

A User Guide
to the GF/CF Diet
for Autism,
Asperger Syndrome
and AD/HD

Luke Jackson

Foreword by
Marilyn Le Breton



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For Autism, Asperger Syndrome and AD/HD

Luke Jackson
with appendices by Jacqui Jackson

Foreword by Marilyn Le Breton



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*This book is dedicated to my best
friend, my Mum*



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Foreword

When Jacqui told me that Luke was writing about his experiences of the diet, I thought, “Great. I wonder, if I ask really nicely, if Luke will let me read bits of it, when he’s finished.”

When Jacqui told me that JKP were going to publish his experiences, I mentally punched the air and shouted, “Yes!” out loud, to the bemusement of my family.

When, a few months later, Luke phoned and asked me if I would write the Foreword to his book, I choked back an emotional sob and tried to reply calmly that I would be honoured and delighted to.

So why am I so excited about Luke’s book? Well, by the time you have got to the end of the first page, you will be able to answer that question for yourself. Luke is incredibly articulate, charming, funny and disarmingly frank about his life and the effects of the diet. So this book is a completely absorbing and wonderful read.

But on a far more personal level, I was curious to find out about how it felt to be on the diet, what differences it made, what the ‘withdrawal’ was like and what life was like prior to the diet, from first-hand experience. I have been able to observe, with my son, Jack, the downright miraculous differences that the diet has made to every aspect of his life. But I could never, ever know what it felt like. My curiosity has been further fuelled by a few remarks that Jack has been making recently. He has refused some foods stating, “No thank you, it will make my tummy hurt/make me sick.” Some of the foods that he had eaten pre-diet with relish (but now off-limits), he has seen and stated very calmly, “I used to eat that; it

made my tummy/head hurt.” Jack is five and a half years old and has been on the diet for a little over two years. I am amazed that he can remember that certain foods made him feel bad, especially as pre-diet, he was so severely autistic, I did not think he was aware of surroundings, let alone able to make the link that certain foods made him ‘ill’. Luke has helped me to fill in the gaps, until Jack is able to do this for himself – of which I have no doubt that he will do one day.

I was also fascinated to read how different foods and additives had completely different adverse effects upon Luke, Joe and Ben. Here are three brothers, all at different points on the autistic spectrum, all benefiting from the diet, but each markedly different in how different foods and additives made them feel and how the diet has affected them. Luke’s ability to observe his brothers and re-count their stories will help other families enormously and has already helped me when talking to parents who phone the AiA help-line. I am constantly being asked, “Will this diet help my child? Isn’t he too old/he’s only mildly autistic/he’s Aspergers/he has ADHD.” After reading Luke’s book, so much becomes clearer.

Luke’s book is a fascinating read: for every parent who has a child on the diet, for every parent contemplating implementing the diet with their child and for professionals everywhere who deal with people on the autistic spectrum.

So I would like to thank Luke, for taking the time and the trouble to write this brilliant book. I have learnt so much from Luke’s book and I am sure that many other people will learn a lot too. I also think that he is a very special person for trying to help other people. I sincerely hope that this will not be the last book that you have published. I would also like to end (finally) by quoting Luke:

“I think that a parent should do all they can to try to help their child with any difficulties they have and so should at least give this diet a go.”

A sentiment echoed by myself and all at AiA.

Marilyn Le Breton
August 2001

Acknowledgements

I would like to use this opportunity to thank these people in public.

- To know that I am not a 'freak' and to find that there is a reason why I have always felt different is one of the greatest reliefs of my life. For this I would like to thank Julia Leach (Educational psychologist) for caring enough to send Mum an article to show me and encourage her that it was time to tell my brothers, sisters, and I that I had Asperger Syndrome.
- Thank you to Marilyn Le Breton for encouraging me when I was fed up and for giving Mum so much help and information when she was learning about the diet.
- Thank you to Barbara from Barbara's kitchen for all her recipes that make the GF/CF diet more bearable and helping Mum to bake so well.
- Thank you to each one of my brothers and sister for adding something special to my life; Matthew for being a wonderful big brother – always there for me; Rachel and Sarah for helping me when times were tough and for trying to understand; Anna for helping with baking and accepting me for who I am; Joe for cheering me up and making me laugh; and Ben for lighting up all of our lives
- Thank you to Grandad and Margaret, Aunty Heather, Uncle Steve, my wonderful cousin Sammy, Uncle Colin and Philippa and Granny for accepting me as I am, funny quirks and all!

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- Thank you to my learning support teacher, Heather Brookman, for providing my word processor and helping me so much with work and other matters.
 - Thank you to Jessica for believing in my capabilities and making this book a reality.

The Autistic Spectrum and the Diet

Over recent years there has been a growing awareness concerning the autistic spectrum but diagnosis criteria still vary enormously. It is however, widely accepted that people on the autistic spectrum have difficulties in the area of language, communication, social interaction and imagination and often engage in obsessive or repetitive behaviours and rituals. Many people on the spectrum also suffer from debilitating stomach and bowel problems. There is increasing evidence that the removal of the 'intoxicating' effects of gluten and casein by implementing a gluten and casein free diet, can result in remarkable benefits in many of these areas. Convinced that the diet was worth a try with my family I embarked on our GF/CF journey. The outcome has surpassed my wildest expectations.

The spectrum includes both people who are severely affected and may be non-verbal, and those at the other end of the spectrum people with high functioning autism (HFA) and Asperger Syndrome (AS). Attention deficit, hyperactivity disorder is identified by a rather different set of diagnostic criteria, but is increasingly recognised as, at the least, a related condition.

Diagnostic difficulties often arise especially at the high-functioning end of the spectrum. Who is it that actually defines a

problem in any one given area? Does a child who approaches a stranger and kisses his or her legs have a problem with social interaction, or is there only a problem when the child is withdrawn and reserved? If someone feels different and isolated inside, but has learned the rules of the game and can behave 'sociably', does he have a problem? Does someone who is perfectly happy with her own company and with being alone have a problem at all? There are now many books that delve into these issues. I work on the premise that, if something constitutes a problem for the individual him- or herself, then it is indeed a problem.

One area of ongoing debate concerns intervention with the intention to normalise. Many people on the spectrum or with a child with these 'conditions' are clear that many aspects are beautiful, unique and to be cherished. Luke writes of his concerns, even annoyance, that this diet was 'devised' with the sole aim of eradicating all aspects of autistic spectrum disorders and he was, initially, exceedingly disgruntled!

Nevertheless, many areas are indeed disabling, and it is those areas that we should seek to eradicate or ameliorate. I know only too well the feeling of desperation and the desire to reach your apparently unreachable child, the feeling of helplessness you experience as your child suffers with disabling stomach and bowel problems.

The GF/CF diet has enabled many, many people to 'connect' with the world in which we live in a much clearer way. For Luke and others with Asperger Syndrome, that connection has led to a much deeper understanding of himself and the social world.

The GF/CF diet, is not a 'cure' for autism, Asperger Syndrome or AD/HD. It may not work for everyone, it may not have the same effect for everyone, but, as Luke says, you will never know unless you give it a try!

– Jacqui Jackson

Introduction to *Moi*

My name is Luke Jackson. I am twelve years old, I have Asperger Syndrome (AS) and I am on a gluten and casein free diet (GF/CF). If you are not sure what either of those are, then I hope you will read on and will understand more fully by the end of the book.

I have written this book for a few reasons. People often tell me how polite I am and I do try to be helpful. I am hoping that this book will encourage parents to learn more and understand what the GF/CF diet can do for a child with autism, AD/HD or Asperger Syndrome. I think that a parent should do all they can to try to help their child with any difficulties they have and so should at least give this diet a go.

I also know that there are some people with autism who do not speak. They may choose not to or may be unable to. If these children are on the GF/CF diet, I would like to be their 'voice' and let their parents know that just because they have not started chattering away, it does not mean the diet has had no effect on them. I hope I can help lots of parents to understand their child a little better.

I also know what some people will be thinking when they read this. You will be thinking, "Does this diet work for people with AS

too?” The answer to that is “yes”. No one is ever too ‘mild’ or too old.

One thing that really annoys me is that Asperger Syndrome is often called a milder form of autism. I actually find that quite insulting, although I do understand that people have to explain it somehow.

I like to think of the autistic spectrum as one long line with people dotted about the line. I am sure there are many undiagnosed people who are on that line somewhere and feel different from others but maybe are not sure of the reason why. One example of this is my brother Joe. He has all the characteristics of AD/HD. He has real problems with listening and concentrating and he is hyperactive and impulsive but he also has some funny little ways that are very like other autistic people I know. To us he is just Joe, but he is definitely somewhere along that line and knowing that makes it easier for us to understand him.

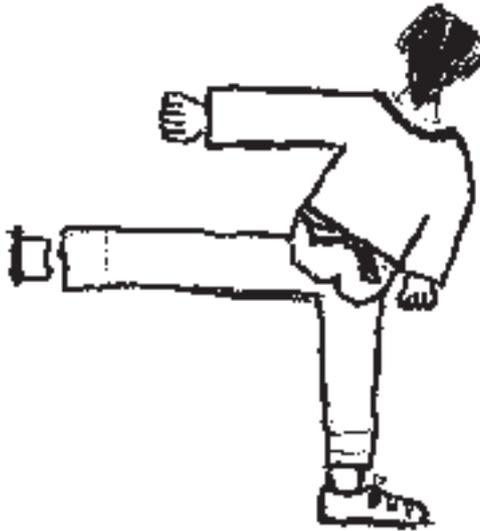
I like computers and we have one at home, which has a HP DeskJet six-sixty printer and a 56K modem. I used it for quite a lot of things, ranging from homework to making web pages but now I only use it for the Internet because I have my own laptop now. I like making web sites.

My family consists of eight people: my Mum who is thirty seven and five months, Matthew who is seventeen and eight months, Rachel who is fifteen and ten months, Sarah who is fourteen and two months, Anna who is eleven and one month, Joseph who is eight and two months, Ben who is four and three quarters, and me. Of course everyone’s age will have changed slightly when this is published but not enough to matter really.

I attend Arnold Private Senior School and my favourite subjects there are French, Latin, German and, of course, IT. I moved from my last secondary school because I was getting bullied. Things are much better where I am now.

I go to a thing called 'learning support' which helps me with crowds and remembering things, generally things to do with Asperger syndrome. The teacher, Heather Brookman, is really nice and helps me a lot.

I also go to a Taekwondo class at Blackpool Sports Centre, which is run by Master Craig Waddington who is sixth Dan (that's well up from a black belt). It is the ILGI Taekwondo association – IL means one and GI means together – I think that's a cool name. I am usually alone so it is nice to think of myself as together as one with others who do Taekwondo. It is really enjoyable and helps me get fit and confident and it improves my reflexes. It is also good if you get into a sticky situation somewhere, as you can defend yourself.



I have also been looking for a relaxation club, like Yoga, but I found out you can only attend Yoga when you are fourteen because the bones are not developed. I'll keep looking anyhow.

That is enough about me.

I have compared doing this diet with a boat journey – a bit rough, a few accidents, but it is worth it because you end up at a much better place.

The Diet in a Nutshell*

A bit of basic biology

First of all I have to say that although I am not your 'regular' kid – I am only 12 years old and I am no child prodigy, so do not profess to know as much as others about the theory behind the diet – I will explain what I know and point you in the right direction to get information about the diet. There are plenty of addresses and links at the back of the book, where you will be able to learn more.

Some people cannot break down gluten and so it damages the intestine and causes big problems. Joe is like that. This is called coeliac disease and the treatment for that is a gluten free diet forever. The problems autistic people have with gluten are not the same as this, though many autistic people have coeliac disease as well.

There are physical signs that someone has a problem with gluten and casein and may benefit from the diet and I will list a few, but that doesn't mean that, if none are present, then the diet won't work, or that anyone has to have them all. Here are the ones that were obvious in our family and I am sure that there are more:

* (I do so love these ridiculous expressions.)

- constant craving for gluten and/or dairy foods
- pale face
- black rings around the eyes
- red ears or one red ear
- bloated stomach
- excessive thirst
- excessive sweating
- poor sleeping habits
- behavioural problems
- diarrhoea
- constipation
- excessive wind (He he!)
- seems unable to feel pain.

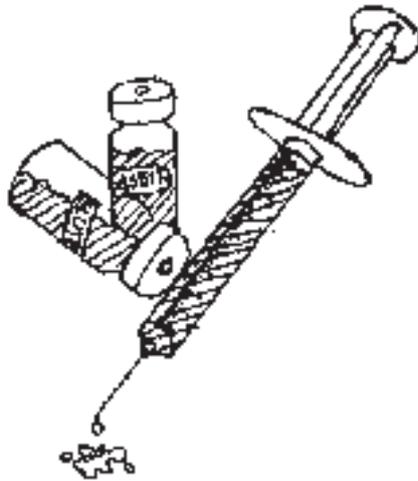
Here is my attempt at an explanation of the theory behind this diet and though it is not so detailed, I think it is accurate. I am not the kind of person that likes to give out false information.

The theory, still being researched, is that people on the autistic spectrum do not completely break down gluten and casein. Gluten is the protein found in most grains (four actually) and casein is the protein found in dairy produce. Because these proteins are not broken down properly, they end up as little bits called peptides. These peptides pass through the wall of the stomach, which is often damaged and 'leaky' in kids like me (hence the fact that most of us have stomach problems, such as constipation or diarrhoea). Gluten breaks down into a peptide called gluteomorphine and casein breaks down into a peptide called caseomorphine. These peptides whizz around the body and cause people to become literally addicted to them. As you can guess by the name,

these have the effect of morphine (or heroin). By removing the offending foods (those which contain gluten and casein) from your or your child's diet, the production of these peptides stops and so the 'heroin' effect stops too, resulting in changes in behaviour (for the better).

I must admit that I cannot remember ever feeling 'high' after eating bread or drinking milk but I do remember my little brother Ben being exactly that. He giggled hysterically at nothing and flicked his fingers in front of his face. He always seemed drugged; that was what made Mum start searching for answers to why he was always laughing.

So what is the problem with getting a quick fix out of foods? Some people may even be envious!



Well the trouble with that is, the times when the body isn't getting its drug, it goes into a withdrawal and then the addict feels ghastly, usually sweating, being dreadfully thirsty and having behavioural problems.

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