

WHAT IS COELIAC DISEASE?

BACKGROUND

Coeliac disease (pronounced *see-lee-ak*) is a permanent intestinal reaction to dietary gluten. With coeliac disease, the cells lining the small bowel (intestine) become damaged and inflamed. This causes flattening of the tiny, finger like projections, called villi, which line the inside of the bowel.

The function of the villi is to break down and absorb nutrients in food. When these villi become flat, the surface area of the bowel is greatly decreased, which interferes with the absorption of nutrients from food. This may lead to deficiencies in vitamins (such as folic acid) and minerals (e.g. iron and calcium).

Coeliac disease is hereditary, however both genetic and environmental factors play important roles in coeliac disease. It is currently estimated that 60,000 to 70,000 New Zealanders have coeliac disease (1 in 70), however up to 80% of those are unaware they have the condition. The symptoms of coeliac disease vary considerably and can include fatigue, weakness, and lethargy, diarrhoea or chronic constipation.

Who is Coeliac New Zealand?

We are a national not-for-profit or 'for purpose' organisation. We have a strong, skilled and engaged board with lived experience of coeliac disease who provide governance to the organisation. The daily operations are carried out by a dedicated small team of five part-time staff supported by 30 volunteers. We are also supported by our Medical Advisory panel of Gastroenterologists, NZ Registered Dietitians, and other specialist clinicians. Having this group allows us to access a panel of experts on coeliac disease and we value their significant contribution to our organisation.

We raise awareness, provide support, information, and resources to people with coeliac disease, their whanau, and the wider community. We support research, education, and initiatives for those working in the health sector. Coeliac New Zealand Incorporated's (CNZ) vision is that people with coeliac disease live healthy lives every day.

For many people with CD and their whanau, CNZ is one of the only places that understands their condition and helps them to not feel alone in managing this lifelong condition and provides monthly newsletters, a dedicated *Coeliac Link* magazine, an annual awareness week each year in June, social media channels, a comprehensive website with relevant information: coeliac.org.nz and a YouTube channel with educational and informative videos.

If you need help, would like more information or have some questions, we're here to help!

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WEB. coeliac.org.nz

FBK. Coeliac New Zealand

Symptoms in adults

DIFFICULTY CONCENTRATING

VITAMIN B12, A, D, E AND K DEFICIENCIES

ULCERATIONS AND/OR SWELLING OF MOUTH AND TONGUE

WEIGHT LOSS

MISCARRIAGES AND INFERTILITY

ANAEMIA: IRON OR FOLIC ACID DEFICIENCY ARE THE MOST COMMON

OSTEOPOROSIS

SKIN RASHES SUCH AS DERMATITIS HERPETIFORMIS

NEUROLOGICAL ISSUES

FATIGUE, WEAKNESS AND LETHARGY

EASY BRUISING OF THE SKIN

NAUSEA AND VOMITING

IRRITABLE BOWEL SYMPTOMS/ DIARRHOEA/ CHRONIC CONSTIPATION

INFERTILITY

BONE AND JOINT PAINS

MUSCLE SPASMS DUE TO LOW BLOOD CALCIUM LEVELS

MORE FREQUENT | LESS COMMON

BECOME A MEMBER

CNZ has the necessary resources to support you with label reading and communication for work colleagues, schools, and organisations. Webinars and videos to keep you informed on our YouTube channel and regular updates via our newsletter and social media channels, as well as our twice a year coeliac link magazine. CNZ is the voice for coeliac disease in New Zealand and we are here to support you.

Help us help you! Having someone commit to being a long-term member makes a significant difference as the work we do is not just about the first or second year after diagnosis, it is about supporting you throughout your coeliac journey for life.

For more information visit coeliac.org.nz

Feature / KAMRAM ROSTAMI



LATE
ONSET
COELIAC
DISEASE

The importance of **EARLY DETECTION** and
TREATMENT of coeliac disease **IN LATER LIFE**

First published Autumn 2022 *Coeliac Link*



C**OELIAC** disease is an autoimmune condition that is triggered by gluten. The gluten's antigens induce an immune reaction against the small intestinal mucosal lining. This reaction is known as inflammation leading to several symptoms

including fatigue, abdominal pain, anaemia, diarrhoea or constipation and bloating. Gluten damages are not confined to the small intestine as there are a range of extraintestinal presentations, like neurological disorders in particular, peripheral neuropathy, unexplained headache, skin and joint related symptoms reported in some patients. Ataxia and neuropathy are two essential neurologic complications of untreated coeliac disease (CD) which can particularly be problematic in older patients¹.

Cognitive impairment, like accelerated dementia, has also been seen in older patients with CD, although its effect is controversial, the gluten free diet should be introduced, as early as possible, because of its potentially protective effect. The other associated autoimmune diseases include type 1 diabetes mostly in younger patients and autoimmune thyroid

disorders (Hashimoto thyroiditis and Graves' disease) more frequently in older patients. Since, in older adults, autoimmune thyroid disorders are more common when they are affected with coeliac disease, screening for thyroid diseases is strongly recommended in these patients. Another important manifestation of coeliac disease is osteopenia or osteoporosis that may affect older people more often. A low bone density can be associated with unexpected fractures and bone pain. For instance, lack of calcium and vitamin D are consequences of malnutrition and bone pain might be the only presentation of CD as this condition may present with atypical symptoms or no symptoms in some cases.

Due to the complexity and atypical presentation, many patients remain undiagnosed, and the lack of treatment expose these patients to complications unfortunately. For instance, malignancy is another long-term complication that is increased in untreated older people with coeliac disease. Atypical presentation is the main reason why some patients not being diagnosed with CD or there is a major delay between

the onset of symptoms and timing of diagnosis. The current guidelines strongly recommend treating all patients with a gluten free diet disregard to their age or whether they are symptomatic or not. The main reason for this policy is the fact that

ONE OF THE CHALLENGES IS CHANGING A LIFETIME OF DIETARY HABITS... OLDER PEOPLE MAY ALSO HAVE LIMITED FINANCIAL OR SOCIAL RESOURCES, AND LIMITED MOBILITY



untreated CD are at high risk for developing complications like above mentioned autoimmune disorders and malignancy. The estimated prevalence of coeliac disease in New Zealand is now about 1% in the general population with many cases remaining undiagnosed².

The challenges are not confined to only underdiagnosis but also the management of this condition especially in older patients. One of the challenges is changing a life-time of dietary habits. In addition, some older people may also have limited financial or social resources, limited mobility that restrict their ability to walk or travel to gluten-free suppliers³. Providing a gluten-free diet might be difficult for patients residing in assisted living facilities. Acknowledging the challenges would hopefully alert the health professionals on how they can provide the best care of older people with coeliac disease. Additional issues require consideration may relate to poor nutritional intake and impaired vision limiting their ability to read the labels which are often minute in size³. Patients should be encouraged to seek out community support and family members should be engaged and participate in the patient's dietary consultation³. Direct communication between the dietitian and the food services at the patient's organisation, if in care, are likely necessary to optimise a safe and uncontaminated gluten-free diet. In the very elderly or debilitated patients who have minor symptoms, consideration of not treating the patient with a gluten-free diet may have some rationale^{3,4}. However, it should be noted that patients can often have a dramatic improvement in chronic symptoms, after starting a gluten-free diet, and the opportunity for possible recovery should not be overlooked. **CL**

¹ Osman D, Umar S, Muhammad H, Nikfekar E, Rostami K, Ishaq S. Neurological manifestation of coeliac disease with particular emphasis on gluten ataxia and immunological injury: a review article. *Gastroenterol Hepatol Bed Bench.* 2021;14(1):1-7.

² Ashtari S, Najafimehr H, Pourhoseingholi MA, et al. Prevalence of celiac disease in low and high risk population in Asia-Pacific region: a systematic review and meta-analysis. *Sci Rep.* 2021;11(1):2383.

³ Rashtak S, Murray JA. Celiac disease in the elderly.

Gastroenterol Clin North Am. 2009;38(3): 433-446.

⁴ Shiha MG, Marks LJ, Sanders DS. Diagnosing coeliac disease in the elderly: a United Kingdom cohort study. *Gastroenterol Hepatol Bed Bench.* 2020;13(1):37-43.

DR KAMRAN ROSTAMI

is well known for his research on coeliac disease and non-coeliac gluten sensitivity.

Having received his MD degree from Carol Davila University Bucharest, Dr Rostami undertook his postgraduate training at Internal Medicine University of Groningen, the Netherlands, after completing his PhD at University of Amsterdam. He continued and accomplished specialist training through the West Midlands Deanery in UK and has been an attending Physician in the Gastroenterology Division, Department of Internal Medicine in both UK and later at Palmerston North, New Zealand.

He acted as clinical lecturer at the University of Birmingham and visiting lecturer in Nutrition Therapy at University of Worcester. His ongoing research interests are on gluten related disorders and nutrition therapy in inflammatory bowel disease. He is deputy editor of Gastroenterology & Hepatology from Bed to Bench Journal, a member of the editorial boards and reviewer of several scientific journals.

He has organised and presented at numerous national and international Gastroenterology conferences, coordinated a number of multicentre studies and has published over 150 peer-reviewed articles.

ADELE ROSTAMI

Adele has worked as a specialist dietitian for 2 decades in NHS, UK in many specialist areas including intensive care, gastroenterology, diabetes, oncology, bariatric surgery and paediatrics.

Being part of the Gastroenterology Nutrition Team at University Hospitals Birmingham NHS Foundation Trust is how Kamran and Adele met in 2003 and eventually got married. Through the years they have supported and learned from each other, not only personally, but also in their various interests of nutrition.



FALL PREVENTION

COELIAC disease influences how our body absorbs nutrients and over time, there is a risk that we absorb less calcium and vitamin D than we need to which means that our bone health, is less than it should be.

The importance of early detection and treatment of coeliac disease in older adults should not be underestimated.

Older people when newly diagnosed later in life are more likely to have a variety of nutrient deficiencies and we recommend you talk to a dietitian about your needs as nutrient deficiencies should be diagnosed not guessed.

One of the primary risk factors for falls in older people is muscle weakness and poor balance. As we age, we naturally lose muscle mass and strength, which can affect our stability increasing the risk of falling. To combat this, regular physical activity is essential. If we are inactive, we lose muscle mass by around three percent per day and exercises that focus on strength, balance, and flexibility, can significantly reduce the risk of falls. Engaging in these activities not only improves physical health but also boosts confidence in mobility.