



# Coeliac Disease

**Easy Read**



Down Syndrome  
Australia

# Introduction

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The Down Syndrome Australia Health Ambassadors made this resource to help explain what Coeliac Disease is.



This information is written in an easy to read way. We use pictures to explain some ideas.

Some hard words are written in **bold**. We explain what these words mean at the end.



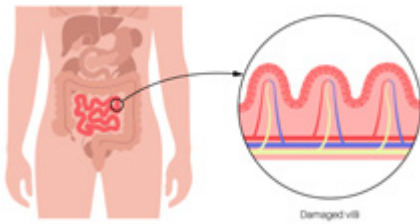
It's a good idea to read this information with someone you trust.

A friend, a family member or a support person might be able to help you.



This is not health advice. Talk to your doctor if you want to know more.

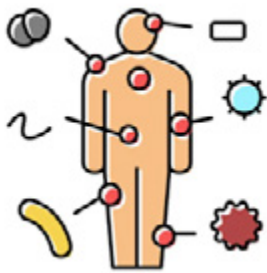
# What is coeliac disease?



Coeliac disease is an **autoimmune disease**.

If someone has coeliac disease and they eat **gluten** the gluten causes damage to the lining of their bowel.

This can make them very unwell.



An **autoimmune disease** is when the body's immune system attacks and destroys healthy body tissue by mistake.

Your immune system helps to keep you healthy.



People with Down syndrome are more likely to have coeliac disease than the general population.



**Gluten** is a protein that is found in some grains. These grains are:

- wheat
- barley
- rye
- triticale – a cross between wheat and rye.

# What foods could have gluten?



Some foods that are made with wheat:

- some pasta
- some bread
- some flour that is used to make things like cakes
- some pastry – pies and sausage rolls.



Some foods that are made with barley:

- malt
- some soup
- some beers.



Some foods that are made with rye:

- some breakfast cereals
- some breads
- some alcohol.

Some foods are made with oats.

Oats do not have gluten.

But some oats are **contaminated** with gluten when they are **processed**.

These oats cannot be eaten by someone with coeliac disease.





Some canned, tinned or packaged foods that you buy at the supermarket can have gluten in them.

You need to check the ingredients list on the product.



The ingredients list might include numbers like:

- 234 (Barley)
- 1400 – 1450 (Wheat)

This means there is gluten in that product.

Read the ingredients list.

If it says barley, rye, oats, wheat or gluten in the ingredients list or allergy statement, the product is **not** safe to eat!



Some packaged foods say

‘May contain wheat’.

It is best not to eat these foods because they may be **contaminated** with gluten.





Some medications are made with gluten.

**If you are not sure, you need to ask – does it have gluten?**



It is important to look for **GLUTEN FREE** on the labels of foods.

Foods that have the Coeliac Australia logo on them are gluten free.



If you are not sure it is important to ask "is this food Gluten Free?"

It is important to let people know you have coeliac disease.

You can carry a card that tells people you have coeliac disease.

# How does coeliac disease happen?

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Coeliac disease is **hereditary**.

That means it is passed along from parents to children in families.

It is carried on your genes in the cells in your body, it is part of your DNA.



Just like Down syndrome, you can not catch coeliac disease.

It is just part of who you are.



People can get coeliac disease at any age.



To find out if you have the gene for coeliac disease you need to have a blood test.

Your doctor can order the coeliac gene blood test.



Not everyone with the coeliac gene has coeliac disease.

Some people who have the gene never get coeliac disease.

Other people who have the gene can get coeliac disease later.



To find out if you have coeliac disease the doctor has to order other blood tests.



# How do I know if I have coeliac disease?

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Some people who get coeliac disease feel unwell.

You may have some or all of these symptoms:

- feeling full or bloated in the tummy
- tummy pains
- constipation
- feeling tired
- have weight loss when you are not trying to lose weight
- babies and children that are slow to grow
- low iron levels in the blood.



Some people do not notice that they have any of these symptoms.



To see if you have coeliac disease you need to have a blood test.

This is a different blood test to the blood test for the coeliac gene.

It can be taken at the same time.



If the blood test says that you have a high chance of having coeliac disease you will need to have a **biopsy**.

A special doctor called a **gastroenterologist** can do a biopsy of your bowel.

A biopsy is the best way to be 100% sure that you have coeliac disease.

# What is a biopsy and how is it done?



You will need to go to the hospital to have a biopsy for coeliac disease.

The gastroenterologist will put you to sleep so you do not feel it.

When you are asleep, the gastroenterologist puts a tube in your mouth and into your small bowel.

This is called a **gastroscopy**.



When the tube is in your small bowel a very small sample of the lining of your bowel is taken.

This sample is sent to be tested to see if you have coeliac disease.

The gastroenterologist will contact you and let you know the results.

When you have a gastroscopy you are only in the hospital for a few hours.

# Can coeliac disease be cured?

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No, coeliac disease can not be cured.

Coeliac disease can not be cured **but** it can easily be managed.

# How do you treat coeliac disease?

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The only way to properly treat coeliac disease is a strict complete gluten free diet.

Even a small crumb of gluten can be harmful for people with coeliac disease.



Even if you feel ok, you should not eat gluten.

You need to have a gluten free diet for the rest of your life.

You do not need to take medication to treat coeliac disease.



You need to make sure that the food you eat has not touched any gluten.

This is called making sure it does not get **contaminated** with gluten.

To do this you need to do things like:

- have a separate toaster
- clean cooking pans and grills properly
- clean chopping boards properly
- use separate butter and spreads
- use separate oil to cook or fry in if it has been used for cooking food with gluten.
- make and cook gluten free foods like pizza in a separate area to gluten foods.



## What happens if I have coeliac disease and I keep eating gluten?

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You can get even more unwell.

It can make other parts of your body very unwell also.



# What else can I do if I have coeliac disease?

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Make sure you tell people that you have coeliac disease when you go out to eat.

Make sure you tell support people, where you go to school and your workplace that you have coeliac disease.



Contact a dietitian to help you work out what food you can and cannot eat.

They may have some good recipes.



Contact Coeliac Australia:

<https://www.coeliac.org.au/s>



There are some good apps that can help:

Gluten Free Scanner

[Find this app here](#)



Coeliac Australia app

[Find this app here](#)



Find gluten free restaurants near you

[Find this app here](#)

# Some other things people talk about



Is coeliac disease the same as being gluten intolerant?

No it is not.

For some people gluten makes them feel unwell but this is **not** the same as having coeliac disease.



**coeliac**

Why is it spelt in 2 ways?

In Australia we spell it coeliac disease and other places around the world it spell it celiac disease.

It is the same thing.



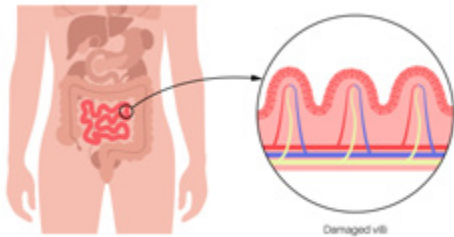
Should I have screening for the coeliac gene?

It is a good idea for people with Down syndrome to have screening for the coeliac gene.

If you have screening and you have the gene you know to look out to see if foods that have gluten make you feel unwell.

You can then get tested to see if you have developed coeliac disease.

# Hard words in this guide



## Coeliac disease

If someone has coeliac disease and they eat gluten the gluten causes damage to the lining of their bowel.

This can make them very unwell.



## Contaminated

When a gluten free product comes into contact with something that is not gluten free.



## Gluten

A protein that is found in some grains like:

- wheat
- barley
- rye
- triticale – a cross between wheat and rye



## **Hereditary**

A disease like coeliac disease that is passed along from parents to children in families.



## **Processed**

Food that has been packaged, cooked or changed in some way has been processed.

# **Other resources that might help explain coeliac disease**

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Here is a YouTube clip that explains coeliac disease:

<https://medlineplus.gov/medlineplus-videos/gluten-and-coeliac-disease/>

<https://www.youtube.com/watch?v=BuGvRUjBGYU>

Down Syndrome Australia wrote this Easy Read guide in January 2024.



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