

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 then you will be advised to commence onto a gluten free diet. You will have an appointment with the ataxia specialist nurses to review your symptoms and provide education on the diet. You will then also be referred onto a dietitian in your local area to help you with 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**. We also advise that you only consume gluten free oats. Whilst oats do not contain gluten, during the milling process they are contaminated with gluten. Gluten free options are available which have been manufactured separately to wheat, barley and rye.

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 at the Sheffield Ataxia Centre. 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. We will also review your symptoms and how you are.

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 as little as £1.24 per month. 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.
- Discounts and offers to help you with the gluten free diet.
- 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



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