

# Ongoing dietary challenges for people with coeliac disease

January 27 2015

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University of Otago researchers have completed the first national survey of people with coeliac disease in New Zealand and found that many experience ongoing health challenges despite adhering to treatments.

Many sufferers experienced ongoing symptoms and restricted their travel and [social activities](#) due to difficulties in following the recommended gluten-free diet, the researchers found.

Coeliac disease – an [autoimmune condition](#) in which the body reacts abnormally to the gluten portion of certain grains (including wheat, rye, barley, [oats](#) and their hybrids) interfering with the [intestine's absorption](#) of various foods – affects about 1% of New Zealand adults. The only treatment is strict adherence to a gluten-free diet.

To gain an understanding of the health and dietary treatment of people with coeliac disease, Dr Kirsten Coppell, along with fellow Otago researchers Masters of Dietetics student, Kiri Sharp and biostatistician, Heather Walker, surveyed 936 clinically-diagnosed members of Coeliac New Zealand Inc. as part of The New Zealand Coeliac Health Survey.

The survey results, recently published in *Nutrition & Dietetics*, indicate that though most participants (88%) described their diet as being strictly gluten-free, many had incomplete recovery and continued to experience symptoms ranging from fatigue to vitamin and mineral deficiencies, weight loss, joint pains and skin rashes.

The survey also revealed that many patients, more than one-third (36%), had some degree of difficulty following a gluten-free diet, often due to problems finding good quality gluten-free foods and identifying whether foods were gluten-free or not from the labels.

The researchers also noted that more than one-third (36.6%) of those surveyed avoided travelling because of coeliac disease at least some of the time, and one-quarter (25.6%) never or rarely ate at restaurants.

Dr Coppell says that the situation has improved with more gluten-free options available in supermarkets and in restaurants than ever before. However these findings indicate that inadequate knowledge and processes for the manufacturing and preparation of gluten-free foods could be contributing to recurrent symptoms among those with coeliac disease.

"The continuation of symptoms is likely the result of accidental gluten consumption rather than deliberately eating gluten. Not all people may have been aware of all the hidden sources of gluten in the diet. Even though 80% of participants were referred to a dietitian upon diagnosis, not all dietitians necessarily have extensive knowledge about gluten-free diets."

This knowledge gap can be passed on to patients, making it difficult for people to accurately follow their gluten-free diets – despite their best intentions, she says.

She hopes the results of the survey will lead to improved knowledge for those with coeliac as well as individuals involved in their care, the restaurant and food industries, and the hospitality sector.

"Better quality control and awareness about gluten-free food production and preparation is needed within the food industry and the hospitality

sector. Having up-to-date, good sources of information about adopting a gluten-free diet could make a significant difference for New Zealanders with [coeliac disease](#)."

The study appears in the international journal Nutrition & Dietetics and was supported by the University's Departments of Human Nutrition and Medicine.

Provided by University of Otago

Citation: Ongoing dietary challenges for people with coeliac disease (2015, January 27) retrieved 5 July 2023 from

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