

Gluten ataxia



This information leaflet describes what gluten ataxia is, how it is diagnosed, and how it is managed.

What is gluten ataxia? [1,2]

Gluten is a protein found in wheat, barley, and rye. Ataxia is a term for a group of neurological conditions that affect balance, coordination, and speech due to problems with the brain's balance centre, the cerebellum.

Gluten ataxia is a gluten-related disorder. Gluten-related disorders are a group of autoimmune conditions triggered by eating gluten and include coeliac disease, dermatitis herpetiformis and gluten sensitivity-related neurological disorders (including gluten ataxia, gluten neuropathy and gluten encephalopathy). Autoimmune means that the body incorrectly attacks itself by producing antibodies and mobilising certain white cells in response to, in this case, gluten. In gluten ataxia, when a person ingests gluten, their body reacts by producing antibodies which attack the nervous system, e.g. the cerebellum, resulting in symptoms of ataxia.

Gluten ataxia is not an inherited type of ataxia. People with a family or personal history of autoimmune conditions may be at higher risk of developing an autoimmune condition, such as gluten ataxia.

What are the symptoms? [3]

Symptoms of gluten ataxia include:

- Gait ataxia – walking difficulties due to lack of coordination and balance problems
- Abnormal eye movements
- Poor coordination in the upper and lower limbs
- Changes in speech – slowing and slurring

Some people with gluten ataxia may also have another co-existing gluten-related disorder such as coeliac disease, dermatitis herpetiformis, gluten neuropathy and/or gluten encephalopathy. This would be identified as part of the diagnostic process.

When do symptoms start? [3]

Symptoms most commonly begin when people are in their 50s, but there are cases where symptoms start in childhood or at older ages. Symptoms tend to be of gradual onset over a period of months to years. In some very rare sub-types of gluten ataxia symptoms develop rapidly over a short period of time.

How is gluten ataxia diagnosed?

The most common route leading to diagnosis usually involves your GP identifying that you have ataxia and referring you to a local neurologist. Your neurologist may refer you to one of the Ataxia Centres in London, Oxford or Sheffield. The neurologists will investigate the possible causes of ataxia. Testing for gluten-related antibodies forms part of the screening blood tests undertaken in patients with ataxia. Notably, the Sheffield Ataxia Centre has close links with the Sheffield Institute of Gluten Related Disorders, and therefore specialist tests for gluten ataxia are more readily available at the Sheffield Ataxia Centre.

A diagnosis of gluten ataxia is usually reached when you have ataxia and a blood test result showing gluten-sensitivity.

The neurologist will ask questions and examine you. They will likely request an MRI brain scan and blood tests. Depending on the stage of the condition, MRI scan may show shrinkage (atrophy) of the cerebellum. You may also have other tests to check for other possible causes of your symptoms. In addition, you may have an MR spectroscopy, which is another type of brain imaging that concentrates on the functionality of the balance centre and can be used as a monitoring tool.

The readily available EMA (endomysial antibody) and tTG2 antibody (tissue transglutaminase-2 antibody) blood tests for coeliac disease may be positive for people with gluten ataxia if they also have coeliac disease. However, testing only for EMA and tTG2 will not detect the majority of people with gluten ataxia. Testing for anti-gliadin antibodies can detect all types of gluten sensitivity-related disorders, but these blood tests are unfortunately not readily available across the UK. Testing tTG6 antibodies is more specific to gluten sensitivity-related neurological disorders, but the test is currently only available on the NHS at the Sheffield Institute of Gluten Related Disorders [4,5,6]. If you are a patient at one of the other Ataxia Centres, there is close collaboration with the Sheffield Ataxia Centre, so such tests can be arranged to be done in Sheffield. Your Consultant neurologist may wish to contact Professor Hadjivassiliou at the Sheffield Ataxia Centre should they wish to consider testing for gluten ataxia.

If your clinician suspects gluten ataxia and you are planning on having a test for gluten ataxia it is important that you are **not** on a gluten-free diet for at least 6 weeks before you are tested, i.e. that you remain on your normal diet including foods containing gluten. This is because the antibodies in the blood that help to diagnose gluten ataxia will be reduced if you are on a gluten-free diet and therefore the diagnostic test will not be reliable.

Given the lack of healthcare professional awareness of gluten ataxia, the diagnostic process can take a long time. By raising awareness and improving understanding, the hope is that this will improve.

How common is gluten ataxia? [7]

It is one of the most common forms of sporadic idiopathic ataxia (where ataxia is found in people with no family history of ataxia and no known cause).

Management of gluten ataxia [8, 9]

It is important to treat gluten ataxia as early as possible to prevent any further damage to the cerebellum and therefore prevent permanent damage.

Gluten ataxia is treated by adopting a strict gluten-free diet. Adopting a strict gluten-free diet should cause an improvement in symptoms, but such an improvement may take between 6 months and a year to manifest. The degree of improvement with a gluten-free diet may vary depending on the stage of the condition. Referral to a dietitian is recommended to help you manage a strict gluten-free diet. It is very important to adhere strictly to the gluten-free diet to allow recovery.

Rarely, a person may be treated with medication to suppress their immune system if the strict gluten-free diet is not sufficient to improve or stabilise the disease.

Response to treatment is monitored at the Sheffield Ataxia Centre by checking levels of gluten-related antibodies (ideally aiming to see complete elimination of the antibodies) and using MR spectroscopy of the cerebellum.

Coeliac UK has useful resources to support people with a gluten-free diet. Click [here](#) for their website.

As well as other resources for people living with ataxia, Ataxia UK runs an **Autoimmune and gluten ataxia support group**. For more details, please contact Carol Bullock - email address: cbullock@ataxia.org.uk, tel number: 07906 702279. Click [here](#) for the **Ataxia UK** website.

Gluten ataxia research projects

- Ataxia UK, Coeliac UK, Neurocare (part of Sheffield Hospitals Charity) and the Greaves and Withey Foundation awarded funding to Professor Marios Hadjivassiliou, Director of the Sheffield Ataxia Centre, and colleagues for a project which aims to improve the diagnosis and management of gluten ataxia. In this study, the Sheffield Ataxia Centre is working with other neurologists throughout the UK who have clinics for people with ataxia (London, Oxford, Manchester, Romford). People who have had tests to rule out other types of ataxias and who still do not have a diagnosis of the cause of their ataxia have been referred to the Sheffield Ataxia Centre to be tested for gluten ataxia. This includes tTG6 and antigliadin antibody tests, a brain scan, and if positive for these antibodies and deemed appropriate, a gut biopsy. Those diagnosed with gluten ataxia will be advised to follow a strict gluten-free diet. They will then be followed up after one year to assess the impact of the gluten-free diet. **This study has completed recruitment, and Ataxia UK will communicate results as they become available.**

References:

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This information leaflet was written by Ataxia UK in collaboration with Professor M Hadjivassiliou, Director of the Sheffield Ataxia Centre (Ataxia UK accredited Ataxia Centre), Sheffield Teaching Hospital NHS Foundation Trust, June 2026.

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