currently even have to use a special remedy to enable me to tolerate water!

Some time ago, I began to react to all waters - filtered, bottled, the lot, except for distilled water - but, having M.E., I found all the palaver associated with distillation (descaling, etc.) too much, in addition to which, this process removes all the minerals as well as everything else, so I settled on one brand of water filter and had a remedy made up from a sample of the water from this. As long as I continue to take this remedy, I am able to tolerate this filtered water.

Source: http://www.foodsmatter.com/foodsmatter_forums/showthread.php?t=107&highlight=homeopathic

Digestive enzymes By John Scott

Many people find that the use of a good quality digestive enzyme product such as Biocare's 'Digestaid' helps boost their tolerance to food, but some are unable to tolerate these products. Experimentation with different products can sometimes identify a tolerable product, but I find it best to use only the following technique, which has the advantage of being free!

Stimulating the 'digestive enzyme point' encourages the production of our own digestive enzymes. This is located on the front of the ribcage, just to the left of the bottom of the sternum.

To find the correct spot, run your fingers down the sternum (breast bone) from the central hollow at the base of your throat to where the bone ends and the bottom ribs attach to it. The DE point is located slightly to the left of the bottom of the sternum, a centimetre or two along the lower edge of the bottom left hand side rib.

In someone whose enzyme production is under par, this spot may be slightly sensitive or sore, but rubbing it for thirty seconds or so will usually ease the soreness and will stimulate the body to produce its own digestive enzymes.

Some years ago, I became intolerant to digestive enzyme supplements, and a kinesiologist recommended that try this technique. Subsequent kinesiological testing established that, in my case, stimulating the DE point produces the same digestive effect as taking four high quality digestive enzyme capsules.

I have used the technique ever since, gently rubbing the DE point whenever I eat, and have found it produces excellent results. It has also saved me a small fortune, because good quality digestive enzyme supplements are expensive.

In addition to rubbing the DE point, I have found that occasionally massaging all the way along the lower edge of the bottom rib on both left and right sides has a generally beneficial effect on my digestion, which is perhaps not surprising because the whole of the front bottom rib margin is linked to the small intestine. I often find tender spots along this margin, and a few minutes of gentle massage always eases these and improves my digestion.

Source: http://www.foodsmatter.com/digestive_conditions_coeliac/ibs_treatments/articles/free_digestive_enzymes.html

Treating Total Food Intolerance

Wriggling out of food intolerance and fatigue By John Scott (Foods Matter Nov 2009)

Taking part in the short Hookworms for Crohn's Disease trial (http://www.foodsmatter.com/natural_medicine_comp_therapies/helminthic_therapy/articles/appetite_worms.html) at Nottingham University in 2007 had provided me with a brief but tantalising glimpse of how my health might be improved by hosting a small colony of benign intestinal worms, and I was determined to acquire a long-term infection as soon as possible.

To this end, I had secured the agreement of my gastroenterologist, who referred me back to the trial team for reinfection. However, in spite of an earlier indication that they would be willing to provide me with a further dose of hookworm, the trial coordinator then told me that this would not be possible until the study was complete.

This was a considerable disappointment because the trial was taking an inordinately long time - probably due to difficulty finding sufficient volunteers willing to host a small worm colony - and it became clear that the trial would not be complete until the middle of 2009.

In the meantime, I had required further bowel surgery, to repair yet more Crohn's-related intestinal strictures, and I was still unable to eat any normal foods due to multiple allergies and overwhelming food intolerance, not to mention having a number of other long-term health problems, including M.E., a subgroup of Chronic Fatigue Syndrome characterised by inordinately exaggerated exhaustion following any activity, either physical or mental.

I was becoming impatient, not least because the only food that I was then able to tolerate was a solitary hypoallergenic formula feed prescribed by my GP, and I realised that, were I to lose my tolerance to this also, I might well follow in the footsteps of those, such as Annabel Senior, who have lost their lives as a result of medicine's failure to engage with food intolerance. (http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/annabel_senior.html)

Even if this aspect of my health proved not to be amenable to the help of a group of helminthic 'old friends' (<http://evmedreview.com/?p=103>), there is considerable evidence to suggest that I should at least benefit from a reduction in allergic symptoms, and an attenuation, or perhaps even cessation of the development of intestinal strictures.

As one door closes...

It was extremely frustrating to know that a possible solution to at least some of my health problems was wriggling in a laboratory at Nottingham University, just a few miles down the road from where I live, and that I was being denied access to them.

I was not well enough to travel to the tropics to collect a worm infection the natural way, by walking barefoot in open-air latrines, besides which, to do this might result in me picking up an altogether less friendly parasite, perhaps even with a nasty bacterial infection riding piggyback.

What I really needed was an easily accessible, hygienic source that would deliver worms direct to my home. At the time, I knew of only one such supplier - Ovamed (<http://www.ovamed.org/>), who sell pig whipworm eggs, but at a horrendously high price that put them beyond my reach.

More out of desperation than hope, I turned once more to the internet, where, miraculously, I discovered Autoimmune Therapies (<http://autoimmunetherapies.com/>), who sell *Necator americanus*, the hookworm used in the Nottingham trials, and at a much more realistic price than Ovamed's porcine product.

Reading the information available on the Autoimmune Therapies website and talking to the company's founder, Jasper Lawrence, I discovered far more about helminthic therapy (http://www.foodsmatter.com/natural_medicine_comp_therapies/helminthic_therapy/index_worms.html) than I had been able to glean from talking to the researchers who are working with the worms in the clinical trials context.

So far, the Nottingham scientists have only looked at the safety aspects of using just ten worms in patients with only a couple of diseases, and the trials have been too short to assess efficacy in either case. In contrast, Autoimmune Therapies have provided realistic numbers of worms to scores of people with a growing range of autoimmune conditions, as a result of which, Jasper Lawrence and his colleagues have acquired a unique understanding of the therapeutic potential and use of hookworm.

After talking to these guys, it became clear that ten worms - the number I had received on the Hookworms for Crohn's Disease trial, and would likely have been offered again, if I were to obtain them from Nottingham - would not be enough to deal effectively with all of my problems, so I opted to purchase 35 *Necator* larvae from them.

The experiment begins

My new team of little wrigglers arrived at my home in two tiny vials, each containing only a couple of millilitres of clear, colourless liquid. These few precious drops held the microscopic hookworm larvae which, after being carefully dispensed onto a dressing and placed on my arm, began the synchronised burrowing that would commence the journey which I hoped would ultimately bring me so much relief.

On the second day after my new gut buddies moved in, their ministrations brought significant relief from the nasal congestion that I had had, on and off, for most of my life. The only relief that I had been able to obtain previously had come from taking drugs, but all of these had presented unpleasant side effects, such as the migraine headaches that invariably followed the use of steroid nasal sprays.

An itchy rash, which had developed rapidly at the site on my arm where my invisible friends had entered their new home, began to reduce somewhat in intensity on the third day. Tiny bright red dots then became visible within the

main central area and the itch continued with a vengeance, though, fortunately, this responded well to generous applications of Benedryl cream.

The bright red dots intensified on the 4th day and became quite raised, remaining till the seventh day, after which the redness, bumpiness and itching all began to subside. By the second week, the rash was fading, flat, and no longer itchy.

Towards the end of the second week, my nose became clearer than ever, and the third week brought a distinct sense of perkiness - a quality that had been sadly missing from my life for many years, buried deep beneath the thick blanket of M.E.

Both the clearer nose and the perkiness continued for another three days, until I was eventually plunged back into the much more familiar continuous exhaustion, beginning a see-saw fluctuation in symptoms that would continue for the next few months.

Ups and downs

At the start of week four, I had a day without any headache - a departure that was extremely rare for me - and my nose was so clear that I began to find myself breathing through both nostrils at once. Again, this is something quite new - something I haven't done much since I was a child.

Such was the depth of exhaustion that I had grown accustomed to, it would normally take an inordinate act of will in order for me to initiate any movement at the start of each new day. However, on the fourth day of the fourth week, I woke to find myself raring to go! For the first time in many, many moons, I couldn't wait to get up and greet the day.

As it happened, I was to have visitors that day - something that would usually wipe me out for several days at least, yet, on this occasion, I not only survived the visit unscathed, but actually had moments during the day that brought back distant memories of what it felt like to be well.

I began the next day by celebrating a distinctly less severe level of exhaustion than I would have expected to experience after a visit, but, then, I noticed a change in my bowel habit. My normal, single daily defaecation was replaced by several smaller ones, and the warning sensations before these were more like those I associate with impending diarrhoea.

This gastrointestinal sea change continued with a sudden increase in gas production, and was accompanied by periods of queasiness and even a couple of unexpected spells of sweating.

In spite of having Crohn's disease and, over time, developing strictures that have required surgery, I have been spared the worst gasro-intestinal symptoms, so these new digestive developments were obviously due to the presence of my little friends.

The diarrhoea began at the end of week four, accompanied by nausea, more gas and sweats - no doubt all due to my body's attempt to rid itself of what it perceived to be 'invaders'. But, undaunted by the onslaught against them, my already highly treasured companions continued their ministrations and, at the start of week five, delivered another headache-free day.

Chilling out

One of several weird symptoms that have manifested as part of my experience of M.E. is poor temperature control, and this has been a problem for me for many years. During this time, I have had to carefully control the temperature of my environment in order to remain comfortable, and, in spite of installing numerous thermostatic heating controls, it has still been necessary to resort to frequent adjustments to clothing during the day, and to bed clothes at night, in order to maintain comfort.

Half way through week five, I began to realise that I was able to tolerate a slightly lower ambient temperature, and found that I could keep the temperature in both my lounge and bedroom half a degree Celsius lower than I would have needed previously - an insignificant change for a healthy person, but a major improvement for me. And whereas, previously, it would take me over an hour to cool down sufficiently after a shower to be able to put my usual clothes back on, I was now able to get fully dressed less than half an hour after showering.

Having been unable to eat normal food for many years, it was fortunate that, during most of this time, I was not really interested in normal food. I could inhale the aroma of other people's cooking, but not feel any desire to eat what was being cooked. Now, at almost the sixth week since inoculation, I found myself suddenly taking an interest in any cooking smells that assailed my nostrils, and I began to have yearnings to eat whatever foods were being prepared - my first experience of real hunger in years.

Then, just as I was beginning to adjust my thinking towards the possibility of maybe trying some normal food again, I began to get stronger abdominal cramps and more diarrhoea as week six began.

From then on, diarrhoea, gut ache, nausea and intestinal rumblings began to be the norm on about three days out of every seven, interrupted only by occasional constipation, and accompanied by increased fatigue. The latter, however, was not so much my usual 'weary-but-wired' fatigue as an almost pleasant, very relaxed, languorous state, and I was actually feeling quite perky again in spite of this. And my headaches were also now significantly less severe than hitherto, so there was plenty to feel grateful for while sitting on the loo!

Profound change

Early in week six, I began to feel pleurably better than I had for a very long time, with a new buoyancy and optimism. I also realised that the eczema in my ears, which used to itch more or less constantly, unless regularly creamed, was now somewhat less itchy than it had been for years, having been improving gradually for the previous couple of weeks.

During week seven, it dawned on me that I was no longer being woken during the night by the intractable catarrhal throat irritation that had dogged my nights for countless years. What an absolute joy it was, finally to be free of that particular symptom!

Week eight brought another headache-free day and, in week nine, I had a truly remarkable encounter with my osteopath.

He and I had often discussed M.E. while he worked on my back and, having told me that M.E. is a condition that he sees in a significant number of patients, he had explained that he doesn't need a patient to tell him that they have this illness because its presence is clearly revealed by the quality of their tissues.

On this particular occasion, which was prior to me telling him about my hookworm experiment, he said that not only was there a marked improvement in the longstanding problem with over-tight ligaments in my lower back, but the quality of my tissues was now also quite different, and no longer what he would expect to find in someone with M.E!

Then, I was promptly brought back down to earth by several days of feeling quite lousy, as if I had an infection. Yet I recognised this as potentially another positive development, because an absence of infections had long been a feature of my condition. Others around me would drop like ninepins when bugs were going around, but never me! My immune system was apparently in permanent overdrive.

If the sudden light-headedness, weakness, runny nose and sore throat that I now had were indeed the symptoms of an infection, then perhaps this was evidence that my immune system was at last being brought back into line by my accomplished companions.

For the following few weeks, the gut symptoms held sway and I continued to experience frequent nausea, general abdominal discomfort, diarrhoea and increased fatigue. All of this could have been reduced, or even avoided entirely, had I introduced my 35 little wrigglers in stages, rather than all at once, but there is evidence that a more rapid introduction promotes a greater therapeutic dividend in the long term, so I had decided to go for broke.

Even though I was now on a roller coaster that one day lifted me to the heights and then, the next, plunged me back towards the depths, there was already SO much to be grateful for, and I had absolutely no regrets. I knew that the gastrointestinal upheaval would eventually be over and my carefully chosen companions would re-establish their ancient role and keep their covenant with my species. So I dug in and looked forward to that day.

Not just a dream

I don't normally remember dreams but, eleven weeks and five days after my new 'old friends' moved in, I woke suddenly in the night with an extremely vivid recollection of a dream.

I was in an oriental take-away (not my usual haunt, of course!) trying to decide what, if anything, I could safely eat, when I became aware of someone telling me that I could have rice, meat and vegetables.

Could this, I wondered, be a message from my little hookies that my immune system was now sufficiently subdued for me to resume eating these normal foods?

Bizarre though the idea may be, this dream did appear at just the time when allergies typically begin to respond, so, over the next few days, I began, very gingerly at first, to try a little chicken and, as that was OK, some rice, and then potato. That I coped with all of this without any adverse reaction was utterly amazing after so many years of overwhelming food allergy and intolerance.

As I experimented, I found a few foods that brought on some of the old symptoms, although not so much the abdominal pain, which had been the worst feature of my reactions to food, and I eventually established a list of foods that I could tolerate, including a good selection of proteins (white fish, goat's milk products and eggs); starches (rice, potatoes, buckwheat and polenta); root vegetables (carrot, parsnip and sweet potato) and several fruits (apple, pear, peach and raspberries). And chocolate, which I just HAD to try and, to my delight, found I could also now tolerate!

From week 13 onwards, I began to feel generally rather good and, by 18 weeks, my boon companions were treating me to meals consisting of gradually increasing portions of a variety of normal foods, along with a correspondingly reduced quantity of my formula feed. At week 20, I counted 45 foods that I could tolerate and, by week 24, I was meeting half my nutritional needs with normal food.

At week 26, I had my first meal in 16 years without any of the special feed, and, the following week, had three entirely normal meals in a row, although this revealed that, while I was able to tolerate the food, my gut was not coping as well as it might with the additional bulk, having only had to deal with a highly refined, low-residue diet for so many years.

So much to celebrate!

The diarrhoea, which had continued as an intermittent backdrop to all the other developments, finally petered out at week 24, at which point I calculated that I had had a total of 47 days of diarrhoea during 19 weeks. As this was the only major 'side effect' I had experienced, it seemed a very small price to pay when viewed alongside all the benefits that were now evident.

As well as the really quite astonishing fact that, after such a short space of time, I was now able to eat a sufficiently large range of foods to be able to enjoy what was beginning to look like a normal diet, there had also been several other improvements, as a result of the considerable control that my resident technicians were clearly exerting over my longtime errant immune system.

As I took stock of the events of these momentous months and reviewed the detailed diary I had kept, it became clear that, during the time between starting to eat normal foods again and finally waving goodbye to the diarrhoea, several additional aspects of my health had gradually been improving, in many cases imperceptibly.

I had recently felt able to trim the small hedge at the front of my house - something I have had to get others to do for me for such a long time - and, although exhausted afterwards, I didn't need several days in bed to recover, as I would have done in the past. Admittedly, I was weak and wobbly the next day, but I felt remarkably well at the same time and exhilarated that I had achieved so much.

Whereas exhaustion had previously encompassed and pervaded every aspect of my life and been inescapable, it was, by now, far less extensive and much more clearly defined. It would still come and go, but now started from a higher base line, so I actually got to have moments without it, and it was easier to manage with judicious resting.

I found that I no longer needed to go back to bed for a couple of hours in the middle of the day in order to prevent myself from sinking into extreme exhaustion, and a brief rest in a chair was now all that was required to recharge my battery. Perhaps this was related to the positive changes in my tissues detected by the osteopath, and which he has since confirmed are continuing, towards normality.

After years without a single headache-free day, I am now enjoying periods of up to nine days in a row without this affliction, in addition to the greatly improved temperature control, and the generally much clearer nose.

Even the Restless Leg Syndrome that would often interrupt my rest, meditation and sleep, has ceased to be a problem, and the excruciating itches that would frequently develop on my hands, feet and back without any obvious sign on my skin, and which, in spite of treatment, would persist for two or three days, have almost disappeared.

Looking forward

There is still fluctuation in my health; there may still be foods that I can't yet eat; and the M.E. is still evident, although improved, but it is still quite early in the long process of readjustment between my new companions and my own body.

Based on the available information, I don't expect a final equilibrium to be reached until my helminthic helpers and I have been together for approaching a year, and the experience of the few others who have trodden this path before me suggests that the beneficial changes could even continue to accrue beyond this point. Obviously, the magnitude of any additional benefits will gradually reduce as time passes, but it is clearly not unrealistic to hope for yet further improvement.

My situation now is very similar to what it was 20 years ago, when I was forced to take very early retirement due to the M.E. and had already lost a number of foods from my diet as a result of the encroaching food allergy and intolerance. Today, however, thanks to just 35 tiny worms, I'm moving in the opposite direction - a truly incredible result!

One of the developments that I consider most significant is my regained tolerance for herbs and food supplements. After having been unable to tolerate any supplements for a number of years, I have now already reintroduced several, and am looking forward to once again being able to use food-derived 'medicines' to treat any illnesses that I might develop in the future. I should also be able to more effectively treat whatever degree of M.E. I might be left with when my wonderful companions have done as much as they can to restore my health.

Looking back eight months, to when I decided to take the plunge and acquire some health-promoting helpmates, I remember feeling a surprisingly strong sense of urgency that drove me to make the final decision quite quickly, in spite of the cost involved.

I am now SO pleased that I responded positively to this urgent prompting, because the particular hypoallergenic feed, which has been the only form of food that I could tolerate for several years, has recently been discontinued, and I am currently coming to the end of my remaining stock of this lifeline.

Had I not decided to employ a team of time-served technicians to tinker continuously with my immune system, there would eventually have been no food left that I could eat, and my survival would clearly have been in doubt. As things have turned out, however, I can now look forward to the future with considerable confidence and optimism.

Source: http://www.foodsmatter.com/allergy_intolerance/food_intolerance/articles/worms_for_food_intolerance.html

Food intolerance - not 'all in the mind'!

First-Time Link Between Food Intolerance And Illness

Researchers from University College London have found the first compelling evidence linking food intolerance and symptoms of serious illness.

Their discovery could prove to be the much-needed catalyst to prompt a rethink by the medical profession of its hostile attitude to food intolerance, which is typically dismissed as 'all in the mind'.

In a six-month programme, the UCL researchers have demonstrated potential links between foods and Crohn's Disease, and ulcerative colitis.

They worked with three specific groups of patients - one with Crohn's Disease (28 patients), a second with ulcerative colitis (25), and a control group with a benign coincidental thyroid lump (24).

Each patient was asked in advance which of 113 foods they felt gave them a bad reaction and, specifically, whether this was a gut reaction or non-gut one.

Then, over the six months, each had their blood tested for individual intolerances to the 113 foods, using the Yorktest Laboratories IgG antibody test.

Patients in the control group were found to have few intolerances, but those with Crohn's Disease and ulcerative colitis were typically found to be intolerant to three or more foods.

The bowel disease subjects most commonly reported sensitivity to wheat (40 per cent compared with 8 per cent of controls), milk (36 per cent versus 8 per cent), kidney and haricot beans (both 24/0), coffee and onions (20/4) and oranges (20/0).

Intolerance to peanuts, cashew nuts, hazelnuts, brazil nuts and chilli were about twice as high among the bowel disease patients as they were in the control group.

If there had been no link between food and disease, the results would have averaged around 50/50 - i.e. a random chance association between the patients with an objective measure of food sensitivity and those making a subjective report of food sensitivity.

The researchers are planning further double-blind placebo-controlled food challenge experiments to investigate whether IgG antibodies can predict which foods provoke disease and, conversely, whether specific food avoidances based on antibody results might be worthwhile.

IgG and Gastrointestinal Disorders

Dr Anton Emmanuel, consultant gastroenterologist and senior lecturer in neuro-gastroenterology at University College Hospital, London, outlines some of his recent work. Additions in italics in brackets are intended to help our less medically literate readers to understand Dr Emmanuel - they might also be helped by reading our article on [allergy testing](#).

The possible role of food hypersensitivity in causing gastrointestinal disease was first suggested in 1950. While there is good evidence of the clinical importance of food allergy in certain gut diseases (eosinophilic enteritis, coeliac disease), the role of gastrointestinal hypersensitivity (allergic) reactions in other gut disorders remains controversial.

Food allergy and intolerance in IBD (Irritable Bowel Disease)

While there is no evidence that specific immune-mediated (allergic) reactions to food play a role in most patients with either Crohn's disease or ulcerative colitis (UC), it is common for patients with gastrointestinal (GI) disorders to believe that something in their diet has caused their condition. Some studies have claimed that food sensitivities are common in Crohn's and have found that when food intolerances are detected, patients on an exclusion diet maintain remission significantly longer than those on an unrestricted diet. However, when these patients are subjected to double-blind food challenges only 15% show a positive response.

In contrast UC does not seem to respond to bowel rest or elemental diets (totally allergen-free formula food made solely from nutrients so there is no waste to be eliminated via the bowel). However, when patients with UC were surveyed regarding the frequency and pattern of food intolerance there existed no significant difference in findings between UC and Crohn's disease. Food intolerance was reported at a significantly higher rate in patients with IBD than in normal controls.

Potential mechanisms for food allergy in IBD

While the bowel mucosa (lining) acts as a physical barrier to dietary and microbial antigens (substances which the immune system recognises as harmful), even under normal physiological conditions intact food antigens can penetrate the mucosal barrier via transcellular or para-cellular routes. The integrity of the GI mucosa is further compromised by inflammatory conditions such as infectious gastroenteritis or IBD. This increased permeability exposes the immune components of the GI tract, principally resident in the lamina propria and Peyer's patches (parts of the mucosal lining of the gut), to the potentially antigenic components of the luminal contents (the food moving through the intestines).

IgE mediated food hypersensitivity Immediate phase reaction

Previously sensitised mast cells are induced to release inflammatory mediators by IgE in the immediate phase reaction (see [IgE reactions](#)). These mediators result in increased vascular permeability, smooth muscle contraction and the classical wheal and flare (allergic) response. There is evidence that similar mechanisms may operate in mucosal (gut lining) hypersensitivity reactions. Certainly food antigen induced mast cell degranulation (the process by which histamine etc is released when the IgE antibody 'binds' to the antigen) has been demonstrated in the rat intestine. In addition degranulating mast cells have been found in the gut mucosa of patients with Crohn's disease.

Delayed phase reaction

The immunomodulators and pro-inflammatory agents released by mast cell degranulation result in granulocyte, lymphocyte and monocyte/ macrophage (all white blood cells involved in an immune response) migration and activation. This results in a more protracted hypersensitivity (allergic) response. The role of this delayed phase reaction in asthma and atopic eczema is well demonstrated. It has also been suggested that a similar mechanism may play a role in food allergy. However a clear role in IBD has not been demonstrated.

IgG mediated food hypersensitivity

Whilst raised IgG levels are seen in patients with asthma, hayfever, eczema and atopic dermatitis, the published data regarding IgG mediated immune reactions in food hypersensitivity (allergy) is contradictory. In fact it has been suggested that IgG production may be a normal immunological response to dietary antigens. However, increased levels of food-specific IgG and IgG4 antibodies have been demonstrated in atopic eczema and respiratory allergy. In food allergy the immunological response may be heterogenous with a predominance of one type of antibody response in different patients.

Antibody combinations

One study comparing raised levels of IgE, IgG4 and double blind food challenge found that elevation of any one immuno-globulin (Ig) sub-class correlated with a positive history of food hypersensitivity in only 63% of patients, but that the combination of IgE and IgG4 correlated in 91% of patients. These high specificities have been reproduced elsewhere also with IgE and IgG food specific antigens in combination.

IgG, Crohn's and IBS

Our group has shown that there are increased levels of food specific IgG antibodies in Crohn's disease compared to controls (in the people in the study with Crohn's Disease compared to the 'control' participants who did not have the disease). There was no significant correlation between food antibodies and patient reported sensitivity, possibly a result of the small number of patients in this study. These results suggest further experiments to investigate whether IgG antibodies can predict foods that provoke disease on double blind, placebo-controlled food challenge and conversely, whether specific food avoidances based on antibody titres (tested levels) might be worthwhile.

In the setting of IBS, an exclusion diet guided by the presence of IgG food-specific antibodies gave greater symptom relief and global rating scores as compared to a sham exclusion diet which did not avoid the foods indicated on IgG testing. Examining the patterns of IgG4 food-specific antibody positivity in patients with IBS compared with controls, it is apparent that subjects with IBS have significantly higher titres (tested levels) of antibodies to wheat, beef, pork and lamb than controls. An exclusion diet based on these IgG4 titres, significantly improves IBS symptoms and rectal sensitivity and compliance.

Challenge to dogma

These findings challenge the dogma that IgG antibodies to food are non-specific and of no relevance to gastrointestinal (GI) disease. The possibility exists that IgG antibodies to food could be useful in guiding dietary management of other GI disease responsive to dietary manipulation, in particular Crohn's disease.

IBS is often associated with adverse reactions to food and food allergy might be a mechanism for symptoms in a subgroup of these patients. The observation that faecal IgE levels are increased in a subgroup of patients with IBS but not in healthy subjects lends weight to the concept that allergy might be relevant in at least some patients with IBS.

Research findings

Investigation into the role of food intolerance in IBS dates back to 1982 when Jones et al. evaluated 25 consecutive IBS patients with a one-week elimination diet followed by open challenge with suspected foods. Of patients taking part, 67% had a resolution of symptoms. Wheat, corn, dairy products, coffee, tea and citrus were the most commonly implicated foodstuffs. Since then several studies of dietary exclusion have been reported, with response rates ranging from 15-71%. The most favourable symptomatic response in these studies of dietary manipulation has been in the sub-group with diarrhoea-predominant IBS.

The correlation of a positive dietary challenge with immunological markers of hyper-sensitivity (Type 1, IgE food allergy) has been poor. Three of the above studies examined the association between a positive dietary challenge and skin prick tests and/or radioallergosorbent (RAST) tests. One of these studies demonstrated a positive correlation in those IBS patients with a history of atopy (suffering from allergy) only.

Additional indirect evidence of an association between allergy and IBS takes the form of two small, double blind, placebo-controlled studies of disodium cromoglycate in IBS.

Disodium cromoglycate inhibits the release of inflammatory mediators by inhibiting degranulation of mast cells (prevents the release of histamine etc) following contact with an allergen. Hence, the effect of this drug in IBS may be due to the curtailment of an allergen-mediated response. A larger study of 428 patients comparing disodium cromoglycate and elimination diet demonstrated that disodium cromoglycate was as effective as an elimination diet in improving symptoms.

Further investigation

While there is no clear evidence to suggest that IBS is an infective condition, the observation that 30% of patients develop symptoms after an episode of gastroenteritis raises a question as to possible mechanisms for the association. One possibility is that inflammation of the bowel causes increased mucosal permeability thus increasing exposure of the immune system to dietary and microbial antigens. This might allow 'priming' of the mucosal immune system and predispose to hypersensitivity responses. Specific serological data (derived from analysis of the blood) to support this hypothesis do not exist however. Clearly investigation into the mechanism of this association warrants further research.

Source: http://www.foodsmatter.com/allergy_intolerance/miscellaneous/articles/igg_emmanuel.html

See also: 'Doctors allergic to truth about food' at: <http://news.bbc.co.uk/1/hi/health/192161.stm>

Further information

For articles about children with Total Food Intolerance, see:

Samuel's Story

http://www.foodsmatter.com/allergy_intolerance/egids/articles/samuel.html

Rhiannon's Story

http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/articles/rhiannon.html

The boy who is allergic to (almost) every food

<http://www.msnbc.msn.com/id/21246628/>

Other articles

The Management of Multiple Food Intolerances

http://www.foodsmatter.com/allergy_intolerance/food_intolerance/articles/hunter_huntley_food_intol.html

Coping with Food Intolerance

<http://www.chemicalfree.co.uk/food-intolerance/131-coping-with-food-intolerance?highlight=WyJjb3BpbmciLCJ3aXR0IiwidG90YWwiLCJmb29kIiwY29waW5nIHdpdGgiLCJ3aXR0IHRvdGFsIiwid210aCB0b3RhbCBmb29kIiwidG90YWwgZm9vZCJd>

More articles on Total Food Allergy and Intolerance

http://www.foodsmatter.com/allergy_intolerance/total_food_intolerance/index_total_food_intolerance.html

Facebook groups

Food Intolerance, IBS and Autoimmune Support

<https://www.facebook.com/groups/482748865146568/>

Beyond Failsafe...GAPS

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