Understanding Coeliac Disease

- Cake
- Oat milk
- Pasta
- Sauces
- Instant noodles
- Scotch eggs
- Dumplings
- Fish fingers
- Bread
- Bagels
- Cereal
- Crumpets
- Biscuits
- Pies
- Pizza
Welcome to Understanding Coeliac Disease! This comic has been designed to raise awareness about coeliac disease among professionals, families, and communities. It includes a range of lived experiences with coeliac disease from the perspective of parents, children, adults, as well as a dietitian who specialises in the condition. The comic also provides some introductory information about coeliac disease, tips & facts, and resources for further reading.

This comic was produced in collaboration with Professor Jenny Woof from the School of Life Sciences at University of Dundee. In 2017, Jenny received the University's Stephen Fry award as Engaged Researcher of the Year in recognition of her outstanding work with schools and the public to raise awareness of various health-related topics and advances in the underlying science. Soon after, Jenny proposed a collaboration between the Schools of Life Science and Humanities on coeliac disease to help promote an understanding of the condition for the community. This built on an earlier public engagement project that started when Dana Hutton, then a pupil at Grove Academy, spent time in Jenny’s lab as part of her Science Baccalaureate. The cross-School collaboration sparked a productive exchange between Life Sciences and Humanities as the project allowed specific areas of expertise to be brought into dialogue.

The comic would not have been possible without the stories of each contributor, and we thank them wholeheartedly for taking the time to share their experiences. We also thank the brilliant artists who brought the stories to life. Special thanks to Rebecca Horner for her teamwork and production on this comic, as well as to Chris Murray and Phillip Vaughan for their feedback and editorial work. Extra special thanks to Myles Fitt and Coeliac UK; Myles was a tireless partner on this comic and provided expert guidance every step of the way. Thank you, Myles!
COELIAC DISEASE (pronounced see-iac) is a lifelong autoimmune condition where the body’s immune system reacts to gluten, a protein found in wheat, barley and rye. Some people are sensitive to oats too.

The body’s reaction to gluten causes damage to the lining of the intestine, the place where food and nutrients are absorbed.

This deprives the body of the nutrients it needs, and can lead to malnutrition.

People with undiagnosed coeliac disease can have a wide range of symptoms, many of the symptoms are related to the damage in the gut, while others are the result of the body being starved of nutrients, which can lead to fatigue and anaemia.

Around 1% of the UK population has coeliac disease, but only 30% of those with the condition have been diagnosed.

While coeliac disease affects around 1 in 100 people in the UK, it is a genetic condition.

On average, 1 in 4 people diagnosed with coeliac disease were previously misdiagnosed with irritable bowel syndrome (IBS) as the symptoms often look similar such as stomach cramps, bloating, diarrhoea, constipation and exhaustion.

This means that if you have an immediate family member (parent, sibling or child) who has coeliac disease, then your chances of having the condition increases to 1 in 10.

Over the page, you’ll meet some people who share their experience of coeliac disease, learn some helpful tips for managing the condition, and find out where you can turn for more resources on the subject.

For those who think they may have coeliac disease, check out Coeliac UK’s online assessment called ‘Is it coeliac disease?’. Symptoms are assessed and, upon completion, advice will be given as to whether further testing is required from a GP.

If you’ve been diagnosed with IBS in the past, still have symptoms, and haven’t been checked for coeliac disease before, you should ask to be tested. Make sure you are eating enough gluten in your diet so the test works.

www.isitcoeliacdisease.org.uk
LYNSEY’S DIAGNOSIS STORY
ART BY CATRIONA LAIRD

I’m Lynsey. I was diagnosed with Coeliac disease 12 years ago when I was 20.

What are the signs of Coeliac disease?
People with Coeliac disease can have a range of symptoms: frequent bouts of diarrhoea, nausea, feeling sick and vomiting, stomach pain and cramping, gas and bloating, regularly feeling tired and ongoing fatigue, anaemia, weight loss, regular mouth ulcers, constipation or hard stools, or skin rash.

Anaemia, that’s me.

I get stomach cramps a lot.

I regularly have diarrhoea but don’t know why.

You know, if you keep having these symptoms regularly, you should see your GP and ask to be tested for Coeliac disease.

How long did it take for you to be diagnosed with Coeliac disease?

Well, it wasn’t as straightforward as I would have liked...
WHEN I WAS 20, I STARTED TO FEEL UNWELL. MY MUM ALREADY HAD COELIAC DISEASE AND EVEN THOUGH NONE OF MY SYMPTOMS MATCHED HERS, WE WERE WORRIED THAT IT MAY BE GENETIC. THAT'S WHEN I DECIDED TO GET TESTED.

MY INITIAL TEST RESULTS CAME BACK NEGATIVE. I WAS DIAGNOSED WITH IRRITABLE BOWEL SYNDROME (IBS). IBS HAS SIMILAR SYMPTOMS TO COELIAC DISEASE.

I WENT TO THE DOCTOR A COUPLE OF TIMES. THEY GAVE ME MEDICINE FOR IBS TO STOP SPASMS BUT MY SYMPTOMS KEPT GETTING WORSE.

I ASKED FOR ANOTHER BLOOD TEST.

I THINK IT'S JUST STRESS. I CAN TELL JUST LOOKING AT YOU THAT YOU DON'T HAVE COELIAC DISEASE.

OKAY, IF IT HELPS, LET'S RUN ANOTHER TEST.
This time, the test results came back positive! After an endoscopy, it was confirmed that I have coeliac disease.

My case isn’t that unusual. 1 in 4 people with coeliac disease are misdiagnosed with IBS. People with IBS should get tested for coeliac disease if they haven’t already.

Actually, you should make sure that you keep eating gluten until you have a diagnosis. Otherwise the tests won’t be accurate.

It’s important that GPs spot the symptoms quickly. But also that people with symptoms go to the GP quickly too. The sooner you can get a diagnosis the better.

It’s great to have a diagnosis now, because it means that I can look after and restore my health.

It’s important that we educate ourselves about coeliac disease, and there are lots of great resources out there.

I’m also lucky to have supportive friends, family and colleagues.

For more information on resources please see p.19 of this comic.
I’m Simon. I didn’t know much about coeliac disease until I was diagnosed in 2011.

I would get aching limbs after playing cricket, and it would last for days.

I thought it must be normal, but other cricketers told me that they didn’t get that sort of pain.

They persuaded me to go to the doctor, where I had blood tests which showed coeliac disease.

I then had an endoscopy that confirmed the diagnosis.

Once you get diagnosed, the changes you have to make to your lifestyle take some time to get used to.

I’ve had to change my diet, and we have to spend a lot of time researching where is safe to eat out.

The risk of coeliac disease is 1 in 100, but for close family members of someone with a diagnosis, it is 1 in 10. All of my family have been tested for coeliac disease. The tests showed two of my kids have it but the whole family follows a gluten free diet to help make the home safe from cross-contamination with gluten – and because the gluten free food we cook is delicious!
PREPARATION IS KEY. WE PREPARE FAMILY MEALS IN ADVANCE, AND THINK ABOUT MEAL PROVISION FOR TRIPS, HOLIDAYS, AND EATING OUT.

EATING FRESH FOOD RATHER THAN PROCESSED MEALS IS THE HEALTHIEST WAY TO STAY GLUTEN FREE.

MY WORK TAKES ME OUT OF THE OFFICE A LOT, SO WHEN I TRAVEL I MAKE SURE TO HAVE SNACKS WITH ME IN CASE I CAN’T FIND ANYWHERE SAFE TO EAT.

MOST MEETINGS I NEED TO ATTEND ASK FOR DIETARY REQUIREMENTS BEFORE THE EVENT. SOMETIMES I’LL GET A FAR BETTER LUNCH THAN EVERYONE ELSE, BUT OTHER TIMES I’LL JUST GET FRUIT.

DON’T BE AFRAID TO CHALLENGE DOCTORS IF YOU SUSPECT YOU HAVE COELIAC DISEASE. I WAS MISDIAGNOSED AS HAVING IRRITABLE BOWEL SYNDROME BEFORE A DOCTOR TESTED ME PROPERLY.

THIS DELAY MEANT I DEVELOPED OSTEOPOROSIS, ANOTHER SERIOUS HEALTH CONDITION.

SO LONG AS I’M SAFE, I DON’T MIND.
I wish people knew how serious it is for a coeliac to ingest even a small amount of gluten.

It can make me ill for days, even weeks, and can cause long term damage to my body.

I try to stay as informed as possible on coeliac disease. I have become a member of Coeliac UK, and use their app and food & drink guide.

Their resources help you to find food that’s safe to eat and restaurants you can eat in.

Coeliac UK also have local groups that can help you with lifestyle changes and give you support. There are also online communities that are really helpful.

Since our diagnoses, our family has found a new community. We have found new places to eat that we wouldn’t have considered before.

Coeliac UK has made life so much easier because they provide all of the information we need!
I was diagnosed with coeliac disease when I was nine. Because dad and Lewis were already coeliac, I was diagnosed when I was five. I don't have coeliac disease but I do have a wheat allergy, so I cut out gluten too.

Before I was diagnosed, I'd get tummy aches every morning. Mum thought it was because I didn't want to go to school.

Now, I take packed lunches to my secondary school because it's difficult to find gluten free food there. I can't go to the bakery or food vans with my friends.

It turned out that I was having a reaction to my breakfast, which was full of gluten!

We always remember to check the ingredients on packaging. Even if it's a brand we think is safe.

Gluten is found in wheat, barley, rye and in oats, so these are what we look out for and avoid!

We also look for the crossed grain symbol or a gluten free statement.
I enjoy being coeliac. It makes me feel special and lots of people know me. The dinnerladies at my primary school make sure I have gluten free options.

There are lots of choices now, at school and even in restaurants or on holiday!

At parties people will buy gluten free food for me, or I’ll take my own because I have to be careful of cross contamination.

At boys’ brigade they plan food around our needs!

I’m not allowed most biscuits and cakes, and the things I can have are usually more expensive.

I don’t feel bad though, I just get on with it.

I wish more people knew how serious it is if we eat gluten.

And mum is a bit of a hero. She doesn’t have coeliac disease but cooks gluten free.

Dad always knows where to get info about gluten free foods.

We all support each other!
Niamh’s School Story

Art by Ashling Larkin

It’s not fair that Niamh has been excluded. It would have been easy for us to give you gluten-free alternatives.

I couldn’t help make, or eat the pancakes, because there wasn’t any gluten-free flour.

If you’re doing something like this again, please let us know in advance. We can help with providing gluten-free flour or whatever food you need.

Thank you. Getting feedback from parents is really important and we never want to exclude a child. The guide would be so useful.

We’re planning a school BBQ, and the burgers and rolls will contain gluten.

Okay! We’ll provide some burgers and rolls that are gluten-free.

Here’s your gluten-free burger, Niamh!

I had an awesome day at school! I didn’t feel left out today!

It’s great the school are speaking to us about supporting Niamh’s gluten-free diet. Look how happy she is!
I opened Roseangle Kitchen Cafe as my daughter has coeliac disease and I wanted her to have a safe, hassle-free option for eating out.

Eating out can be challenging for my daughter and others who have coeliac disease.

Every time someone with coeliac disease eats out, they are placing trust in someone else making their food.

They risk becoming violently sick and unwell for several days if their meal contains gluten – even a crumb.

They may need to plan ahead every time. Not all venues have gluten free options and there may be a risk that some do not properly understand that gluten free food requires careful preparation to avoid cross contamination.

When going to new venues, they need to spend time checking that they can provide gluten free options, and that they can rely on this option.
When at a venue, my daughter needs to speak up and be prepared to ask questions about the ingredients in dishes, and to ask how meals are prepared.

She needs to trust that the waiting staff are correctly taking her order and serving her meal, and then confirm that she is being served the gluten free dish.

Is this prepared in a separate fryer?

Is this the gluten free dish?

If she is out enjoying herself with friends or colleagues who decide on spur of the moment to go to a venue which she isn’t familiar with, she needs to quickly work out if it provides safe gluten free options.

So, my options are politely decline and eat at home; go in but just have a drink; or take friends to a Coeliac UK Accredited Gluten Free venue that I found online.

OK, if this venue doesn’t do gluten free I’ll need to think of an alternative plan. Some quick online research will help.

Providing safe, gluten free options isn’t difficult—provided you follow the right steps. Here are some of my tips!

Firstly, choose and use the right ingredients.
SAFE PREPARATION AND COOKING OF GLUTEN-FREE FOOD.

GLUTEN-FREE ONLY!

EFFECTIVE CLEANING AND GOOD PERSONAL HYGIENE.

WOULD YOU LIKE THE GLUTEN-FREE OPTION?

SERVING GLUTEN-FREE MEALS: COMMUNICATING CLEARLY WITH CONSUMERS IS ESSENTIAL.

CLEARLY LABELLING YOUR MENUS.

STAFF TRAINING ON ALLERGENS.

ABOUT COELIAC DISEASE

EDUCATING YOUR STAFF IS ALSO REALLY IMPORTANT.

IT'S REALLY SATISFYING MEETING THE NEEDS OF CUSTOMERS, WHO ARE VERY APPRECIATIVE OF HAVING SOMEWHERE THEY CAN SAFELY EAT AND RELAX. THEY COME BACK AGAIN AND AGAIN ONCE THEY KNOW WE CAN SAFELY LOOK AFTER THEIR GLUTEN FREE DIET.
A DIETITIAN’S PERSPECTIVE

HI! MY NAME IS FIOMA.

I AM A SPECIALIST DIETITIAN WHO LOVES WORKING WITH PEOPLE WITH COELIAC DISEASE.

“DIETITIANS ARE HERE TO HELP SUPPORT PEOPLE WITH COELIAC DISEASE MANAGE THEIR DIET AND LIFESTYLE AND TO HELP IMPROVE THEIR OVERALL QUALITY OF LIFE.”

“COELIAC DISEASE CAN BE DIAGNOSED AT ANY AGE ONCE GLUTEN HAS BEEN INTRODUCED INTO A PERSON’S DIET.”

“GLUTEN IS FOUND IN WHEAT, BARLEY AND RYE. SOME PEOPLE ARE ALSO SENSITIVE TO OATS. ONCE DIAGNOSED, THE ONLY TREATMENT FOR COELIAC DISEASE IS A STRICT LIFELONG GLUTEN-FREE DIET. ONCE GLUTEN IS REMOVED FROM THE DIET, YOU SHOULD START TO FEEL MUCH BETTER.”

COELIAC DISEASE IS NOT AN ALLERGY OR INTOLERANCE BUT A SERIOUS ILLNESS WHERE THE BODY’S IMMUNE SYSTEM ATTACKS ITS OWN TISSUES WHEN YOU EAT GLUTEN.

ALLERGY & INTOLERANCE

AUTO-IMMUNE DISEASE

“EVEN A CRUMB OF GLUTEN IS ENOUGH TO MAKE SOMEONE ILL, SOMETIMES FOR DAYS ON END. KEY SYMPTOMS CAN INCLUDE FREQUENT DIARRHEA, RECURRING STOMACH CRAMPS, CHRONIC FATIGUE, ANAEMIA, REGULAR MOUTH ULCERS, AND WEIGHT LOSS.”

THIS CAUSES DAMAGE TO THE LINING OF THE GUT AND MEANS THE BODY CAN’T PROPERLY ABSORB NUTRIENTS FROM FOOD.
“YOU HAVE TO HAVE THE RIGHT GENETIC MAKEUP TO GET COELIAC DISEASE.”

“IF YOU HAVE COELIAC DISEASE, THERE IS A 1 IN 10 CHANCE THAT AN IMMEDIATE RELATIVE MAY ALSO HAVE THE CONDITION.”

ATTENTION

IF YOU THINK YOU MAY HAVE COELIAC DISEASE, DO NOT REMOVE GLUTEN UNTIL A DIAGNOSIS IS MADE.

“YOU WILL START TO FEEL BETTER ONCE YOU BEGIN TO AVOID GLUTEN BUT IT TAKES TIME FOR THE GUT TO FULLY HEAL. IT VARIES BETWEEN PEOPLE BUT IT CAN BE UP TO 5+ YEARS.”

“THERE ARE MANY NATURALLY GLUTEN FREE FOODS AVAILABLE.”

“MANY PROCESSED FOODS ARE GLUTEN FREE. TAKE TIME TO READ THE LABELS CAREFULLY.”

“LEARN BASIC COOKING TECHNIQUES SO YOU CAN COOK WITH FRESH INGREDIENTS.”

“BY LEARNING SOME USEFUL TIPS YOU CAN ENJOY A RICH AND VARIED GLUTEN FREE DIET!”
ON AVERAGE, IT TAKES 13 YEARS TO GET A DIAGNOSIS OF COELIAC DISEASE FROM THE FIRST ONSET OF SYMPTOMS, SO WE NEED TO KEEP RAISING AWARENESS ABOUT THE CONDITION.

FOR 1 IN 100 PEOPLE, COELIAC DISEASE IS THE REASON THEY DON’T FEEL WELL. YET THERE ARE HALF A MILLION PEOPLE THAT ARE UNDIAGNOSED, LIVING WITH SYMPTOMS SUCH AS DIARRHOEA, STOMACH CRAMPS, CHRONIC FATIGUE, ANAEMIA, MOUTH ULCERS AND WEIGHT LOSS.

HERE ARE SOME TIPS FOR PEOPLE WITH COELIAC DISEASE, THEIR FAMILY & FRIENDS (THANKS LYNSEY!):

- If you are looking for support on coeliac disease, there are lots of sources such as the Coeliac UK website, and various social media pages where you can post questions and talk to other people with the condition.
- Be organised! Batch cook meals and have convenient snacks on hand.
- When travelling, consider where you’ll be staying and take gluten free bread and other essentials, as needed.
- When eating out, call venues in advance to ensure they offer gluten free options. Also check they know the importance of preparing gluten free food safely, free of cross-contamination.
- If you are ‘glutenened’, drink plenty of water.

Rely as much as possible on naturally gluten free foods.
FURTHER RESOURCES

Coeliac UK
www.coeliac.org.uk

To join Coeliac UK
coeliac.org.uk/join-us/ or call 0333 332 2033

Symptoms
coeliac.org.uk/coeliac-disease/about-coeliac-disease-and-dermatitis-herpetiformis/symptoms/

Online Symptom Assessment
isitcoeliacdisease.org.uk

Getting Diagnosed
coeliac.org.uk/coeliac-disease/getting-diagnosed/

Coeliac Disease in Children
coeliac.org.uk/coeliac-disease/coeliac-disease-in-children/

Coeliac Disease in School
coeliac.org.uk/gluten-free-diet-and-lifestyle/school-meals/

Gluten Free Diet
coeliac.org.uk/gluten-free-diet-and-lifestyle/

Gluten Free Recipes
coeliac.org.uk/gluten-free-diet-and-lifestyle/recipe-database/

Coeliac UK Accredited Venues

Support for the Food Industry
www.coeliac.org.uk/food-industry-professionals/

Eating Out
coeliac.org.uk/gluten-free-diet-and-lifestyle/eating-out/

Venue Guide
coeliac.org.uk/gluten-free-diet-and-lifestyle/venue-guide/
A Dietitian’s Perspective. Art by Norrie Millar. Traditional pencils, scanned and inked digitally.

What is Coeliac Disease? Art by Ashling Larkin. Roughs, inks, and finished colour.

Simon O’Loughlin & Family. Art by Rebecca Horner. Layouts, in-progress stage, and finished panel.
Understanding Coeliac Disease. Art by Letty Wilson and Helen Robinson. Helen's design sheet for the back cover, referencing Letty Wilson's front cover and character design.
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Ashling Larkin is a freelance comic artist & illustrator based in Dundee. She has been part of a number of University Publications and is currently working on her personal project, *The Enchanted Book*. You can find more of her work on her website: ashlingdraws.com

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Katie Quinn is an illustrator and comic book artist based in Edinburgh. Her work has been exhibited and sold around the UK and published in the likes of *Counterpoint Magazine* and *Wilma*, Ink Pot Studio’s anthology of girls’ comics. Her illustration clients include Royal Botanic Gardens Edinburgh and Cranachan Publishing. oohkatieq.co.uk

Helen Robinson is a comics artist and illustrator from Northern Ireland. She has recently had work published in international anthologies such as *Wayward Sisters* and *Shout Out!* You can find her work at gofishblues.com.

Letty Wilson is a comic artist and illustrator from the Scottish Highlands, currently working in Glasgow. Her recent work includes illustrations for Choose-Your-Own-Path book *Into the Dungeon*, and contributions to anthologies including BHP and 404 Ink’s *We Shall Fight Until We Win*, and Dark Horse’s *Secret Loves of Geeks*. You can see more of her work at toadlett.com.

Myles Fitt is Scotland Lead for Coeliac UK, the charity which supports people with coeliac disease and those who need to eat gluten free. He also as a personal interest in coeliac disease as his 10 year old daughter was diagnosed with the condition as a baby.
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