

Some people believe that a gluten- and/or casein-free diet will help eliminate problem behaviours in people with ASDs. **Dr Paul Whiteley** of the Autism Research Unit at the University of Sunderland gives his opinion.



Dietary interve

“ In the summer of 1996, I was put to task designing a small-scale, preliminary trial to examine the effectiveness of a gluten-free (wheat-free) diet with children with autism and ASDs. The results suggested that for a proportion of participants, the diet was helpful in ameliorating some of the problems associated with attention and motor disturbances, as well as showing some improvement in cognitive scores¹. The limited experimental research and anecdotal reports available at the time made interesting reading and opened up some intriguing areas outside of psychiatry and neurology. A small network of parents and professionals were already discussing this form of dietary intervention, exchanging recipes, hints and tips. Their experiences of the diet ranged from the absolutely remarkable turn-around in behaviours to the very unremarkable, with everything in between.

Today, there are many people attempting this form of intervention. The orthodox view of dietary exclusion tends to be either a ‘wait-and-see’ approach or a ‘why take these foods away from these children without the proper experimental science being done’. Indeed, the argument against, based on a lack of suitable long-term, double-blind, randomised placebo-

controlled trials, remains a popular one in some quarters.

In reality, there is quite a body of literature that suggests there may be

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something in this whole diet thing for autism.* The evidence in favour of gluten- and casein-free diets for autism is however far from clear: lots of open trials, a sprinkling of speculation and a vast amount of information (and misinformation), care of the internet and other media. The reality is that nobody really knows why such diets work for some children and not for others or which children are going to be best responders and nobody knows what the long-term effects are. All we do know is that for some it can be a useful, complementary form of intervention; for others, a very expensive, socially-isolating exercise.

To the question of whether to ‘diet or not diet’: a few pointers may be useful.

Firstly, such drastic changes to a child’s diet should not be entered into lightly and should be done in unison

with medical professionals. Your child's GP is an obvious starting point. Not only will a good GP offer some guidance about the pros and cons of such an intervention, but they can also refer you to a local community dietician, as well as undertaking some routine analyses, such as blood screening for coeliac disease and/or iron deficiency, prior to intervention.

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Knowing what foods are to be included or excluded from the diet, what vitamin and mineral supplementation may be necessary as a result and having a professional there to provide a little personal guidance are all important.

Tell school teachers, relations and friends that you are going to attempt the intervention. The approach needs to be followed fairly rigorously and breaks from it – Granny deciding that just one chocolate digestive won't hurt – are often reported to be followed by negative changes in behaviour. Think about when you are going to start – Christmas or two weeks before your child's birthday may not be ideal!

Set a start date and stick to it. Any type of management approach to autism should be viewed as a time-limited experiment. This means circling



an end-point too, representing the time when you can objectively ask whether it has made any difference.

So, how do you measure difference? For some parents, difference is measured as a great developmental advance – perhaps the child starts to use more words. For others, difference is represented by their child going to the toilet, for the first time in a long



time, without the accompanying indications of stomach pain. Try to be objective – weigh up the benefits against the costs. Is it enough that the child can say two more extra words against the difficulties of maintaining the diet and the child eating gluten-free cake when everyone is merrily enjoying the real thing?

You may want me to tell you about all the marvellous changes to expect. I'm afraid that you are going to be disappointed. Currently, there is no unanimously accepted position on what the diet does or doesn't do. The reported effects seem to be as wide-ranging and heterogeneous as autism itself. For some children, there will be absolutely no positive effects whatsoever. A child may be miserable because they can't eat what they want and may feel they are being punished, by not having their favourite cakes and yoghurts. On top of this, the diet may have done nothing to improve their behaviours, self-esteem or their quality of life. As uncomfortable as this may be

to read, this could very well be the scenario after the trial period.

However, for a proportion of children, the results may be slightly more promising. Improvements in some of the core and peripheral behaviours associated with autism, such as attention problems, sociability and hyperactivity, are reported by some. I want to stress the impact on *core* and *peripheral* behaviours, rather than just the good old triad of impairments. The reason is, I am yet to be convinced that the diet does just act on the triad, in such a simplistic sense. As with many things in life, changes in one area will lead to knock-on changes in another. You get a better night's sleep, you wake up a little more refreshed (and less grumpy) the next day; if you are able to concentrate better at school and able to stay focused a little longer, you will probably learn a little better. I believe it's the same with the diet.

Another side to this issue is the impact on non-behavioural factors. Some children who go on the diet, who previously had functional bowel problems, such as constipation and diarrhoea, do actually go to the toilet with a little less discomfort and pain.

So, in conclusion: gluten and casein-free diets are not for everyone who has autism and just because it worked for the other child, don't assume it will for your child. Nobody really knows why the diets work for some and not for others. If you are going to do it, do it properly with your GP and dietician, in a time-limited experiment; and watch the toilet as well as their behaviour. Finally, I don't profess to be an expert in diet and autism so don't take my word for it. Do a bit of research yourself. ”

- * → You can search for further reading on this subject at: www.autism.org.uk/autismdata
- Visit: www.researchautism.net for up-to-date, reliable and scientifically-valid information on interventions for people with autism.
- For more information on gluten-free diet, visit: www.coeliac.co.uk
- The Autism Research Unit at the University of Sunderland is at: <http://osiris.sunderland.ac.uk/autism>