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Autism and gluten/casein-free diets

The gluten and casein free diet is one of the most researched dietary therapies used with autistic people. There is a subset of autistic children with gut problems who may benefit from a trial of a gluten and casein free diet. In a survey of parents of autistic children in England, 19% had tried a gluten and/or milk free diet and 43% of these had never seen a dietitian (Huxham, 2012).

A majority of these parents reported significant improvements in various aspects of their child's wellbeing on a gluten and/or milk free diet with significant improvements in bowel habits, general health, sleeping patterns, concentration and social communication. These results are consistent with other anecdotal reports and surveys worldwide (Whitely et al 1999, Knivsburg et al 2002, Whiteley et al 2010).

Gluten is a protein found in wheat, rye and barley and foods made from them, for example bread, pasta, biscuits and breakfast cereals. Casein is a protein found in cow, goat and sheep milks and foods made from them, for example cream, yoghurt and cheese.

This article is based on clinical experience and discusses both some of the factors that can cause gastrointestinal problems, and important considerations when deciding whether to trial a gluten and casein free diet. This is supported with a case study which illustrates how a gluten and casein free diet can be beneficial for some individuals.

Why gluten/casein-free diets?

There are several hypotheses as to why gluten and/or casein may be harmful to some individuals, including the hypotheses that improperly digested gluten and/ or casein in the form of peptides (the building blocks of protein) may adversely affect the central nervous system, or that gluten and casein may provoke adverse autoimmune responses in the gastrointestinal (GI) system. Further research is needed as studies have been inconclusive (Whitely, 2014).

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Gastrointestinal problems such as constipation, diarrhoea and a bloated stomach are quite common in autistic people and can affect their mood. A review by Valicenti-McDermott et al (2006) found that 70% of autistic children had gastrointestinal problems compared to 42% of children without a diagnosis of autism. The Missouri study (Ferguson et al 2016) found that 23-85% of autistic children have gastrointestinal difficulties.

There is not enough evidence to recommend the gluten and casein-free diet for all autistic people but some do report feeling better when following it. A gluten and casein free diet involves avoiding all foodstuffs which contain gluten and casein. Following a gluten and casein free diet is not without risk. For example there are increased risks of an inadequate intake of nutrients such as energy, iodine, calcium and fibre which could cause weight loss and poor growth.

These risks are further exacerbated if the child or young person already has a limited diet and by following a gluten and casein free diet will miss out on some of their 'favourite' foods. The diet can also involve significant inconvenience and cost. NICE Autism Guidelines for children and young people 2013 advises not to use exclusion diets (such as gluten or casein free diets) "for the management of core features of autism in children and young people".

Other possible causes of gastrointestinal problems

PICA

PICA can be defined as the persistent craving and compulsive eating of nonfood substances e.g. mud, sticks, grass or cardboard and is common in autistic children. It can also be a sign of an underlying nutritional deficiency e.g. iron (Borgna-Pignatti and Zanelle 2016). PICA can be life threatening if foreign bodies are swallowed - there have been some cases of children swallowing rubber gloves which have led to bowel obstruction.

Anxiety

Autistic children and young people have much higher levels of anxiety than the general population (Gobrial and Raghavan 2012). In a study by Ferguson et al (2016), diet did not appear to be the main reason for gut problems, and this Missouri study found that autistic children in the study had a closer correlation between gut problems and stress.

Cramming

As a result of sensory difficulties, many autistic children will cram food into their mouths and swallow it without chewing, making the food much harder to digest which can result in reflux and abdominal discomfort etc.

Undiagnosed food allergies

The incidence of food allergies in children is increasing and has been estimated to be 3-6 % in the developed world (BSACI 2011), and autistic children are just as likely to suffer from a food allergy.

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Malabsorption of fructose and fructans

The potential importance of malabsorbed fructose and fructans as a trigger for symptoms in patients with IBS has generally been underappreciated. The evidence that a fructose or fructans load can provoke acute gastrointestinal symptoms is substantial (Shepherd and Gibson 2006). There is also support for the view that in patients with fructose malabsorption, chronic symptoms of IBS can be effectively reduced by reducing dietary intake. I have observed favourable results on a number of occasions when a child's intake of fruit juice, dried fruit and other fruits is reduced.

Good practice prior to starting diet

- Explore reasons for considering starting the diet and other factors which may be causing symptoms e.g. PICA, food intolerances, allergies.
- Serological Coeliac screening prior to commencing diet to exclude Coeliac disease
- Assess for and correct any nutritional deficiencies e.g. Iron and Vitamin D.
- Baseline monitoring of child's behaviour and gastrointestinal symptoms over a period of several weeks.
- Practical considerations e.g. recipes, liaising with school, nursery etc and ensuring diet is nutritionally adequate for optimum growth and wellbeing.
- Baseline measures of behaviour and wellbeing e.g. growth and nutritional intake, so that any changes once the diet has started can be demonstrated.
- Explore how re-introduction of foods will be managed.

Case study

Anna (not her real name) was referred by the Paediatrician due to problems with constipation, limited diet, tooth decay, sensory issues and reflux. She had a diagnosis of autism and learning disability and was aged 6.

Her diet was found to be low in iron, calcium, energy and fibre. Tests for Coeliac disease were negative and she was taking iron medication.

Anna refused to sit down at mealtimes and wandered round the room, swallowing foods without chewing. Mum had previously excluded gluten and dairy containing foods, and on reintroduction they were found to make Anna's constipation worse. Anna was seen by a Gastroenterologist who prescribed laxatives and anti-reflux medication. Anna's appetite remained poor, she complained of heartburn by crying after meals, grabbing at her throat and refused to take the prescribed medications.

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In school Anna was very unhappy; she was withdrawn and refused to take part in any activities, as frequently upset and had periods of aggressive behaviour. She communicated by pointing or shaking her head.

The family were advised to once again remove gluten and dairy from Anna's diet to see if this helped with her symptoms of heartburn and constipation. The dietary aims were to ensure that Anna continued to meet her nutritional requirements on a dairy and gluten free diet. When dairy and gluten were once again removed from Anna's diet her constipation resolved, she was observed to be very happy in school and started to communicate verbally.

Unfortunately despite this improvement in symptoms since commencing the milk and gluten free diet, Anna's weight gain has been poor. We discussed food fortification (the addition of extra protein, fat and other nutrients to foods), and trying an over the counter liquid calcium and vitamin D supplement. The cramming of food which Anna exhibited is very much related to her sensory difficulties and so the following strategies at mealtimes (to encourage Anna to chew her foods) were suggested:

- pacing mealtimes
- increasing her oral awareness before a meal e.g. trying a vibrating oral motor tool or ice cubes.
- counting the number of chews for each bite.
- having a visual schedule. Visual schedules are a series of picture which communicate a set of activities or the steps to a specific activity.

This case study demonstrates that there can be multiple factors to take into consideration besides a gluten and casein free diet.

In conclusion the links between diet and autism are very complex and there are often many different factors at play. Due to the risks of nutritional deficiency a gluten and casein free diet should only be attempted under the supervision of a dietitian or physician, preferably one who has expertise in the area of autism. Autistic people who present with gastrointestinal symptoms warrant a thorough evaluation and in some cases referral to a Gastroenterologist.

Further reading

British Dietetic Association is the professional association and trade union of UK Dietitians. The website contains information on the Dietitians in Autism sub-group

Research Autism has extensively evaluated different interventions for autism. The website contains a detailed peer reviewed evaluation of the gluten and casein free diet.

Wales Autism Research Centre has produced a booklet for parents called 'Information to guide you when choosing an intervention'.

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Autism Links

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