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Understanding coeliac disease

Many of us would struggle to imagine a diet that went along the lines of 'avoid most cakes, biscuits, breads and slices, unless they have been made with particular types of flour and other special ingredients'. But this is the daily reality for children who are diagnosed with a condition called coeliac disease.

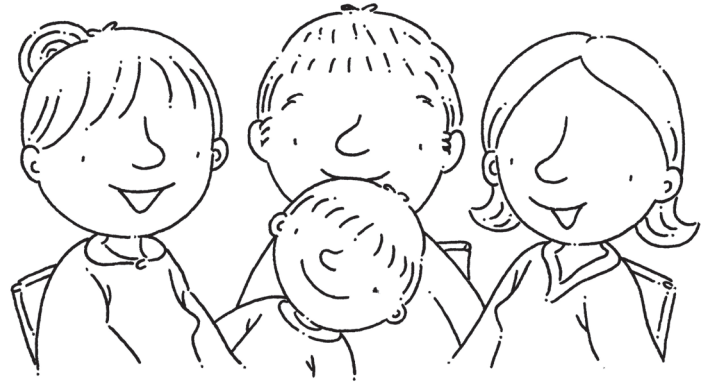
However, far from being a major life trauma, a diagnosis of coeliac disease can be the starting point for a lifetime of feeling healthy, lively and full of beans – just what we want for all the young children in our care each day. And the reality is that there are many, many foods that can be eaten safely by children who have coeliac disease.

Catering for a child who has coeliac disease should never mean simply avoiding the whole issue of food at your school or centre. In fact, food and meal preparation is an important part of everyday life and can be a key component of your curriculum planning. It is far more useful to take the time to educate yourself about coeliac disease and the gluten-free diet and so ensure that all children can fully participate in all daily activities, even those which involve food.

This book will guide you through a basic understanding of coeliac disease, and will ensure you feel able to appropriately support children who:

- may arouse your suspicions that coeliac disease could be the cause of some difficulties
- are going through the process of being diagnosed with coeliac disease
- have previously been diagnosed with coeliac disease
- wish to be a part of food-based events and activities at your school or centre.

Regardless of which point in the process you are at, it is important to combine your reading of this book with individual information which is specific to the child in your care. This could include consulting directly with parents and carers or obtaining information from general practitioners or specialists (with permission) or from a local coeliac society.



What is coeliac disease?

Coeliac disease is an auto-immune disease which affects children and adults. It is a lifelong medical condition that can cause significant harm if left untreated. Coeliac disease causes the production of antibodies which attack the body's own tissues. People with coeliac disease are affected by eating or drinking anything containing gluten.

Gluten is a protein found in foods and drinks containing wheat, rye, barley or triticale (a cross between wheat and rye grains). Oats contain a protein which is similar to gluten. Oat products can be contaminated with gluten, but gluten-free oats are also available. Some people may be sensitive to gluten-free oats. In people with coeliac disease, eating gluten causes damage to the lining of the small intestine.

The villi (those small finger-like projections that protrude from the surface of the intestine) become flattened and so the surface area available for absorbing nutrients across the intestine becomes reduced. This means the body is less able to effectively absorb the nutrients essential for good health and growth through the intestine.

Having coeliac disease is more likely if someone has a family member (related genetically to them) than for the general community.

There are genes which are indicators that a person is predisposed to developing coeliac disease. These can be tested for via a blood test or a cheek swab. Having a positive gene test does not mean

Gluten

So what is this thing called gluten and where do you find it? For people coming to terms with coeliac disease, this inevitable question can lead to hours of label reading, shelf searching and personal learning as they travel along the pathway to being 'gluten aware'.

Where do you find gluten?

Gluten is a protein found in wheat, rye, barley and triticale. It has both obvious and less obvious sources.

Some of the obvious places to look for gluten are:

- products made from wheat flour – cakes, biscuits, slices, bread, pasta, semolina, couscous
- products coated in breadcrumbs – fish, chicken nuggets, vegetable patties
- porridge
- breakfast cereals – often made from wheat or rye grains.

Some of the less common places to look for gluten are:

- gravies and sauces – if these are packaged they should have wheat, rye or barley declared on the ingredients list.
- packaged seasoning mixes – single herbs and spices will be naturally gluten-free. Check the ingredients list of blends of different spices as some may have wheat flour added.
- soups – these could contain pearl barley or may be made using a gluten-free stock. Check the ingredients list for wheat, rye, or barley.
- crisps and other snack foods – some crisps or snack foods can contain wheat flour as an ingredient and would need to be checked.
- flavoured drinks – problems here include lemon barley cordial (as barley contains gluten) and malted milks (as they contain gluten).
- foods that have been lightly dusted in flour prior to cooking.
- lollies/sweets.
- processed deli meats with bread crumbs.

- breakfast cereals – some cereals will contain an ingredient called barley malt extract. It depends on the amount used on if these cereals can be included in the diet or not. Individual brands would need to be checked. If unsure contact Coeliac UK Helpline on 0845 305 2060, who will be able to advise you.
- products such as cakes which are labelled as wheat free but which also contain gluten from rye or barley (and so are not 'gluten-free').

What about oats?

Oats do not contain gluten. They contain a similar protein called avenin. The main problem with oats and oat products is that they are often contaminated with gluten from wheat, rye or barley. Oats that are not labelled as gluten-free should always be avoided.

Oats labelled as gluten-free will be free from contamination and can be tolerated by most people. However some people can be sensitive to even gluten-free oats.

It is important that children see their health care team for individual advice regarding oats.

Parents will be able to advise you if their child can include gluten-free oats in the diet.

The 'find and replace' system

Often the trick to good gluten-free catering is to use the 'find and replace' system. This is really just a matter of learning a few typical sources of hidden gluten as well as remembering the more obvious ones. Once these hidden sources can be readily identified, they can be replaced by gluten-free alternatives.

Here are some examples:

- soy sauces – many of these contain gluten in the form of wheat
- baked beans – some brands contain wheat in the sauce, check the label to see if they can be included in the diet
- some breakfast cereals using malt – use a gluten-free variety in the free from section of the

Label reading

There are two options when it comes to choosing foods that are safe for a child with coeliac disease. Both approaches can help to ensure the child eats a sound and varied diet and that foods that are safe to eat are not removed from the diet unnecessarily.

Foods labelled as gluten-free

The first is to select foods specifically labelled as 'gluten-free'. Foods labelled gluten-free will contain 20 parts per million (ppm) of gluten or less. Research shows that this tiny amount of gluten can be included in the diet for people with coeliac disease.

In the past foods labelled as gluten-free could be 200ppm of gluten or less. The new stricter standard of 20ppm was introduced by the European Commission in 2009 and came into full effect in January 2012.

Foods with no gluten containing ingredients

The other option for choosing gluten-free food is to read the nutrition label on the back of the package. All pre-packaged foods bought in the UK are covered by European wide allergen labelling laws.

This means that if a product contains gluten as a deliberate ingredient, manufacturers must list the grain used. For example wheat, rye, barley and oats.

Some manufacturers also use an allergy advice box to highlight if there is any gluten in a product. This is not compulsory but also helps in the selection of products on a gluten-free diet.

It is also important to check both the ingredients list and the allergy advice box when choosing foods.

Safe to eat

You can generally assume that foods which do not indicate that they contain wheat, rye, barley or oats are safe for a child with coeliac disease to eat.



Barley malt

Barley malt vinegar is made using a fermentation process. This means that the amount of barley, and therefore gluten, in the end product is extremely small and is well below a level which is safe for people with coeliac disease. In addition, barley malt vinegar is usually only eaten in small amounts, for example, drained pickled vegetables, sauces with a meal or on chips.

Balsamic, cider, sherry, spirit, white wine and red wine vinegar are not made from barley and can also be included in your gluten-free diet.

Malt extract and malt flavourings are commonly made from barley, although they can be produced from other grains. Barley malt extract is a flavouring often added in small amounts to breakfast cereals and chocolates.

Foods that contain barley malt extract in smaller amounts can be eaten by people with coeliac disease. However if the amount of barley malt extract is too high it should be avoided.

Any foods that contain barley malt extract will be labelled as containing barley and you will not be able to tell from the ingredients list how much has been used. If unsure if a food can be included due to barley malt extract either leave it out the diet or, contact Coeliac UK Helpline on 0845 305 2060, who will be able to advise you.

The basic rule to remember is:

- If it contains wheat, rye, barley or oats, it should be written on the ingredients list. If there is