



GREAT Healthcare

Coeliac Disease Education

Loretta Jay describes the excellent new educational resource developed by the US-based National Foundation for Celiac Awareness (NFCA)

It's official. Coeliac disease is becoming more common. Dr Joseph Murray and his team at the Mayo Clinic in the United States showed that the disorder is affecting four times as many people today than it was in the 1950s. People with coeliac disease have trouble digesting gluten (the protein in wheat, barley and rye) causing malabsorption. The only treatment is permanently removing these grains, and their derivatives, from the diet.

Coeliac disease affects 1% of the population of Europe, Australia, New Zealand and the United States. Though some parts of Europe and Australia have diagnosis rates at close to 50%, the United States lags far behind with only 5% of those affected diagnosed. Challenging the identification of all of those affected is the disease's broad range of manifestations coupled with poor medical awareness.

Linda Goldkrantz was one of the few diagnosed as a child in the 1940s. At the time it was believed that children outgrew the disease, and she was told to go off the gluten-free diet when she reached puberty. Her ailments continued over the next 50 years, but her complaints were dismissed by her doctors. Finally, Linda's friend, who was recently diagnosed, urged Linda to get tested, and of course she still had coeliac disease.

The National Foundation for Celiac Awareness (NFCA) is based in Philadelphia, Pennsylvania. Its mission is to raise the awareness of coeliac disease and drive its diagnosis. NFCA has

developed the first of its kind, medical education programme for the entire healthcare system: Gluten-free Resource Education and Awareness Training (GREAT) Healthcare.

Medical Awareness

The crux of GREAT Healthcare is that the entire spectrum of medical professionals needs to be made aware of coeliac disease in order to better recognise when a person may be experiencing symptoms.

Historically, coeliac disease was thought to be a disorder affecting children, and one that caused diarrhoea. We now know that coeliac disease may surface and be diagnosed during all stages of life: from childhood through old age.

Many physicians erroneously believe it is a disease that predominantly affects those who are malnourished looking and of Irish descent. People with coeliac disease may be thin, but they may also be obese. They may be short – but they could also be stars in a basketball team. And they need not be of Caucasian or European descent.

Coeliac disease affects 5.6% of the northwest African Saharawi people. (*Catassi, C. et al. Why is coeliac disease endemic in the people of the Sahara? Lancet. 1999*) This Arab-Berber population's diet is predominantly (wheat) bread. Similarly, coeliac disease is found in the Middle East, India and Latin America at rates close to those for people of European descent.

Coeliac disease is a common ailment that affects people of all walks of life, of all ethnicities, of

all body builds. And it is very treatable.

Treatment

At the beginning of the 20th century, many children with coeliac disease survived on 'the banana diet', the only treatment known, at the time, to stop the persistent diarrhea associated with the disorder. Linda Goldkrantz's mother was told to feed her daughter lots of bananas and bacon. It was Dr WK Dicke who noted that gastrointestinal symptoms of Dutch children with coeliac disease improved during the bread shortage of World War II; the symptoms worsened when the allied planes dropped bread for relief. Dr Dicke later published research that showed coeliac's trigger to be wheat and rye. This formed the basis for the gluten-free diet, which remains the only known treatment for coeliac disease today.

Symptoms/diagnosis

No longer is diarrhoea considered the predominant presentation of untreated coeliac. Over 50% of people with coeliac disease don't have any gastrointestinal symptoms at the time of their diagnosis. Now we know the signs of untreated coeliac disease are broad, impacting all bodily systems. This is part of the reason why so many with coeliac are misdiagnosed or undiagnosed.

Rather than rely solely upon the primary care provider to recognise new cases of coeliac, GREAT Healthcare educates all healthcare providers, bringing them onto the team to increase diagnosis.

Infertility and migraines, ataxia and childhood developmental delays are some of the symptoms, beyond the more commonly recognised gastrointestinal ailments, of undiagnosed coeliac disease. The list goes on. When the disease goes unrecognised other problems ensue: osteoporosis, thyroid disorders and some cancers.

The Medical Team

Although GREAT Healthcare serves providers in many disciplines, primary care providers are likely to interface with patients and have the opportunity to make a diagnosis. GREAT Family Practitioners trains nurse practitioners, physician assistants and physicians to know when and how to screen for coeliac disease and how to support the diagnosed coeliac.

When someone is hospitalised, the attending physician can be counted on to stop by in the early morning hours, during rounds. She provides oversight of the patient's care, but must rely on the nurses, the primary carers during the hospital stay to convey the patient's status. Similarly, when someone is already diagnosed with coeliac and following a gluten-free diet, the nurses are responsible for administering medication, providing snacks and helping with communication to the food service department.

GREAT Nursing Professionals empowers nurses with information about coeliac disease so they can both recognise possible symptoms of the disorder and bring these observations to the medical team, and support the implementation of the gluten-free diet for those who are already diagnosed.

Depression, anxiety and eating disorders are all ways that untreated coeliac disease may present. So are ADHD, learning disorders and chronic fatigue syndrome. The mental health professionals serving these populations need to be aware of neurological presentations, as well as how to support those who have already been diagnosed and are struggling to maintain a positive outlook while on the restrictive diet. GREAT Mental Health meets this need.

The Gluten-free Diet

Gluten, the protein in wheat, barley and rye, is a staple in many diets. Not only are the grains in their raw form toxic to those with coeliac disease, but so are their derivatives. Malt is made from barley, soy sauce has wheat in it and the typical bagel or pasta is forbidden. Safe food preparation must ensure gluten-free ingredients and avoid cross-contamination.

In 2008 NFCA conducted a survey of people with coeliac disease who received services from Philadelphia area hospitals. Of those who required gluten-free food during their hospital stay 55% were unable to secure safe food when needed, and instead had friends or family bring food for them. GREAT Kitchens is a train-the-trainer course for kitchen managers, cooks and chefs. Hospital food service departments and restaurants alike can train their staff and provide safe, gluten-free food for their patrons.

GREAT in practice

Saint Barnabas Health Care Systems in New Jersey recognised the need to both identify

its patients with coeliac disease, and be able to accommodate the gluten-free diet. Last year they established the Kogan Celiac Center, and piloted GREAT Healthcare for its 18 facilities. First the food service managers and dietitians were trained. Then nurses, mental health and allied health providers were offered the training. The pilot was successful, and they reported it led to 'heightened awareness and education about coeliac disease ... and the gluten-free diet.'

Since researchers have identified gluten as the trigger for the disorder, those affected are no longer limited to bananas and bacon. Gluten-free food manufacturers have created tasty delights incorporating other foods that are naturally gluten-free. Now, resources are available to support the healthcare provider with the identification of the undiagnosed, and to help them assist their patients with the gluten-free lifestyle.

Loretta Jay became passionate about coeliac disease when she had difficulty in getting diagnoses for both of her children. Realising that her experiences were not unique, she set out to raise awareness and joined with the NFCA; she is now their Director of Program Development. She can be reached at lorettajay@CeliacCentral.org.

For more information or a link to the GREAT Healthcare modules, please visit www.CeliacCentral.org and click on the GREAT logo. Questions or institution queries may be directed to GREATHHealthcare@CeliacCentral.org.

Programme

GREAT Family Practitioners
GREAT Nursing Professionals
GREAT Mental Health
GREAT Allied Health
GREAT Dietitians
GREAT Kitchens

Discipline

Physicians, Nurse Practitioners, Physician Assistants
Nurses, Nursing Assistants
Psychiatrists, Psychologists, Social Workers, Counsellors
Occupational Therapists
Healthcare and Clinical Settings or Food Service, Dietitians, Nutritionists
Chefs, Cooks, Food Service Managers