

**\*\* Embargoed to 00.01am Thursday 24 March 2022\*\***

## **NO MORE LOST CHILDHOODS**

### **New campaign helps parents identify signs of autoimmune disease**

According to the latest Coeliac UK survey<sup>i</sup> one in four children (25 per cent) with coeliac disease took two years or more to receive a diagnosis. And a further one in four took between seven months and two years; meaning a large portion of their childhood was spent with unnecessary suffering and discomfort. Today, the national charity is launching a new symptom awareness campaign.

Coeliac disease is a common autoimmune condition which can have a debilitating impact and symptoms may be easily mis-interpreted for other day-to-day childhood illnesses. For example, if a child vomits, has severe stomach pain or extreme tiredness, it can be difficult to know if it's a bug, something they've eaten or if in fact it's coeliac disease. To help, the new 'Is it coeliac disease?' campaign will enable parents and carers to spot the signs earlier, support them to get a diagnosis and provide vital ongoing advice.

Once diagnosed, coeliac disease can be treated and, in most cases, symptoms cleared, by maintaining a strict gluten free diet for life. So Coeliac UK's expert advisers are urging parents and carers to look out for the following in their children:

- Tiredness
- Sickness
- Bloating
- Stomach pain
- Slow growth

When one, some or all of these are spotted persistently, parents can complete an easy [self-assessment form](#) which will signpost if the child should go to their GP for testing. It also provides a print-out for parents to share with their GP to advocate for them and help to get the answers they need.

If testing is recommended, parents should not remove gluten from their child's diet during the diagnosis process as the test for coeliac disease measures the antibodies produced in response to eating gluten. Even reducing the amount of gluten in the diet can potentially give a false negative result.

Heidi Urwin, Director of Evidence and Policy at Coeliac UK, said: "Families have faced a multitude of issues due to the coronavirus pandemic, combined with a general lack of awareness of the key symptoms of coeliac disease – which can differ in children and adults and be easily missed. This has led to a significant fall in diagnosis rates. It's time to get back on track and work towards no more childhoods being lost to undiagnosed coeliac disease.

"We are launching this campaign to raise awareness of symptoms and to support families on this journey. We hope our self-assessment test can be the first step on the road to recovery. By completing it, concerned parents will have the information to know exactly what to do next."

One in 100 people in the UK population have coeliac disease<sup>ii</sup>, a serious autoimmune condition. It is caused by a reaction to gluten, a protein found in wheat, barley and rye, which is included in many

everyday foods. When someone with coeliac disease eats gluten, their immune system reacts and causes damage to the gut resulting in a range of symptoms, some of which can be very severe, significantly affecting daily life.

Dr Peter Gillett is Consultant Paediatric Gastroenterologist at the Royal Hospital for Sick Children in Edinburgh, and a member of Coeliac UK's Health Advisory Council. He urges parents not to delay: "I have seen time and time again how coeliac disease has a daily impact on those who suffer and truly can destroy childhoods.

"But, there is good news - it can be managed by a carefully controlled, gluten free diet and as soon as gluten is removed from the diet, the body begins to repair the gut lining and so symptoms reduce and for most will stop fairly quickly.

"I find it astounding, every day, how transformational moving to a gluten free diet can be for a child with coeliac disease and their family."

Gloucestershire girl, Daisy, was diagnosed with coeliac disease when four years old. From just 18 months she was very tired a lot of the time and suffered constipation, bloating, an uncomfortable tummy - all classic symptoms.

Her mum Helen captures the family's journey: "As a very young girl, Daisy only had the energy to play for half an hour, then would need to sleep.

"I remember one day after months of illness her being on all fours in the living room being sick and having tummy troubles at the same time. She was just three at the time and said to me 'Mummy, I am so poorly'. This broke my heart as I just wanted my little girl to be happy and healthy.

"We were so relieved to finally have a diagnosis and know it was treatable. It took some time for her gut lining to heal, but she is so much better now."

Daisy, now 13 and symptom-free, says: "Before I was diagnosed, I felt that I was stuck forever being sick. That I would never get better. It was horrible.

"But now, I feel so much better and I'm not tired at all. I can play with all my friends because I am not poorly anymore."

MasterChef winner and Coeliac UK ambassador, Jane Devonshire, whose youngest son has coeliac disease, says: "Ben was diagnosed when he was just two years old. He would cry constantly and was obviously very distressed. He had a terribly upset stomach. He looked grey and had dark circles under his eyes. He was just not healthy, not thriving.

"As a parent it is so distressing to see your child have to cope with these symptoms - but also such a relief to then have a diagnosis and know that diet changes is all it takes to improve their quality of life.

"We are now 18 years on, and I have seen the difference a diagnosis can make. Of course it takes some time to adapt to a gluten free diet, but there is so much support available and the transformation to his childhood and our whole family's quality of life, has been astounding."

To access the self-assessment which only takes three minutes to complete please visit:

<https://isitcoeliacdisease.org.uk>.

[www.coeliac.org.uk](http://www.coeliac.org.uk)

Facebook: [www.facebook.com/CoeliacUK](https://www.facebook.com/CoeliacUK)

Twitter: [@Coeliac\\_UK](https://twitter.com/Coeliac_UK)

Instagram: [@coeliacuk](https://www.instagram.com/coeliacuk)

Helpline telephone: 0333 332 2033

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### **Note to editors**

#### **About Coeliac UK**

For over 50 years, Coeliac UK has been the expert on coeliac disease and the gluten free diet. We are an independent charity helping people living without gluten to live happier, healthier lives. We do this by providing trustworthy advice and support, funding critical research into coeliac disease, working with healthcare professionals to improve diagnosis and fighting for better availability of gluten free food. And we do it all so that one day, no one's life will be limited by gluten. For more information visit [www.coeliac.org.uk](http://www.coeliac.org.uk)

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<sup>i</sup> Coeliac UK conducted a survey with 197 parent/carer members to understand more about their experiences with getting their children diagnosed, in August 2021.

<sup>ii</sup> <https://pubmed.ncbi.nlm.nih.gov/14764493/>  
<https://pubmed.ncbi.nlm.nih.gov/12801951/>