



Implementing a Gluten & Casein Free Diet in Children with an Autistic Spectrum Disorder (ASD) &/or Other Associated Conditions

Introduction

Parents of children with autistic spectrum disorders (ASD) or attention deficit hyperactivity disorder (ADHD) have made contact with the Parent Partnership Service requesting information on Gluten free and Casein free diets.

In late 2003 I approached Helen Geldard, of the County Durham Autistic Support Group and asked her to help us to put together some hints for parents/ carers who were considering removing gluten and/or casein from their child's diet.

Helen promptly produced the contents of this leaflet based on a combination of her own experiences and the recommendations of P. Shattock and P. Whiteley of Sunderland University (see back page for references).

Elaine Chandler
Parent Partnership Co-ordinator
East Durham Education Centre
York Road, Peterlee
Co Durham SR70JR
Tel: 0191 5873541

What is Gluten?

Gluten is the protein found in wheat. Similar proteins are found in: Rye, Barley and Oats.

Many people also exclude these as well when implementing a Gluten free diet - hence the confusion between Gluten Free and Wheat free diets.

Naturally Gluten Free - Many foods are naturally Gluten Free as they don't contain wheat, rye, barley or oats. These are: all fresh meat, fish, cheese, eggs, milk and fruit and vegetables.

Gluten Free or Not? - Be careful once these foods are processed or added to other foods because often wheat or other gluten containing cereals are added in the manufacturing process.

Obvious sources of Gluten - are wheat flour, ordinary bread, biscuits, cakes, pastries, puddings and pies.

Hidden sources of Gluten - This is the difficult bit as wheat flour is commonly used as; a processing aid, a binder, a filler and a carrier for flavourings and spices. Also contamination with wheat or wheat flour can happen during Cereal production, storage, processing or manufacture.

How to select Gluten Free foods

Don't trust the labels on foods - Unfortunately they don't always tell you everything. Labels tell you if there is obviously wheat or wheat flour in the product but if the flour is used as a processing agent or a small percentage of a compound agent it doesn't have to be declared on the label.

Food Labelling

Food labelling is getting better but at present the best and most accurate gluten free food list is published by the Coeliac Society. This is updated constantly throughout the year.

Supermarkets often provide lists of their own brands which are Gluten Free. These are available free on request and sometimes on their web sites. More and more supermarkets are also clearly labelling their products as gluten free or containing gluten.

There are also many manufacturers of Gluten and Casein Free products. You can buy almost anything very easily and things are much, much cheaper and readily available in supermarkets.

What is Casein?

Casein is the protein in Milk. Milk is in commercial products such as tinned and packet foods so always read the label carefully and check the ingredients.

Avoid anything that contains; Milk, Skimmed milk, dried milk, condensed milk, evaporated milk, milk solids, Casein, Whey, Whey solids, Lactose and Caseinate.

The Gluten free & Casein Free Diets

After starting the diet in the initial 7-21 days many children show regressions in behaviour.

These include:

- Anxiety & anxious behaviour
- Clinginess and over-affectionate behaviours
- Crying and general whinginess
- Episodes of staring into space
- Dizziness
- Increase in Frequency of Urination and defecation (going to the toilet)
- Aching or evidence of pain

This is thought to be a type of withdrawal period and children who exhibit these regressive withdrawal behaviours tend to be those who show the most positive reaction to the diet. The withdrawal for Casein is much quicker about 36-48 hours.

Implementing the Diet

The suggested trial period for the Gluten Free Diet is 6 months. The feeling is that some of the product from Gluten may be stored in the body and require time to be used up. The suggested trial period for the Casein Free Diet is 3 months.

The positive effects of the diet;

- Increased levels of attention and concentration
- Calmer and more settled
- Decrease in aggression directed against themselves and/or others
- Improved sleeping patterns

Other reported effects;

- Improvements in communication - verbal and non-verbal
- Improved physical co-ordination
- Improved eating habits -eating a wider variety of foods that the child perhaps hadn't eaten before

Getting Started with the Diet

Getting Started

Recommendations

Inform your GP

- inform them of changes you are making that may have a bearing on your child's health
- In many cases your GP may help you with the implementation of the diet
- The GP can make a referral to a dietician. The restrictive nature of the diet means that your child may need vitamin or nutritional supplements. The dietician can recommend what is needed and these may be available on prescription. They can also help with ideas for alternative meals
- GP may also prescribe Gluten and Casein free products - they don't have to and may not!

Inform your child's school

If they are going to get hold of Gluten and Casein here's the place to do it!!! So it's important the school knows and can keep an eye on things. Many schools will provide Gluten and Casein free meals. However your child may need to take a packed lunch.

Set a date to start the diet

This will give you a target date to inform everyone who needs to know. Perhaps during the school holidays while you have stricter control over your child's dietary intake. Avoid Christmas. When to start is up to you and your child but once you have started you must stick rigidly to it. Research shows that if Gluten and Casein are reintroduced into the diet then negative behaviours return. So once they are on the diet they have to stay on it indefinitely.

Getting Started with the Diet

Don't take Gluten and Casein out of the diet together - do it in stages it's easier to monitor the effect and adapt to the diet.

What if they break the Diet?

Don't panic! - They will !! If your child gets Gluten or Casein you may see some regression in behaviour but this depends on the individual. The research shows the after effects last for about 12-36 hours depending on how much then have eaten. When this happens assess how they got the Gluten or Casein and put in measures to stop it happening again.

Will the diet work for my child?

There are no guarantees, but keep a diary; start with a base line of your child's behaviour before the diet. Record your child's behaviour as you implement the diet. Videos are also a good way of recording behaviours.

Involve the school as well, do they see a difference? This will give you a good idea of any changes in behaviour and whether the diet has made a difference.

Some Practical Advice

- Get your food information lists before you start
- Allow a bit longer for your shopping at first
- Set a cupboard aside and/or shelf in the fridge for foods that are ok for your child to eat
- Clearly mark what's ok for them – e.g. with a blue star so everyone knows at a glance what's ok for your child to eat
- Let the rest of the family know then they can help
- It's not as hard as you think - you can do it and it may well help your child.

The Theory Behind Gluten Free Diets and/or Casein Free diets & Autistic Spectrum Disorders (ASD) & Other Associated Conditions

The idea for Gluten and Casein Free diets comes from the work of Paul Shattock and Paul Whiteley from the Autism Research Unit of the University of Sunderland.

Their theory is called the Opioid Excess Theory

The theory is that the peptides from the incomplete breakdown of Gluten and Casein are able to cross into the blood stream due to the leakiness of the gut wall and then across the blood brain barrier and affecting the Central Nervous System (CNS). Normal processes within the CNS are then severely disrupted causing problems for the individual affecting perception, cognition, emotions, mood and behaviour.

The theory means that individuals find Gluten and Casein Toxic to their systems, they are not Allergic to them so blood tests and skin patch tests will not work.

If this theory is right then by eliminating these food stuffs (Gluten &/or Casein) from the diet the person with ASD or associated condition should show some improvement.

Indeed many children do benefit from the use of diet but not all. The most positive changes are noticed in children who are: very young, exhibit self injurious behaviour, exhibit signs of high pain tolerance and are more severely affected by ASD or associated conditions.

Useful Addresses

The Coeliac Society
P O Box 220
High Wycombe
Bucks
HP11 2HY

National Helpline:
0870 4448804

The British Dietetic
Association
7th Floor
Elizabeth House
22 Suffolk Street
Queensway
Birmingham
B1 1L

www.glutenfree-foods.co.uk

www.glutenfree.com

www.alotoforganics.co.uk/cats/diet.php

www.haldanefoods.co.uk/products/dairyfree

www.gluten-free.co.uk

www.tescodiets.com/dietprofile2/dietintro.cfm?dietchoice=20&code=700500

For Further Information Contact:

Helen Geldard
Co-ordinator of
County Durham Autistic Support Group
PO Box 35
SPENNYMOOR
Co Durham DL16 7WY

Tel: (01388) 819880

e-mail: helen.geldard@cdasg.org.uk

References

Whiteley, P. & Shattock, P. (1997) -
Guidelines for the Implementation of a Gluten and/or Casein Free Diet with
People with Autism or Associated Spectrum Disorders.
Autism Research Unit, University of Sunderland.

Whiteley, P. & Shattock, P. (1997) -
Autism as a Metabolic Disorder.
Autism Research Unit, University of Sunderland.

<http://osiris.sunderland.ac.uk/autism/>

Parent Partnership

For further information or support from a volunteer Independent Parental Supporter or advice from the Parent Partnership Service please contact:

Parent Partnership
East Durham Education Centre
York Road
Peterlee
Co Durham
SR8 2DP
Tel No. (0191) 5873541

Other publications available from Parent Partnership include: -

A brief Guide to Inclusion Panels
The SEN Audit explained
Support for the Under 5's
Individual Education Plans
What is Assessment?
Choosing a School
Appeals and Tribunals
Keeping School Informed
What are Special Educational Needs?
Home School Agreements
Anti-Bullying
Statutory Assessment Information Pack