

COELIAC DISEASE

Health

A guide on what you need
to know about coeliac
disease.



COELIAC DISEASE



Why do I need to know about coeliac disease?

- It's more common in people with Down syndrome. Coeliac disease occurs in 0.2- 1 % of the general population of people of, but it occurs in 4 - 17% of people with Down syndrome.
- It can be harder to diagnose in Down syndrome. Features of coeliac disease can overlap with normal features of Down syndrome. So symptoms which could lead to a diagnosis of coeliac disease in the general population may be discounted as just due to Down syndrome in our children.

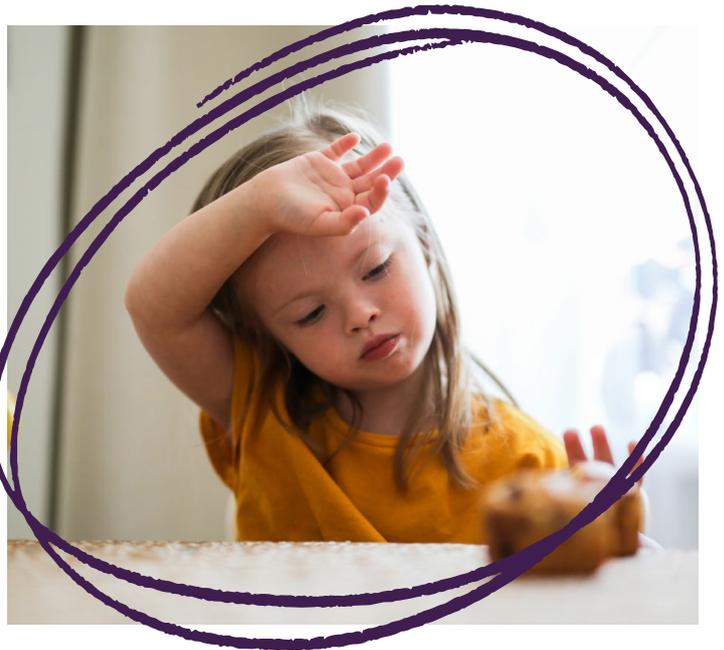
What is coeliac disease?

People with coeliac disease

- Become ill if they eat gluten.
- Get villous atrophy; a breakdown of the lining of the intestine caused by a reaction to gluten.
- Cannot absorb the nutrients needed for growth and maintenance of the body.
- Recover completely if they don't have gluten for the rest of their lives.

What is gluten?

- It's in food made from flour.
- Gluten is formed when two proteins, gliadin and glutenin, are mixed in water. These proteins are found in grains such as wheat, rye and barley. Wheat flour is used extensively in food manufacture, so many foods like bakery products, snacks and processed foods contain gluten.
- In coeliac disease gluten causes the body to attack its own intestine.
- Gluten causes a reaction, rather like an allergy, when it passes through the wall of the small intestine of people with coeliac disease. This triggers a series of events which ends with the body attacking and damaging the lining of the small intestine. Diseases which attack the cells in a person's own body are called autoimmune diseases. People with Down syndrome are at a greater risk from autoimmune diseases, including diabetes, alopecia and thyroid disease.



How can I tell if my child has coeliac disease?

Symptoms do not develop until your child starts eating gluten, but can then occur at any time, even if earlier tests have been negative. Usually symptoms start at between one and five years of age.

Key symptoms to look for in children with Down syndrome are:

- Bowel problems; often diarrhoea but sometimes constipation as a new problem.
- Poor growth (on Down syndrome charts your child's growth line is dropping across lines or is below the bottom line). In older children coeliac may present with delayed puberty.
- Abdominal distension.
- General unhappiness and misery.
- Other associated problems such as arthritis, dermatitis herpetiformis, diabetes, thyroid disease or anaemia.



Your child should be tested for coeliac disease at ages 1, 2 and 4, and at any time there is concern.

Tests may show coeliac disease

Biopsy

- Coeliac disease is diagnosed by seeing characteristic changes on a biopsy of the small intestine. At a minor operation, the child swallows a tube containing a camera and pincers. A doctor then biopsies (cuts a small piece out of) the small intestine. The biopsy is looked at under a microscope. Usually healthy intestine has villi, finger like protrusions that wave around and absorb nutrients. If the child has coeliac disease, there will be villous atrophy so the villi will be smaller, smoother and unhealthy.

Blood tests

To avoid doing a biopsy on every child with Down syndrome, blood tests have been developed to show which children are at high risk of coeliac disease.

- The New Zealand guidelines recommend testing at 12 months, two years and four years six months, and at any other time if there is clinical suspicion of coeliac disease.
- If screening tests are positive or if a child has symptoms, then a biopsy is usually done
- The current test looks for the antibody proteins that attack the muscles of the intestinal wall, the endomysium. It looks for antiendomysial antibodies so is called the AEA or EMA test. A previous test called the AGA is not useful in Down syndrome.
- A newer test looks for tissue transglutaminase antibody and compares it to total IgA antibodies levels.
- People who develop coeliac disease have a genetic predisposition to do so. It has recently been discovered that 99% of people with coeliac disease have the HLA types DQ2 or DQ8. It is suggested that children with Down syndrome could be first screened at age 5 for HLA type. Those with HLA types DQ2 or DQ8 would then need yearly screening for coeliac and those with other HLA types would not need screening.

So,
what can people with
coeliac disease eat?



Staple fillers

What to eat

- Rice
- Potatoes
- Gluten-free bread
- Gluten-free pasta
- baked beans

What to avoid

- Bread
- Pastry and other wheat products
- Pasta
- Most breakfast cereals

“Every Sunday we make gluten-free pancakes for breakfast, we always make extra, and freeze them so Emily can have pancakes in her school lunch.”

“For breakfast James has his own cereal kept in a separate, plastic container made up of a mix of commercially available gluten free cereals. Then I add extra organic almonds walnuts and raisins.”

Meat and dairy

What to eat

- All meat and dairy are naturally gluten-free

What to avoid

- Batter-coated takeaways
- Many sausages
- Meat pies
- Chicken nuggets

“Dinner time we all eat gluten-free. Many of our meals are a piece of plain meat cooked on the BBQ along with vegetables.”

“Kelsey takes gluten-free frankfurters to school with a small pottle of sauce and she has them instead of sandwiches with a pottle of yoghurt, an apple and cheese.”

Fruit and vegetable

What to eat

- All fruit and vegetables are naturally gluten-free

What to avoid

- Processed foods like snack bars with fruit
- Apple pie

“James likes gluten-free pizza. On his pizza I put on some of the following: peas, carrots broccoli, fruit, salmon, bacon, tomato, red pepper, tomato sauce and all covered with cheese. This is the only way I can get him to eat fruit and vegetables.”

Snacks and treats

What to eat

- Ice cream
- Popcorn
- Meringues
- Gluten-free biscuits
- Chocolate

What to avoid

- Cakes
- Biscuits
- Flavoured chips and processed savouries
- Pizza
- Burgers in a bun

“We can still do the family thing at McDonald’s. Emily gets a large fries, and toy in a happy meal bag, this way she doesn’t feel left out.”

“As far as Kelsey being invited to parties - I always send a supply of food along, like a piece of gluten-free chocolate cake (to replace the birthday cake even though she may not eat it) carrot or celery sticks, popcorn etc.”



How can baking be adapted to suit?

Gluten-free pizza

300ml warm water
1 tsp sugar
1 tsp dried yeast
3 cups Horley's bread mix 1/2 cup fine cornmeal
1/2 cup Bakels GF bread mix 2 Tbsp olive oil

Mix the yeast, sugar and lukewarm water in a jug or bowl; set aside in a warm place until frothy. Meanwhile measure the flour mixture into a large bowl. Add the oil to the yeast mixture, then add to the flour. Mix well. Then turn on to a floured board and knead well, adding extra flour if needed. Divide in two, roll out into pizza bases and place on greased trays. Leave to rise while the oven heats up, adding the toppings as you prepare them. Bake@220C for 15 minutes.

Gluten-free bread rolls

2 tsp dried yeast
2 cups Horley's bread mix 1 tbsp sugar
1/2 cup Bakels GF bread mix 1/2 cup warm water
1/4 cup ground linseed
50 g butter
1 tsp guar gum
1 cup milk

Mix the yeast, sugar and lukewarm water in a large mixing bowl; set aside in a warm place until frothy. Meanwhile, melt the butter with the milk, heating to the same temperature as the yeast mixture. Add the milk mixture and flour to the yeast mixture, and beat well, then knead well, adding extra flour if needed. Divide into 12-16 pieces and shape into rolls. Place on a lightly oiled tray, and cover loosely with oiled plastic. Leave somewhere warm to rise, usually not for longer than 45 minutes. Bake@ 230C for 10-15 minutes.

Gluten-free cupcakes

60g butter
1/2 cup sugar
grated rind of 1/2 lemon or orange
2 eggs
1 heaped cup GF bread mix
1 tsp baking powder
1/4 cup milk

Cream butter and sugar, and beat in grated rind. Add eggs one at a time, then dry ingredients and milk. Mix well. Place a spoonful in patty cases. Bake@ 200C for 15 minutes. When cool, ice with lemon or orange juice and icing sugar

Gluten-free chocolate cake

1 tbsp vinegar
1 cup milk
250g Horley's flour
50g cocoa
250g castor sugar
1 1/2 tsp baking soda
125g melted butter
1 tsp vanilla essence
2 eggs
2 tbsp jam

Grease two 23cm round sandwich pans; line bases with baking paper. Combine vinegar and milk in a small bowl and leave to curdle. Sift flour, cocoa, baking soda and sugar into large bowl of electric mixer; beat on low speed 1 minute. Add butter and half of the milk mixture and beat 2 minutes at medium speed. Add remaining milk, eggs, vanilla and jam, and beat a further 2 minutes at medium speed. Spread mixture into prepared pans, smooth tops. Bake in moderate oven about 30 minutes. Stand cakes 5 minutes before turning out on wire racks to cool. Fill and ice cakes with chocolate icing.

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NZDSA
resources

Want to know more?

The NZ Down Syndrome website can provide more information and link you to many more articles and organisations.

www.nzdsa.org.nz



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