



News Release

Immediate Issue: 4 May 2018

Undiagnosed at risk with delays in coeliac disease diagnosis

Coeliac UK, the largest independent charity for people who need to live gluten free, says that delayed diagnosis of coeliac disease is creating a growing health problem across the UK with undiagnosed patients at risk of suffering with complications of the disease including irreversible neurological damage.

In its 50th Anniversary year, the charity is urging health professionals and the general public to take coeliac disease seriously and as part of the charity's Awareness Week activities (14 - 20 May 2018) will be highlighting the symptoms and emerging evidence relating to previously unknown complications of the autoimmune disease.

Sarah Sleet, chief executive of Coeliac UK said that even though awareness of coeliac disease has grown, there still exists a perception that the disease is not that serious because it requires a gluten free diet as its medical treatment. "Many see coeliac disease as just a disease of the gut, when in fact it is a systemic disease that can affect other parts of the body. A coeliac disease diagnosis is often missed because the patient is not presenting with gut symptoms, but rather they may present with neurological symptoms and are directed to a neurologist rather than a gastroenterologist."

In a study of patients with newly diagnosed coeliac disease, who had been referred to a gastroenterology clinic around three out of five had established neurological symptoms including severe headache (45%), balance problems (26%) and sensory symptoms (14%).¹

"Delayed diagnosis of coeliac disease is associated with development of neurological conditions such as gluten ataxia and gluten related neuropathy which can have lifelong debilitating impacts," Ms Sleet said.

The treatment of gluten related neurological conditions is - like coeliac disease - a lifelong strict gluten free diet. The longer the symptoms go untreated, the more likely there will be no or limited improvement in the condition. When there is gluten related neurological damage the gluten free diet can make a difference with improvements being related to earlier diagnosis.

Coeliac disease is a serious autoimmune condition caused by a reaction to gluten, a protein found in wheat, barley and rye. People diagnosed with coeliac disease must maintain a strict gluten free diet for the rest of their life if they are to avoid very serious complications such as osteoporosis, infertility and although rare, small bowel cancer.

One in hundred people in the UK has coeliac disease but around half a million people in the UK are currently undiagnosed. It still takes an astonishing 13 years on average for a person to be diagnosed. Although many people present with a range of [symptoms](#) including those that are gut related, other symptoms include mouth ulcers, anaemia, repeated miscarriages and neurological problems. The charity urges anyone that has ongoing symptoms to visit their GP and request a blood test for coeliac disease. It is essential not to remove gluten from their diet prior to testing as this could lead to a false negative result.

Sarah Sleet, chief executive of Coeliac UK said: “The fact that it still takes 13 years on average for a person to be diagnosed is unacceptable and is creating severe long term health problems for many people. We still have half a million people living undiagnosed with coeliac disease and we need to move faster to get them diagnosed to prevent these long term complications occurring. For example some patients have lived with the condition for so long, that by the time their neurological condition is identified as being caused by coeliac disease, the damage is irreversible and they face a lifetime of debilitating symptoms.”

Ms Sleet said that along with getting people diagnosed much earlier, there was also a more urgent need for more research. “Coeliac disease is one of the most understood autoimmune conditions and therefore has potential for finding answers to other autoimmune diseases such as type 1 diabetes. This makes coeliac disease research a much more appealing proposition because it means it has the potential to help millions of people, not just those with coeliac disease” Ms Sleet said.

The charity launched a Research Fund in March this year to raise £5 million towards research into coeliac disease and other gluten related autoimmune conditions. As part of the launch, the charity has thrown more light on the association with neurological conditions, along with the more severe and life threatening form of the disease, refractory coeliac disease type II, which is rare and affects a very small proportion of the coeliac population. For more information and video of case studies see: www.coeliac.org.uk/researchfund.

Marks and Spencer is the retail partner for Coeliac UK's 50th Anniversary celebrations which includes sponsoring parties the charity's supporters are being encouraged to hold throughout May. Helen Seward, Nutritionist from Marks and Spencer said: “We are thrilled to be supporting Coeliac UK during their special 50th Anniversary year. Gluten free options have come a long way over the last 50 years and we are pleased to be playing a part in this growth to help all those on a gluten free diet.”

Ends

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Reference: ¹ *Hadjivassiliou M et al. Neurological evaluation of patients with newly diagnosed coeliac disease presenting to gastroenterologists (manuscript submitted)*

Notes to editor

Coeliac UK's Awareness Week Monday 14 – 20 May 2018

- Coeliac UK is the national charity for people who need to live without gluten, whether due to coeliac disease or another medical condition requiring a gluten free diet.
- The charity was launched in 1968 and is celebrating its 50th Anniversary this year
- Coeliac disease is a serious illness where the body's immune system reacts to gluten found in food, making the body attack itself.
- Symptoms include diarrhoea, vomiting, stomach cramps, mouth ulcers, fatigue and anaemia.
- In undiagnosed, untreated coeliac disease there is a greater risk of complications including anaemia, osteoporosis, neurological conditions such as gluten ataxia and neuropathy, and although rare there's an increased risk of small bowel cancer and intestinal lymphoma.
- 1 in 100 people in the UK has coeliac disease
- Average time to diagnosis is 13 years.
- 1 in 4 people diagnosed with coeliac disease had previously been diagnosed with IBS.
- Gluten is a protein found in wheat (including spelt), rye and barley. Some people are also sensitive to oats. Obvious sources of gluten include breads, pastas, flours, cereals, cakes and biscuits. It is often used as an ingredient in many favourite foods such as fish fingers, sausages, gravies, sauces and soy sauce.
- Coeliac UK has a Helpline on 0333 332 2033 and further information can be found at www.coeliac.org.uk