



WHAT IS ATAXIA ?

A neurological and progressive condition that is life changing for the patient. There are many different types of ataxia but they all fall into roughly 4 main categories.

- Autoimmune that is caused by the immune system going awry and attacking the cerebellum.
- Genetic/hereditary where the genes passed on through the generations cause ataxia.
- Acquired ataxia is caused by medications, toxins, alcohol abuse, accidents and damage to the cerebellum, or as a result of another disease or condition.
- Idiopathic means doctors simply do not know what has caused it.

Please see pages on Research for more information.

For the purpose of this website we are mostly interested in the autoimmune reaction from ingesting gluten and causing damage to the cerebellum.

In the UK it can take several years, and often does, to get to a final diagnosis of Gluten Ataxia. There are other autoimmune ataxias such as PACA but Gluten Ataxia is the most common type.

To date, January 2025, firstly one will have a diagnosis of Ataxia of unknown type and then referral to The Sheffield Hallamshire hospital specialist Ataxia Clinic for a further diagnosis of possibly Gluten Ataxia.

Doctors at primary care level know little about GA, in fact throughout their working life they are unlikely to see a patient with GA. Even neurologists at hospitals outside of Sheffield are unlikely to be familiar or diagnosis it. The MRI spectroscopy is only available at Sheffield and the TG6 blood test too (transglutaminase) as well as screening for autoimmune and other forms of ataxia, is only available at this specialist clinic. The clinic will also pick up other forms of ataxia for those that are not autoimmune related.

It is a good idea to have all your tests, findings and appropriate dates written down and take with you to medical appointments to save time and be consistent. Also it is worth talking about the link to Coeliac Disease which is an autoimmune condition that your doctors will have seen before in other patients. The explanation of the autoimmune reaction from eating gluten takes place in the brain's cerebellum and not in the digestive system as with coeliacs, I have found to be a way to describe GA to doctors with little knowledge.

Another idea is to put together an information pack on GA to show at medical appointments. It may start up an interesting conversation and so bring awareness to GA.

Remember TIME IS CRITICAL with a diagnosis for Gluten Ataxia, to stop eating gluten, go gluten free and switch off the autoimmune reaction, before irreparable damage is done to the cerebellum.

It is further complicated by the fact that we are all different and can have different symptoms. With the start of symptoms at the beginning of ataxia it is hard to differentiate between what type of ataxia it is. Added to that is the outdated thinking of some neurologists who don't believe that gluten and an autoimmune reaction and the consequent damage to the cerebellum can cause ataxia. That leaves us sufferers in a difficult situation with a dilemma.

Do we try a Gluten Free diet or wait until tests prove positive?

It is up to you! Some will self-diagnose with a Gluten Free diet and wait to see if the symptoms subside. It could be a long wait 6 to 12 months or more. While others will accept medical opinions and carry on eating gluten until they are tested. The antibodies need to be circulating in the blood for the TG6 test. Or we can always take the option of going Gluten Free and then taking the 6 week Gluten Challenge. The choice is yours? (ref to [GLUTEN PAGE](#))

Getting a full diagnosis can and is usually, a lengthy process. This journey leaves us and our families stressed and drained.

The early symptoms of Gluten Ataxia are commonly:

- Poor balance and walking problems
- Fatigue and feeling tired all the time
- Painful, stiff and aching legs or/hands
- Peripheral neuropathy, pain and tingling sensations in feet and hands
- Speech problems and difficulty getting words 'out'
- Dizziness
- You may or may not have digestive issues.

The list is long and we are all different with different symptoms. You may be experiencing only a couple of the symptoms early on with the condition, and there will be different degrees of how they affect you. The above list is not definitive.

In the UK there are 3 specialist Ataxia Clinics:

- The Sheffield Hallamshire Hospital run by Professor Hadjivassiliou and his team.
- UCLH Neurology run by Professor Guinti and her team.
- The Oxford Ataxia Clinic.

That does not mean to say that other hospital neurologists are not up to date with recent research and findings, but my experience is that these are few and far between.

To some extent we are lucky to have gluten causing our ataxia because when it is removed and strictly adhered to with a Gluten Free diet then it can stabilise or even reverse some of the symptoms.

Those with a genetic type of ataxia are hoping and relying on the scientists to come up with answers to stop the progression.

Do research, read what you can and take your health seriously!

(See the RESEARCH page for more information)

Disclaimer

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