

## **Gluten and casein free diets for children with ASD or ADHD – An idea worth trying?**

The use of a gluten free or casein free diet for children on the autistic spectrum is quite popular. This information sheet tells you more about the theory behind this diet. It also discusses some of the practical issues. After you have read this, we hope that you will be able to make an informed decision about whether or not it might be worth removing dairy products (containing casein) and gluten (from wheat, barley and rye), from your child's diet.

### ***How is removing foods from the diet supposed to help?***

For children with diagnoses like Autism or ADHD, it is thought that removing certain foods from the diet may improve specific aspects of brain function in some children. This can mean improvements in mood, concentration, behaviour, sleep or anything else that the brain is responsible for. For some children, physical health may also be improved. For example, there can be improvements in gut symptoms, skin or lung function. Diets where certain foods have been removed in an attempt to improve health and wellbeing, are called "**exclusion diets**".

### ***Is a gluten and casein free diet the only diet related approach for children with Autism or ADHD?***

Most of this information sheet will tell you about the pros and cons of removing wheat and milk products from the diet. Wheat is the main source of gluten, and milk products are the only source of casein. There are many other ways to improve health & wellbeing using different foods, diets and nutrients. Some of these involve taking other foods out of the diet. Others involve putting new foods into the diet. Some involve nutritional supplements. Many of these can be easier and often more effective than removing milk or gluten. Spend some time reading through the various Highland Information sheets on diet, ASD and ADHD before you decide which, if any of these ideas are likely to be of benefit to your child.

### ***Could a gluten or casein free diet help any children who do not have Autism or ADHD?***

There will be a significant minority of children, in the general population, whose health and wellbeing could be improved by removing casein, gluten or both. There will also be a large number of children (possibly the majority) with Autism or ADHD, who have nothing to gain by removing casein or gluten. It is thought by some scientists, that there are "sub-groups" in the population who are more likely to be vulnerable to gluten and casein. Many websites claim that **all** children with Autism should be on a gluten and casein free diet. The scientific evidence does not support this.

### ***If a gluten and casein free diet helps, does this mean my child has a food allergy?***

Probably not. It is more likely they are "intolerant". The difference is that classic food allergy involves the immune system. Food intolerances do not. However, there is a "grey area" of negative reactions to food, that could be intolerance or could be a form of allergy. This grey area exists because medicine does not yet know all there is to know about the human immune system, or what tests to carry out to show that there is a reaction.

### ***If there are no obvious physical symptoms, does it mean that their brain is not affected by gluten or casein?***

Not necessarily. It is true that physical symptoms means that there is a greater chance that gluten or casein are also affecting the brain. However, it is clear that both gluten and casein can affect the brain in some children, even when there are no obvious physical symptoms.

### ***Is there anything to lose by trying a gluten or casein free diet?***

Some gluten and casein containing foods are a good source of important nutrients. Some are not. Avoiding some gluten and casein containing foods can make it harder to get all the nutrition we need from our diet. Also, some of the foods are a major part of our food culture. Avoiding them can make it harder to join in with family meals and other social events involving food. Many children already have very limited diets and are low in some of the 40 different nutrients that the developing brain and body needs. Taking even more foods out of the diet can sometimes make this worse.

### ***But I've read so many positive comments from other parents of children on this diet.***

The internet is full of case studies of children whose parents report benefits from removing gluten, casein or other substances from the diet. However, families who did not see any benefit, are far less likely to want to tell other people about their experience. The scientific research, supporting the use of a gluten or casein free diet, is quite limited. Some studies report a benefit and some do not. This is not surprising. It depends on whether or not the children taking part in the study, happened to be the ones affected by gluten or casein. A dietitian can help you work out whether or not a gluten and casein free diet might help your child. They will be able to ensure that any exclusion diet is done in a safe and practical way.

### ***Why gluten and casein?***

The gut partly or fully digests gluten and casein. Partly digested gluten and casein (and other proteins) are known as peptides. In some people, these peptides may pass into the bloodstream, allowing them to affect the skin, lungs, brain and various other parts of the body. Gluten and casein have a similar chemical structure to morphine. Therefore they can fit neatly into "opiate receptors" in the gut, brain and elsewhere. The theory behind gluten and casein free diets is the gluten and casein act like morphine, producing similar symptoms including addiction and changes in mood, behaviour, attention, social interaction and sleep.

### ***So should I try the diet, where would I start, and should I remove both casein and gluten?***

There are a number of options if you are considering the diet. All of these are best done with the support and advice of a State Registered Dietitian, registered with the Health Professions Council. Options include:

1. **Introducing your child to a range of gluten free and casein free foods.** If your child likes these, it may help you decide that an exclusion diet is realistic. Examples include gluten free bread, breakfast cereals and pasta; and milk substitutes or a calcium supplement.
2. **Full gluten and casein exclusion.** Many families attempt to exclude gluten and casein at the same time. However, when you exclude both, if you see an improvement, you will not know if this was due to removal of the casein, the gluten or both.
3. **Excluding casein only.** Some families just exclude casein. This should take only about 3 or 4 weeks before you can assess whether or not the exclusion has been worthwhile. After 4 weeks, you can re-introduce casein to help confirm whether or not it was affecting your child.
4. **Excluding specific kinds of casein only.** There is now some evidence that 1 particular fragment of casein can be the main offending substance. This is found in most forms of cow's milk and not in other animal milks. Also, some people can tolerate yoghurt or cooked milk and cheese. This is because yoghurt making and cooking alters casein.

5. **Excluding gluten only.** Some families just exclude gluten. This can take around 3 to 6 months before you can assess whether or not this exclusion has been worthwhile. If there is no obvious improvement in 6 months, then re-introduce gluten containing foods and observe carefully for any changes.
6. **Excluding food additives first, or at the same time.** Artificial colours, benzoate preservatives, aspartame and monosodium glutamate are all food additives that can affect mood. Some people remove these at the same time as gluten casein. Ideally it is best to remove the food additives for 1 month first, before considering gluten or casein exclusion. These additives have no nutritional value and are often included in poor quality foods and drinks to improve appearance, taste or shelf life.

### **More about gluten exclusions.**

The best known established medical reason for a gluten free diet is a condition affecting the small intestine called Coeliac disease. A gluten free diet is the only treatment and gluten free foods are made available on prescription. This condition is tested for using blood test and by testing a “biopsy” of gut tissue. These tests look for “IgE antibodies”. When these are found, coeliac disease is confirmed and a gluten free diet is started.

We do not know whether or not coeliac disease is any more common in children with Autism or ADHD, than the rest of the population. It is likely that reactions to gluten amongst these children are forms of intolerance rather than allergy. However, it is likely that a small number of children with autism or ADHD whose mood or gut health is affected by gluten, do have undiagnosed coeliac disease. It is only possible to test for coeliac disease if the child is regularly eating gluten containing foods. Even if the tests for coeliac disease prove negative, a child could still have a gluten intolerance. This can still affect mood and health but no IgE antibodies are produced.

Gluten is a form of protein but it is not an important nutrient. However, wheat is both the main source of gluten and a major source of energy. In addition, “wholewheat”, “wholegrain”, “high fibre”, “wholemeal” and sometimes “brown” versions of wheat also contain fibre, magnesium, vitamin E, and B vitamins. Some children get plenty of these from other food in the diet. However, some children will have a much reduced fibre intake if they remove these high fibre gluten containing foods. Fibre is important for gut health and to help regulate blood sugar and mood. Magnesium is important for reducing anxiety. Green vegetables are the best source of magnesium.

There are plenty of gluten free starchy foods that children can get their energy from. These include corn, rice, quinoa, buckwheat, potatoes, turnip, oats and specialist gluten free products like bread and pasta.

Oats can be contaminated with wheat and therefore gluten. Most people who are sensitive to gluten can tolerate oats if they are not contaminated and are labelled as gluten free. Oats contain avenins which are quite similar to gluten but usually different enough to be safely tolerated. Foods like oatcakes and porridge are very healthy, high fibre foods that can be very good alternatives to bread, crackers and gluten containing breakfast cereals.

Gluten free bread, pasta, flour and other specialist foods are not prescribable for children with Autism or ADHD unless they have coeliac disease. They can be purchased without prescription and large supermarkets usually stock a wide range. They are considerably more expensive than regular gluten containing foods. Also, some gluten free foods (especially breads) use milk as an ingredient to replace the protein and improve texture. If your child also needs to avoid casein (from milk) check

the label carefully and choose a dairy free product. Children who like other starchy foods like potatoes and rice, often manage perfectly well without these specialist gluten free products. Bread can be a problem for some children as the texture of gluten bread is different. Toasting or baking your own sometimes helps.

During a trial of a gluten free diet, lookout for changes in gut function, mood, sleep, attention or behaviour. Bowel habits might change. Symptoms like constipation, diarrhoea, abdominal pain bloating may improve. Alternatively, the removal fibre rich gluten sources like wholemeal bread, might increase constipation.

### **More about casein exclusions.**

There are two reasons why people might need to avoid milk products. These are milk protein or casein allergy or intolerance; and lactose (milk sugar) intolerance.

**Lactose intolerance.** Lactose is the natural sugar found in milk. This is not protein or casein. Lactose intolerance affects the gut. Bloating and diarrhoea are typical symptoms. The effects of lactose are limited to the gut. Lactose intolerance can be tested for using a breath test.

**Casein intolerance.** Casein is a kind of protein found in milk and milk products. It can create allergy or intolerance. Effects can sometimes be seen in several parts of the body. These effects can be very obvious or more subtle. The gut, brain, skin, oesophagus, nose and lungs can all be affected by casein.

One particular substance released, when casein is digested, is called “betacasomorphin 7” (bCM7). This has a morphine or opiate like effect in the gut and the brain. Some research links bCM7 (from cow’s milk) to a range of symptoms and medical conditions including diabetes, heart disease, constipation, delayed motor development, mucus productions and inflammation. However at the moment, the evidence for this is incomplete and certainly falls well short of proof. The morphine like effect might also make it addictive to some children.

It could be that some of the children currently on a milk free diet, are only sensitive to bCM7. If so, there may be some animal milk products that they can tolerate. Goats milk and “A2 cow’s milk produce there very little bCM7 when they are digested. This is also true for goat, sheep (Ewe’s) and buffalo milk products. Some of the children with Autism or ADHD who are currently on a milk free diet (due to intolerance rather than allergy), could try these alternative animal milk products to see if they can be tolerated. If they can be, it would improve their protein, calcium, Iodine and B Vitamin intakes of some of these children and also allow them to have some of their favourite meals, foods and drinks that they may have been missing.

Others, including those with milk protein **allergy**, probably need to avoid all animal milks. **It would be dangerous for a child with a true severe milk protein allergy to try these other animal milks unless under close medical supervision.**

Goat milk and other milk products that do not produce bCM7, are called the “A2” milks. Regular cow’s milk usually contains the “A1” type. Human breast milk also contains the A2 type of protein. This A2 cow’s milk is thought to have far less of a morphine like effect. A2 cow’s milk and sheep’s milk (Ewe’s milk) cheeses smell, look and taste like regular cow’s milk and cheddar cheese. Goat milk, goat’s cheese, buffalo mozzarella and goat yogurt are also acceptable to many children, but they will notice the difference in taste, smell and appearance. All of these alternative animal milk products are more expensive than the standard versions.

Many children with casein intolerance are given soya based substitutes like soya milk and soya yoghurts. These can be useful as they have calcium added but are also a good source of protein. Soya “cheese” is also available in slices, as a block or as a spread. Unfortunately some children with casein intolerance or allergy also develop similar symptoms with soya protein.

Another option is the many calcium fortified milk substitutes made from almond, coconut, rice, oats or hazelnuts. Because they are virtually protein free, they are only suitable for children who already eat plenty of other protein rich foods like meat, fish, eggs, nuts, beans or lentils. Check the label to ensure they have added calcium.

If you want start a trial exclusion of milk products, the table at the end of this information sheet should help you decide on the best alternatives.

### **How to avoid milk and gluten when shopping**

Food labels are now much better at displaying which ingredients come from **MILK** or **GLUTEN**, than they were. Labels often use bold and or capitals to highlight common allergens like these.

The kinds of food that will fairly obviously contain milk include ice-cream, custard, milk puddings, butter, cream, cheese, milk, yoghurt, buttermilk, fromage frais and milk chocolate. Less obvious foods that often include dairy products include certain kinds of biscuits, breads, flavoured crisps, cakes and some processed meat products.

The kinds of foods that will fairly obviously contain gluten include almost anything made from wheat, barley or rye including bread, some crispbreads, wheat based or multigrain breakfast cereals, biscuits, cakes, pastry, pies, pasta, pancakes, wafers, cous cous, and pearl barley. Wheat and barley can also appear when you least expect it. Flour for example is used in many processed foods. Cornflour, maize flour and potato flour/starch will be gluten free of course. Malt and malt extract usually come from barley so these contain gluten too.

### Guide to choosing milk substitutes on a cow's milk free diet

<b>Dairy alternative</b>	<b>Likelihood of tolerance?</b>	<b>Suitable for</b>	<b>Nutrition</b>	<b>Cost, availability &amp; other comments</b>
<b>Goat milk or "A2 cow's milk + sheep, goat and buffalo cheese + Goat yoghurt.</b>	Possibly	Avoiding beta casomorphin 7. This may be enough for some children with milk protein intolerance	Similar to regular milk products. No concerns about adequacy of calcium, protein or iodine.	"A2 cow's milk has same taste as ordinary cow's milk. Ewe's (sheep) milk cheeses include manchego, ossau iraty & pecorino, all similar colour and taste to cheddar. Availability mostly in large supermarkets. Goat milk & manchego cheese more widely available. "A2" cow's milk in Morrison's and largest Tescos only. Goat yoghurt in Tescos only.
<b>Cooked milk based dishes and regular yoghurt</b>	Possibly	Protein is altered by prolonged heating and by yoghurt making.	Much the same as unheated milk products.	Examples include pizza, macaroni cheese and rice pudding. May or may not be tolerated.
<b>Butter from cow's milk</b>	Likely except in severe true allergy	Most forms of casein intolerance. Not for severe allergy.	Mostly fat. Contains a little vitamin A & D.	Can choose milk free vegetable fat spreads if sensitive to butter. Goat butter also available.
<b>Soya "milk", "cheese", and "yoghurt". Also soya "ice-cream" &amp; other soya milk desserts available.</b>	Possibly	Risk of reacting to soya protein	Calcium fortified. Contains protein. Lacking iodine.	Widely available in supermarkets except for soya "cheese" which is mostly sold in "health food" shops.
<b>Non-animal milk substitutes (Almond, coconut, rice, oat, hazelnut)</b>	Likely	Most people. May need iodine supplement.	Calcium fortified. Lacking protein and iodine.	All large and some medium size supermarkets. Doesn't taste like milk or behave like milk in cooking. Works well on cereal or in "milkshake" or smoothie. Rice milk not suitable for children under 4.5yrs of age.
<b>Lactose free milk, cheese and yoghurt</b>	Only if the problem is specifically lactose intolerance	Not suitable for casein intolerance or allergy.	Similar to regular cow's milk products	Can also be "lactase enzyme" on line and add to cow's milk or goat milk to break down the lactose.

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