

Why I had to give my I knew would make

Shirley Scriven tells of her struggle to get a coeliac diagnosis for her twins. By Niamh Griffin

How does it feel to feed your little toddlers something you think is making them sick? This was the stark situation faced by Shirley Scriven when her three-year-old twins had suspected coeliac disease but needed to go through a diagnostic test that involved monitoring their reaction to food containing gluten.

Even now, just over four years later, her voice falters as she remembers the confusion they all faced at that time. Sitting in their sunny kitchen in Naas, Co. Kildare, as the girls chatter on about gluten-free ice-cream cones, Shirley says it's hard for a stranger to imagine now how sick they used to be.

There's a trend for people to self-diagnose with coeliac disease and simply remove any suspected gluten-rich foods from their diet. But cutting out gluten undermines the ability of medics to diagnose the illness, as tests will show up negative for gluten intolerance if the gluten has already been removed from your diet.

Shirley and her husband Vincent did everything by the book, but it wasn't easy.

She says: 'Looking back, I'd say they were never really well. They are our only children, so we didn't know any different. They were picky eaters, but food just flew through them – I was constantly changing nappies.'

Shirley has a family history of coeliac disease, so when Hannah got a severe "tummy bug" at about two years of age, she was tested for the illness, but it came back negative.

'We don't know why. And a year later, the same thing happened – they were very unsettled in themselves, not sleeping. I spent a lot of nights next to them on the bed,' says Shirley.

The bug turned into a chest infection for Hannah, and this time,

when tested at Tallaght Hospital, the blood test showed up positive for coeliac disease. But Hannah needed a biopsy to confirm the diagnosis. Because they were twins, Shirley requested tests for Alyson also.

HANNAH'S DIET TIPS

ON BEING SICK WITH COELIAC DISEASE: It does hurt, it's painful but it doesn't happen often. It feels so bad, it's not really nice. Alyson might get away with a crumb but I won't, not even a crumb. I'm very sensitive.

ON SCHOOL: When someone brings treats to school, our teacher calls us up to her desk, she has a spare pack of Haribo jellies always. We can eat them. Our friends are twins too, but they can eat food with gluten in it.

ON LIMITED DIET: It's not boring. I'm always hungry and we always have something to eat. We know the food to eat, and what to take. If someone offers us something, you might take it and not eat it if it's not gluten-free. Our neighbour gave us an Easter egg. It was in a cup. We kept the cup and gave the egg to our cousins. They're not gluten-free. Granny says we're gas.

ON SHOPPING: We eat gluten-free bread, pasta and it's in a different part of the shop to non-gluten-free bread. There's normally only one section for gluten-free. I like SuperValu and Tesco, they have a big section. If Mummy says its gluten-free, we would try a new food.

Double trouble: Twins Hannah and Alyson Scriven were diagnosed as coeliac



Self-diagnosis is not the way to deal with it

Anyone who suspects they have coeliac disease must be tested by a doctor and avoid self-diagnosis, says head of the Coeliac Society of Ireland, Fergal O'Sullivan.

The illness is an auto-immune disease that causes some adults and children to react to the gluten found in wheat, barley and rye. Gluten is also found in less obvious foods, including sauces, gravy and salad dressings, as well as crisps and chocolate. Based on international figures, it is estimated that 47,000 Irish people have this condition, but not all are diagnosed.

Fergal says: 'Symptoms vary but would include vomiting, diarrhoea, failure to thrive. Nutrients are not being absorbed, so osteoporosis and

fertility are issues. One of our members said she had a number of miscarriages, then was diagnosed and went onto have children. There can be a significant impact on fertility. And some risk of intestinal cancer – that's if it's not treated.'

He said there is a need for more awareness of the coeliac condition as a disease, rather than the lifestyle choice that brings people to avoid gluten.

'If you are self-diagnosing as gluten-intolerant, you should get tested. There are three steps – talk to your GP, then get a biopsy to confirm the diagnosis if the blood-test is positive and then talk to a dietitian. Some people self-diagnose then eat the same two things for the rest of their lives; that's not healthy either.'

Find out more at Coeliac.ie



'It was very difficult. At that stage we knew, but we had to keep giving her gluten. I knew what I was giving her was making her ill, that

Determination: The twins' mum Shirley Scriven

was difficult. It took six weeks,' she says.

Her next move was to tackle the kitchen. Unlike people with a gluten intolerance, people with coeliac disease can become ill from as little as a breadcrumb, or even having their gluten-free breads stored in the same space as a regular bread. Side-effects of

untreated coeliac disease include osteoporosis, infertility and anaemia, as well as the more obvious digestive issues.

Shirley says: 'I cleaned that kitchen top to bottom – every drawer. We got extra food presses so everything could be separate. We have two toasters. Their food is always on the top shelf in the

twins food them sicker



ALYSON'S FAVOURITES

- ON COELIAC DISEASE:** It's sore. It's short; you might be sick and very bad one day and then a few days sick.
- ON LIMITED DIET:** If it says it's gluten-free, we try them. Sometimes it's easy, sometimes it's very hard. One time in a restaurant it said gluten-free but it wasn't. Mummy makes gluten-free chocolate cake and our cousins love that as well. My cousins are not gluten-free but they still love it. They can't get enough of it.
- ON TREATS:** We know the list of gluten-frees. Some crisps are gluten-free, and popcorn. We saw a sweet-shop once in Kilkenny... it was huge, all shelves of sweets. But only two jars were gluten-free. I really like everything – everything is my favourite food!
- ON SCHOOL:** We always ask the person in charge about gluten-free if it's new food. People would say "maybe, but maybe not" and say not to try it. We bring our lunch: a sandwich, a bar or a bun. We can eat fruit. I like Cheestrings too.
- ON EATING OUTSIDE THE HOUSE:** We like Mummy's food. Some restaurants are gluten-free but in other places only have gluten-free pizza. You have to stick to it.

remained short in spite of the twins' wish to have long hair.

'After six weeks you could see a difference, but real change took two years,' says Shirley.

It was only when the twins started school that Shirley and Vincent realised how much attention the pair were paying to their health. A teacher handed them some sweets – jellies, which were safe – but the girls didn't recognise them and politely refused.

'I was shocked, that this had so much effect on them. They were clever enough to know it could make them sick. They'd been diagnosed in January, so it was less than a year since they were so sick. It shocked us that they could make that decision,' Shirley says.

Now the girls keep their school lunches separate from those of their friends, never sharing and even keeping their boxes in their schoolbags instead of on the common shelf. All their friends know, and recently two parents even baked gluten-free birthday cakes for their own daughters so the twins could join in the celebrations.

Shirley says they're lucky in that healthy foods like fruit and vegetables are naturally gluten-free, so it's things like bread,

cakes, pasta and sauces she has to be most careful around. The watch-list includes pizza, to the girls' disgust, although they have been treated to gluten-free pizza, Shirley reminds them.

'You're always thinking about it. I would send a box with them – sandwiches, bar and fruit. They get the same, but it's gluten-free.'

As members of the Irish Coeliac Society, Shirley says in the beginning they slavishly read the list of gluten-free foods the society produces, but now they're more confident going it alone.

Asked for advice for parents newly presented with this diagnosis for their children, she says: 'Eat healthily and well. If you think something is wrong, don't be afraid to get them tested, even twice. It's a serious effort. You're either on the diet or you're not – you can't chop and choose or have a break from it.'

Smiling as the twins race past the window shrieking about something, she adds: 'It can be drudgery, checking everything, but when you're on the diet, it's a healthy life. I just hope this is all they have to cope with, that they grow up to be hugely successful and talented girls.'

10 REASONS YOU ALWAYS GET... ILL ON HOLIDAY

1 YOU'RE A VICTIM OF LEISURE SICKNESS
If you spent the Easter break feeling as if you've been hit by a bus, you may be a victim of leisure sickness. In 2002, psychologists in Holland published a study of 1,900 people which showed that one in 30 suffers headaches, fatigue, nausea and flu-like symptoms when going on holiday. The theory is that people with high-pressure jobs produce stress hormones such as adrenaline and cortisol, and when the body relaxes, these levels drop and make them more susceptible to illness.

2 IT'S THAT CRASH DIET
Getting 'beach body ready' by crash-dieting in the weeks leading up to your time off could impair your immune system. A 2004 study at the University of Washington in Seattle found that women who had undergone two to five crash diets, losing 10lb or more each time, had weaker immune cells.

3 TRAVELLING CAN TRIGGER MIGRAINES
Changes in cabin pressure on jets and motion sickness from trains or cars can lead to migraines. Other known triggers include alterations in sleep patterns, diet, time zone changes, and dehydration.

4 YOU CAUGHT A BUG ON THE PLANE
Colds are at least 100 times more likely to be transmitted on a plane than in normal daily life, according to the Journal Of Environmental Health Research – and one of the biggest reasons is the air-conditioning system that extracts moisture from the cabin. It can also dry the lining of the nose, which is coated with a layer of mucus to protect against infection.

5 BLAME THE STREET FOOD
A survey carried out in 2015 found that a quarter of holidaymakers had suffered from food poisoning while abroad, with high-risk items including street food, poorly cooked meat, tap water and buffet items left out for long periods in warmer countries.

6 YOU CAN BE TOO RELAXED
Taking it easy when you're knocked out from jet-lag can be the worst thing to do. A Canadian study on hamsters made to adjust to an eight-hour

time difference found that animals that exercised recovered in just over a day, while those that slept took more than eight days. The longer time spent with a disrupted circadian rhythm, the higher the risk to your health.

7 YOU OVERDID IT AT THE ALL-INCLUSIVE BAR...
A 2016 survey found that the average holidaymaker guzzles 56 alcoholic drinks during a two-week holiday. Given that a pint contains at least two units, this far exceeds the recommended maximum of 17 units a week for men (it's 11 for women). Over indulgence can trigger arrhythmia, where the heart beats too fast or too slow. The condition is also known as holiday heart syndrome.

8 ... AND THE BREAKFAST BUFFET
Researchers claim that we eat more than double our recommended amount of calories on the first day of a holiday, and it not only causes you to feel uncomfortable and nauseous, it can also lead to rapid weight gain. A study in 2010 found that those who increased their daily calorie intake by 70% for four weeks gained 14lb, and six months later only half had lost it, despite eating normally again.

9 YOU FRIED YOUR FACE
After a typical Irish autumn and winter, it may seem tempting for those of a whiter shade of pale to wear a bit of make-up to look fabulous on holiday. But when UV radiation reacts with emulsifiers found in cosmetic products, such as make-up, and many sun creams, it can cause acne aestivalis, also known as Mallorca acne. It most commonly affects women aged 25 to 40, with small red lesions being found on the cheeks, neck, chest and upper arms within hours of exposure to the sun.

10 THE POOL GAVE YOU LEGIONNAIRE'S
Legionnaire's disease, a serious lung infection, has an incubation period of up to ten days, so you may not show symptoms until you get home. It's caused by bacteria in 'wet' air, often found in poorly maintained air-conditioning systems or indoor swimming pools and spas. People aged over 50, as well as smokers, are at higher risk.

fridge, and top of the presses to keep the risk of cross-contamination down.'

Almost miraculously, the girls began to improve within weeks of their new diet following their diagnosis in January 2013. Shirley recalls that the toddlers were very pale, lethargic and underweight – even their hair was affected, as it