

Gluten ataxia



Information for patients

Neurology



PROUD TO MAKE A DIFFERENCE

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST



What is ataxia?

Ataxia is the name given to a group of neurological symptoms that affect balance, coordination and speech. There are different causes of ataxia and people are affected in different ways as a result of problems in the balance centre which is situated in a part of the brain called the cerebellum.

What is gluten?

Gluten is a protein found in wheat, barley and rye. A similar protein is found in oats which some people can react to in the same way.

What is gluten ataxia?

When gluten is eaten by a person with gluten sensitivity, their own body's immune system produces antibodies. These antibodies can attack the balance centre of the brain, resulting in ataxia symptoms.

Sometimes the peripheral nerves located outside the spinal cord, which supply muscles and are also responsible for sensation, can also be affected. This can lead to a condition called peripheral neuropathy. It can result in numbness, tingling or pain in the hands and feet. However, symptoms will vary in every person.

If gluten sensitivity is the cause of the ataxia, then the only treatment for this condition is a **strict gluten free diet**. Gluten ataxia is diagnosed by checking your blood for the presence of antibodies.

Even with a very strict gluten free diet, it can take up to six months, and even as long as a year, for the antibodies to completely disappear from your body. Therefore you must stick to the gluten free diet at all times. If you do consume gluten at any time, further antibodies will be produced, resulting in more damage to the balance centre.

Other conditions that also require a strict gluten free diet are coeliac disease, a condition that affects the gut, and dermatitis herpetiformis (DH), which is a skin condition. Sometimes all these conditions can be present in the same person.

I have been diagnosed with gluten ataxia – what happens now?

If the blood tests show that you have antibodies to gluten, it is usual for us to refer you for a test called a gastroscopy and duodenal biopsy. This is a test that allows the endoscopist to look directly at the lining of the oesophagus (gullet), the stomach and around the first bend of the small intestine (the duodenum).

The gastroscope is a long flexible tube (thinner than your little finger) with a bright light on the end. **It is important that you are not on a gluten free diet when you have this test carried out.**

Using the gastroscope, we can see a picture of the lining of your stomach on a monitor. A biopsy is taken from the first part of the small bowel and this is examined for any evidence of inflammation (seen in coeliac disease). Not everyone who has gluten ataxia will also have inflammation of the bowel.

When we have your results we will let you know either in clinic or by letter. If a gluten free diet is recommended, we will refer you to be seen by a dietitian in your local area.

Once you have seen the dietitian you can start the gluten free diet.

It is very important that you are 100% strict with the diet.

What is a gluten free diet?

A gluten free diet is one where you must avoid all sources of gluten in your diet. This means avoiding any food product that contains wheat, rye and barley.

How will the effect of the diet be monitored?

When you have been on the gluten free diet for six months you will have your antibody profile checked. This is done by having a blood test. This will tell us if things are going well. It takes this length of time for the antibodies to be eliminated from the system. Any gluten that is eaten will result in antibodies being produced and therefore further damage to the balance centre.

After about a year you may have a brain scan to monitor how your balance centre is working.

Will my ataxia get better on the gluten free diet?

The aim of the diet is to prevent further damage to the balance centre, stabilise the disease process and prevent further progression of the ataxia symptoms. Some people find that their symptoms improve, whilst for others this is not quite so obvious. We rely on you to tell us how you feel things are going. By repeating the blood tests and checking that the antibodies have disappeared, along with the brain scan results, we will be in a position to assess the situation and discuss this with you.

Whilst we recognise that going gluten free is not easy, this is the only treatment for this condition. Most people adjust over time and there are organisations that can help along the way. We are keen to support you as much as possible. If you are struggling or have any questions let us know.

Where can I find out more about the diet?

Coeliac UK

Coeliac UK is a charity that provides important information for people who need to follow a gluten free diet. It was founded for people who have been diagnosed with Coeliac disease but they allow membership for anyone who potentially can benefit from a gluten free diet or who wants to learn more about gluten related conditions.

Membership is £24 per year. Concessionary membership is available for those on a reduced income. On joining you will receive:

- A welcome pack providing everything you need to know about following a gluten free diet, with details of your nearest voluntary support group which runs events and activities.
- Their annual 'Food and Drink Directory' listing gluten free foods and ingredients. An electronic version is also available which can also be used on your mobile phone.
- Their gluten free consumer magazine 'Crossed Grain' three times a year.
- Free copies of their information leaflets.
- Access to the members section of their website which has a venue guide, recipe database and further cooking and shopping hints.
- If requested, a monthly electronic newsletter eXG and you can download an app 'Gluten-free on the move'.

Please get in touch with Coeliac UK for details.

- **0333 332 2033** (Helpline)
- **01494 437 278**
- www.coeliac.org.uk

Ataxia UK

Ataxia UK is the national charity for everyone affected by ataxia. Membership is free. In addition to offering a range of support services, they fund research into treatments, organise conferences and produce a newsletter to keep you updated about all issues to do with ataxia.

For more information you can contact Ataxia UK as follows:

- **0800 995 6037** (Helpline)
- **0207 582 1444**
- www.ataxia.org.uk



To help support your local hospitals visit
sheffieldhospitalscharity.org.uk

Registered Charity No. 1165762



**Alternative formats can be available on request.
Please email: sth.alternativeformats@nhs.net**

© Sheffield Teaching Hospitals NHS Foundation Trust 2021

Re-use of all or any part of this document is governed by copyright and the "Re-use of Public Sector Information Regulations 2005" SI 2005 No. 1515. Information on re-use can be obtained from the Information Governance Department, Sheffield Teaching Hospitals. Email sth.infogov@nhs.net