

UNDERSTANDING COELIAC DISEASE

Edited by Chris Murray, Golnar Nabizadeh, and Phillip Vaughan



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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 Dundee. In 2017, Jenny received the Stephen Fry award as Engaged Researcher of the Year in recognition of



her outstanding work with schools and the public to raise awareness of science. Soon after, Jenny proposed a collaboration between the Schools of Life Sciences and Humanities on coeliac disease to help promote an understanding of the condition for the community. This sparked a productive exchange between the Schools 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!

What is Coeliac Disease?

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Script: Golnar Nabizadeh & Coeliac Disease UK

Art: Ashling Larkin

Lynsey's Diagnosis Story

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Script: Lynsey Penny, Golnar Nabizadeh

Art: Catriona Laird

Simon O'Loughlin & Family

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Script: Simon, Lewis, Harris, & Ailish O'Loughlin,

Golnar Nabizadeh & Rebecca Horner

Art: Rebecca Horner

Niamh's School Story

12

Script: Myles Fitt, Niamh Somerville & Golnar

Nabizadeh

Art: Ashling Larkin

Eating Out: Alison's Story

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Script: Alison James & Golnar Nabizadeh

Art: Ashling Larkin

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Script: Fiona Headridge & Golnar Nabizadeh

Art: Norrie Millar

Tips & Facts

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Script: Myles Fitt & Golnar Nabizadeh

Art: Katie Quinn

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Scripts edited by Myles Fitt Front cover by Letty Wilson Back cover by Helen Robinson Production by Rebecca Horner

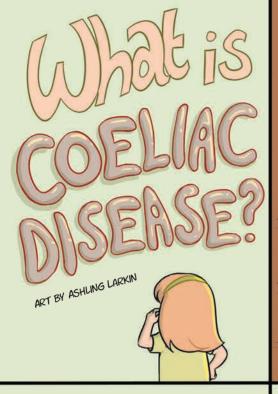








UNIVERSE



COELIAC DISEASE
(PRONOUNCED SEE-LIAC) 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.

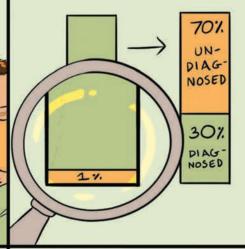


THE BODY'S
REACTION TO GLUTEN
CAUSES DAMAGE TO THE
LINING OF THE INTESTINE,
THE PLACE WHERE FOOD
AND NUTRIENTS ARE
ABSORBED.

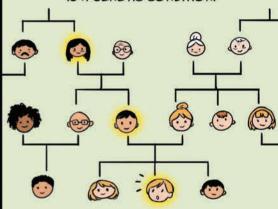
THIS DEPRIVES
THE BODY OF THE NUTRIENTS
IT NEEDS, AND CAN LEAD TO
MALNUTRITION.

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.



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.

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.

COELIAC DISEASE? IBS?



WITH IBS IN THE PAST, STILL HAVE SYMPTOMS, AND HAVEN'T BEEN CHECKED FOR COEUAC DISEASE BEFORE, YOU SHOULD ASK TO BE TESTED. MAKE SURE YOU ARE EATING ENOUGH GLUTEN IN YOUR DIET SO THE TEST WORKS.

OVER THE PAGE, YOU'LL
MEET SOME PEOPLE WHO SHARE
THEIR EXPERIENCE OF COEUAC
DISEASE, LEARN SOME HELPFUL
TIPS FOR MANAGING THE CONDITION,
AND FIND OUT WHERE YOU CAN
TURN FOR MORE RESOURCES ON
THE SUBJECT.

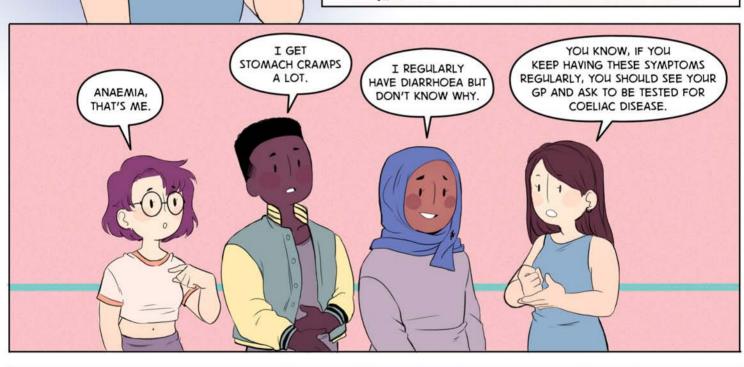
FOR THOSE WHO THINK
THEY MAY HAVE COELIAC DISEASE,
CHECK OUT COELIAC UK'S ONLINE
ASSESSMENT CALLED 'IS IT COELIAC
DISEASE'? SYMPTOMS ARE ASSESSED
AND, UPON COMPLETION, ADVICE
WILL BE GIVEN AS TO WHETHER
FURTHER TESTING IS REQUIRED
FROM A GP.

WWW.ISITCOELIACDISEASE.ORG.UK

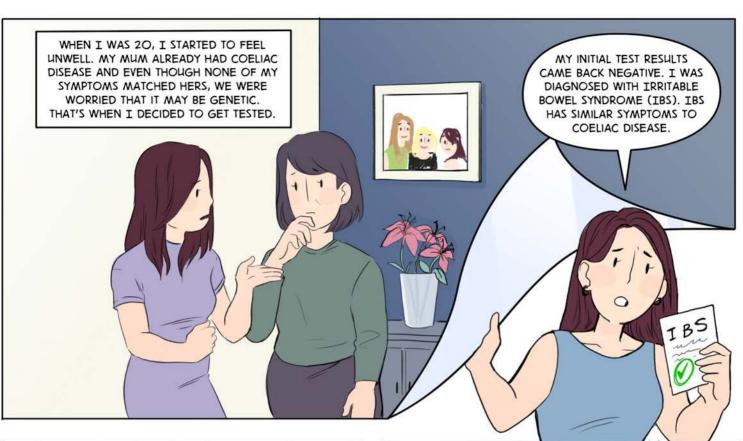


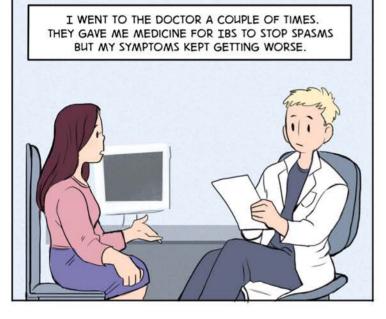


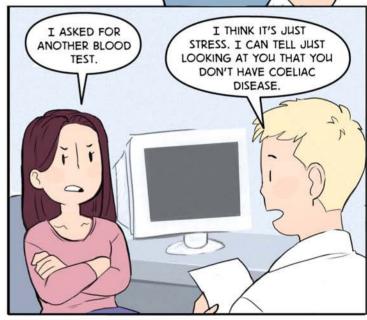
HAT ARE THE SIGNS OF COELIAC DISEASE. PEOPLE WITH COELIAC DISEASE CAN HAVE A RANGE OF SYMPTOMS: FREQUENT BOUTS OF DIARRHOEA, NAUSEA, SYMPTOMS: FREQUENT BOUTS OF DIARRHOEA, NAU CRAMPING, STOMACH PAIN AND CRAMPING, STOMACH PAIN AND CRAMPING, FEELING SICK AND VOMITING, REGULARLY FEELING TIRED AND GAS AND BLOATING, REGULARLY FEELING TIRED AND STOOLS, OR SKIN RASH. ONGOING FATIGUE, ANAEMIA, WEIGHT LOSS, OR SKIN RASH. ULCERS, CONSTIPATION OR HARD STOOLS, OR SKIN RASH.





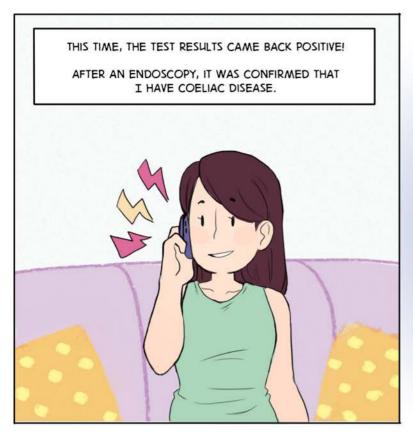










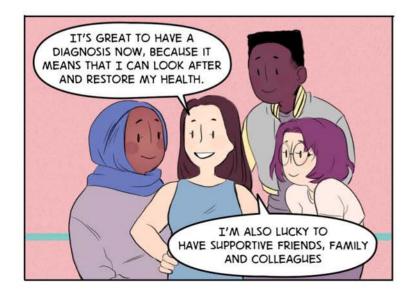


MY CASE ISN'T THAT UNUSUAL. 1 IN 4 PEOPLE WITH COELIAC DISEASE ARE MISDIAGNOSED WITH IBS. PEOPLE WITH IBS SHOULD GET TESTED FOR COELIAC DISEASE IF THEY HAVEN'T ALREADY





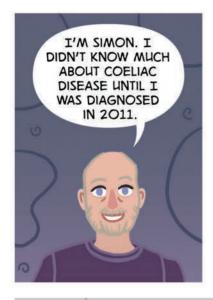
IT'S IMPORTANT THAT GPS SPOT THE SYMPTOMS QUICKLY. BUT ALSO THAT PEOPLE WITH SYMPTOMS GO TO THE GP QUICKLY TOO. THE SOONER YOU CAN GET A DIAGNOSIS

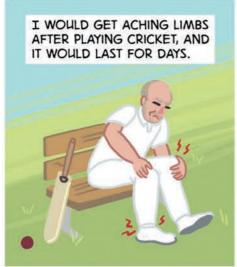




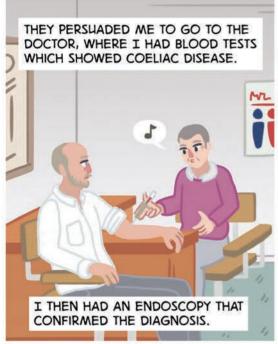
SIMON O'LOUGHLIN & FAMILY

ART BY REBECCA HORNER













I'VE HAD TO CHANGE MY DIET,



PREPARATION IS KEY. WE PREPARE FAMILY MEALS IN ADVANCE, AND THINK ABOUT MEAL PROVISION FOR TRIPS, HOLIDAYS, AND EATING OUT.

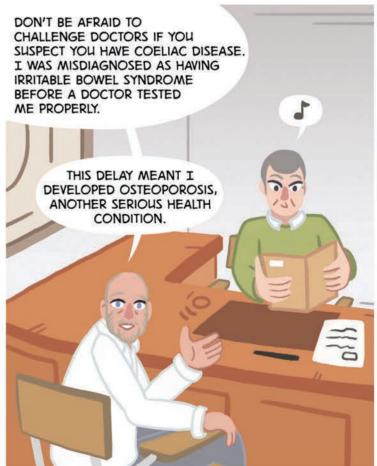


EATING FRESH FOOD RATHER THAN PROCESSED MEALS IS THE HEALTHIEST WAY TO STAY GLUTEN FREE.

MY COLLEAGUES AT WORK KNOW NOT TO OFFER ME DONUTS OR BISCUITS, THEY BRING IN GLUTEN FREE TREATS FOR ME TOO.

























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.









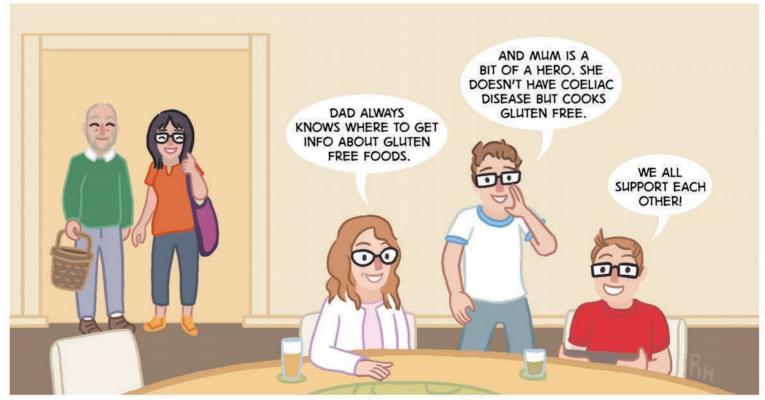


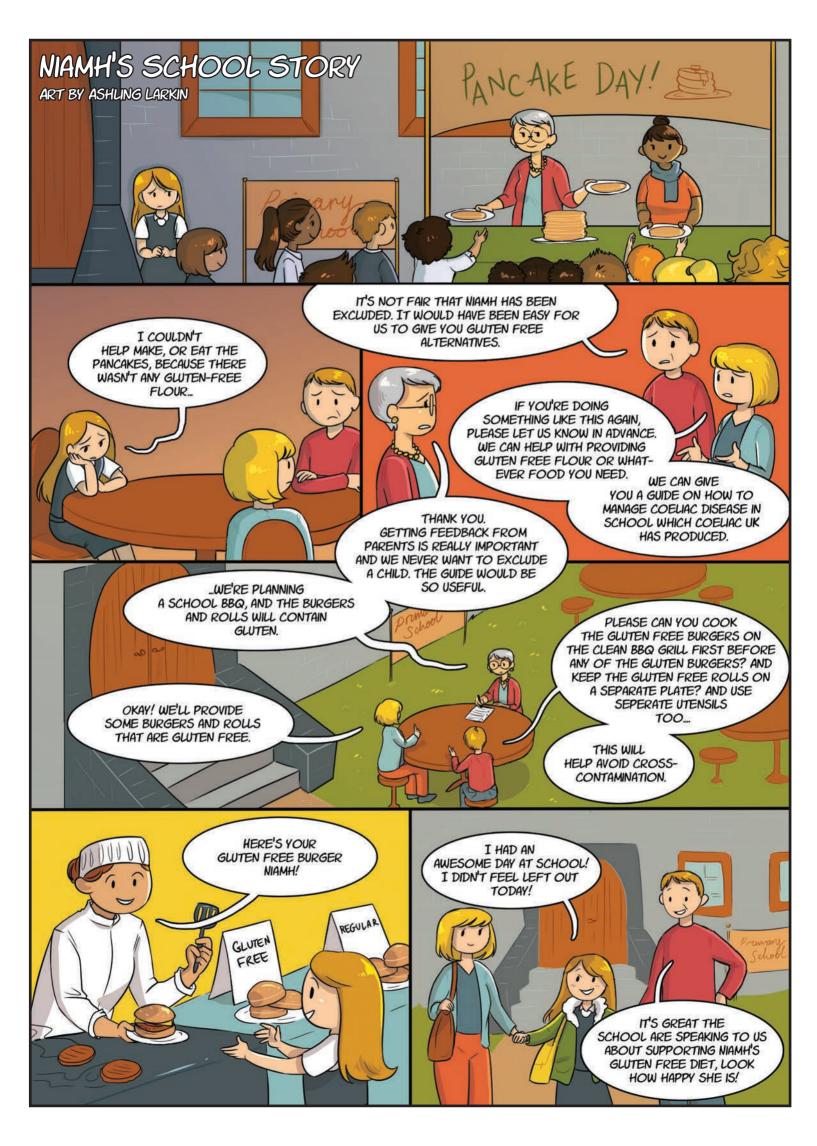


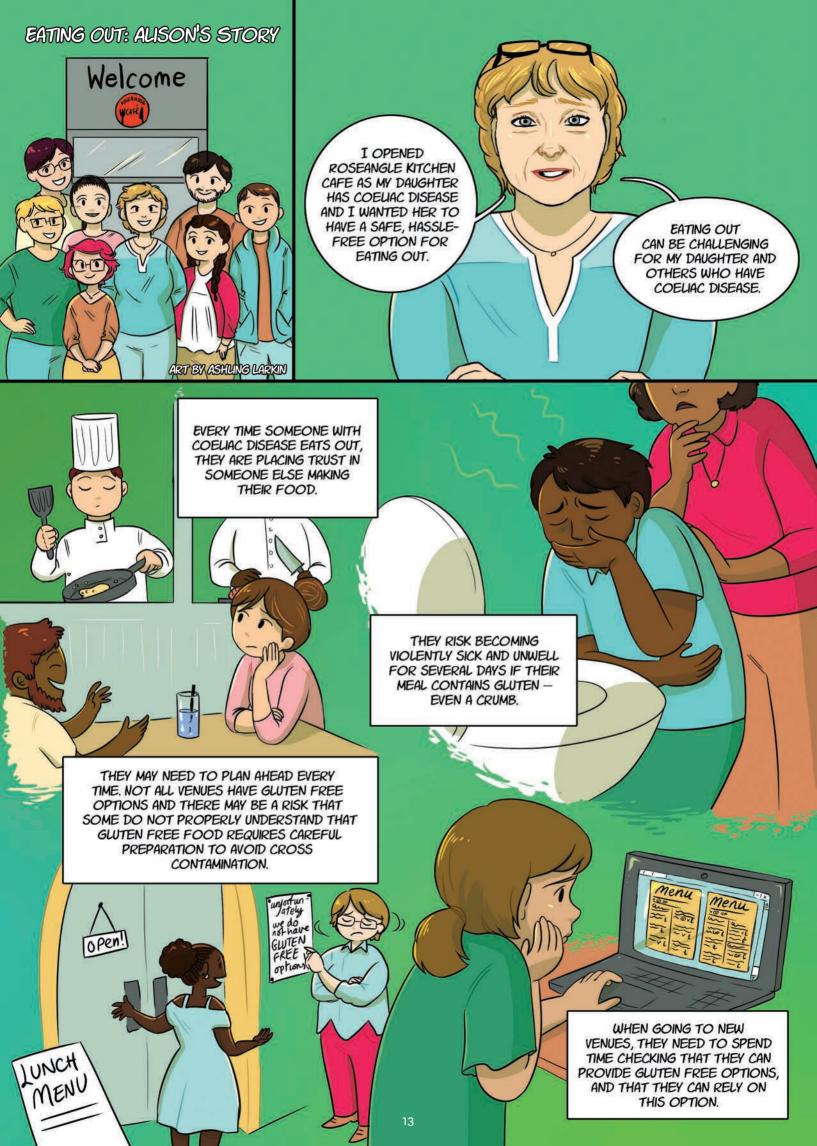












WHEN AT A VENUE, MY DAUGHTER NEEDS TO SPEAK UP AND BE PREPARED TO ASK QUESTIONS ABOUT THE INGREDIENTS IN DISHES, AND TO ASK HOW MEALS ARE PREPARED.



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.



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.



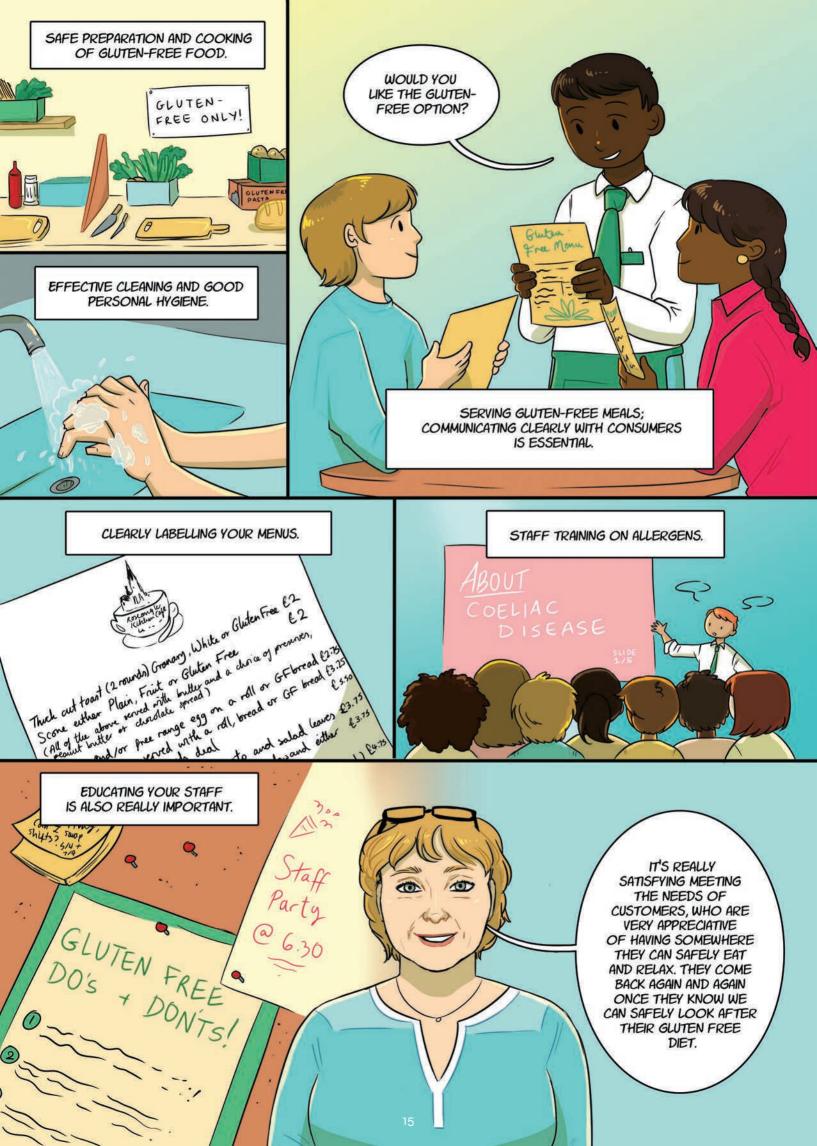
OK, IF THIS
VENUE DOESN'T DO
GLUTEN FREE I'LL NEED
TO THINK OF AN ALTERNATIVE
PLAN. SOME QUICK ONLINE
RESEARCH WILL HELP.



SO, MY OPTIONS ARE POLITELY DECUNE 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.









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





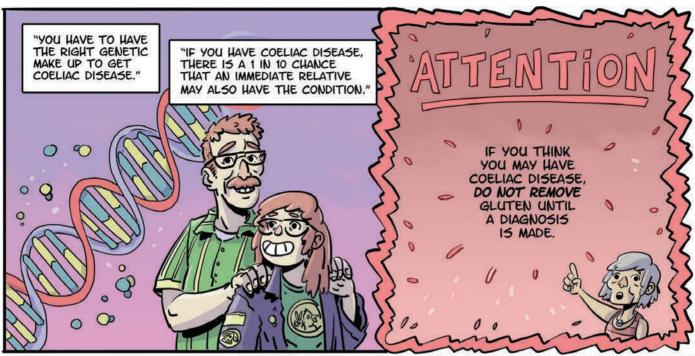
"GLUTEN IS FOUND IN WHEAT, BARLEY AND RYE.
SOME PEOPLE ARE ALSO SENSITIVE TO OATS.
ONCE DIAGNOSED, THE ONLY TREATMENT FOR COELIAC
DISEASE IS A STRICT LIFELONG GLUTEN FREE DIET.
ONCE GLUTEN IS REMOVED FROM THE DIET,
YOU SHOULD START TO FEEL MUCH BETTER."

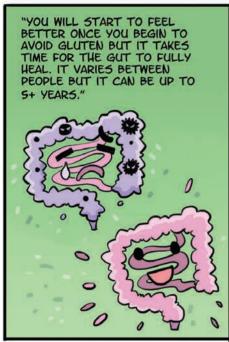




"EVEN A CRUMB OF GLUTEN IS ENOUGH TO MAKE SOMEONE ILL, SOMETIMES FOR DAYS ON END. KEY SYMPTOMS CAN INCLUDE FREQUENT DIARRHOEA, RECURRING STOMACH CRAMPS, CHRONIC FATIGUE, ANAEMIA, REGULAR MOUTH ULCERS, AND WEIGHT LOSS."















FRE are SOME TIPS FOR people WITH COELIAC disease, THEIR family & FRIENDS ———— (THANKS Lynsey!):

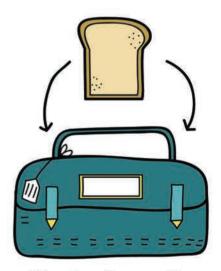


If you are looking for support on coeliac disease there are lots of sources such as the Coeliac UK website, and various social media pages where you can post questions and talk to other people with the condition.



Be organised! Batch cook meals and have convenient snacks on hand

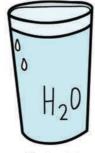




When travelling, consider where you'll be staying and take gluten free bread and other essentials, as needed.



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.

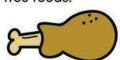


If you are 'glutened', drink plenty of water.



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

<u>coeliac.org.uk/coeliac-disease/about-coeliac-disease-and-dermatitis-herpetiformis/symptoms/</u>

Online Symptom Assessment

isitcoeliacdisease.org.uk

Getting Diagnosed

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

Coeliac Disease in Children

<u>coeliac.org.uk/coeliac-disease/coeliac-disease-in-</u>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/



Eating Out

<u>coeliac.org.uk/gluten-free-diet-and-lifestyle/eating-out/</u>

Venue Guide

<u>coeliac.org.uk/gluten-free-diet-and-lifestyle/venue-guide/</u>

Coeliac UK Accredited Venues

<u>coeliac.org.uk/gluten-free-diet-and-lifestyle/eating-out/eat-out-with-confidence-at-our-gf-accredited-venues/</u>

Support for the Food Industry

www.coeliac.org.uk/food-industry-professionals/

PROCESS

A Dietitian's Perspective. Art by Norrie Millar. Traditional pencils, scanned and inked digitally.



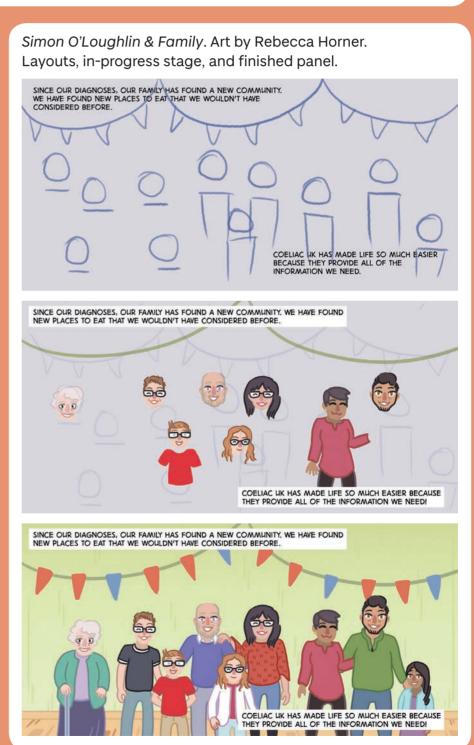


What is Coeliac Disease? Art by Ashling Larkin. Roughs, inks, and finished colour.







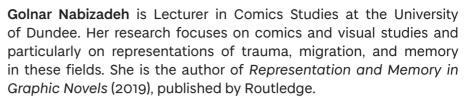


Understanding Coeliac Disease. Art by Letty Wilson and Helen Robinson. Helen's design sheet for the back cover, referencing Letty Wilson's front cover and character design.



CONTRIBUTOR BIOS







Rebecca Horner is a cartoonist and colourist who is constantly working on several projects at once. She is Workshop Lead at Dundee Comics Creative Space and has done production on many books, including this one! *rebeccahorner.com*



Catriona Laird is an illustrator and comic artist and when she's not drawing webcomics and designing characters she's thinking about drawing webcomics and designing characters. Catriona is also a freelance designer for V&A Dundee helping facilitate design workshops and tours for groups of all ages and abilities.



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*



Norrie Millar is a Scottish comics artist based in Dundee. He self-publishes his own work and is also a freelance illustrator, providing work for numerous companies and publishers. behance.net/norriemillar



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 a of ishblues.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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