



**ATAXIA**

What is ataxia?

A brief introduction



**ATAXIA**

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This leaflet is intended as a brief introduction to ataxia, and to answer some of the main questions you may have:

- If you have been diagnosed with ataxia
- If you are caring for someone with ataxia
- If you are a parent, relative or friend of someone with ataxia

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## Feedback

We always strive to ensure our publications are of the highest quality; your feedback helps us do this. Please contact [office@ataxia.org.uk](mailto:office@ataxia.org.uk) if you have any comments or suggestions.

## Disclaimer

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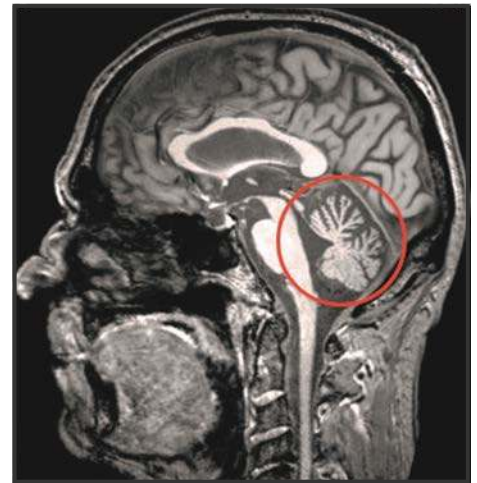
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# What is ataxia?

Ataxia means ‘lack of order’ and is used by doctors to describe problems with balance and coordination. In some cases, people get the symptoms of ataxia for short periods of time and then recover. However, the conditions covered in this leaflet are mostly those in which ataxia is permanent and, in many cases, progressive (i.e. the symptoms get worse with time).

There are many different types of ataxia and more than 10,000 people in the UK have been diagnosed with a type of progressive ataxia.

For more information on the specific types of ataxia please contact the Ataxia UK Helpline on 0800 995 6037



Magnetic resonance imaging (MRI) scan of the brain. The cerebellum (circled) is the organ responsible for coordination and is affected in all the ataxias.

## Causes and symptoms

Some people will inherit ataxia via specific genes that have come from one or both parents. Others can develop ataxia as a result of damage to the brain, for example from a stroke, tumour, viral infection or head injury. Some individuals also develop ataxia due to exposure to alcohol over long periods of time. In many people discovering the cause of ataxia is complicated and involves doing a number of tests and scans.

Sometimes it is not possible to find the cause of ataxia.

People with ataxia have problems with coordination and balance. Often people first notice a problem when they realise they have been falling over more or struggling to walk in a straight line or they may notice that they have become more clumsy.

Other symptoms that can be experienced by people with ataxia include:

- Slurred speech
- Problems with swallowing which can cause you to choke or cough
- Tremors or shaking, often of the hands
- Fatigue or tiredness
- Problems with sight, blurred or jumpy vision due to difficulty controlling eye movements

Ataxia affects people in different ways. Some people are affected very mildly, for example they only experience slight balance problems, while other people experience symptoms more severely and require assistance to carry out everyday living tasks.

Many people with the condition continue to lead full and active lives, attending school, further education and training; working, bringing up families and travelling.

## Diagnosis and treatment

It is sometimes difficult to get a diagnosis of the specific type of ataxia you have as there are many different conditions that cause the symptoms. Some people may have inherited the condition. Others go on to develop ataxia later in life. A neurologist can do many tests and in some cases you may get referred to a Specialist Ataxia Centre for additional tests if necessary.

### What investigations might help me to get a diagnosis?

A neurologist may need to do extensive tests to diagnose the type of ataxia you have. Tests include:

#### Patient history

This helps identify whether the ataxia is caused by something specific, for example, by the amount of alcohol intake.

#### Family history

Ataxia may sometimes be due to being born with a genetic variation not previously found in your family. However, taking a medical history of your family can help to determine whether the ataxia has been inherited.

Even if no-one else in the family is affected this does not necessarily mean that ataxia is not inherited. In some ataxias you need two variant genes to develop the condition (eg in Friedreich's ataxia). This means that parents may not have developed any symptoms because they are carriers of only one variant gene.

Doctors may test for inherited ataxias; this is called genetic testing.

#### Brain scans

Magnetic resonance imaging (MRI) brain scans give an image of the cerebellum and other parts of the brain that can show whether they are affected. Sometimes an additional specialised scan — called MR spectroscopy—can tell us more about how the balance centre is working.

#### Other laboratory tests

A range of blood tests can be done to look for the cause of ataxia including specific tests for gluten sensitivity or Vitamin E deficiency, as well as other unusual causes of ataxia.

### Are there any treatments for ataxia?

Some types of ataxia are treatable, which makes it very important to try to find a cause if possible. You can ask your GP or neurologist to refer you to a Specialist Ataxia Centre if you think this might be helpful as they can sometimes look into things more deeply for you. Guidelines for the diagnosis and management of progressive ataxias have been published by Ataxia UK and it may be helpful to provide your doctor with a copy. These are available from the Ataxia UK office.

Sometimes doctors are unable to find a cause for the ataxia but can try and help with some of the symptoms. 8

# Frequently asked questions

## Who gets ataxia?

Ataxia can affect anyone at any age depending on the cause.

## How quickly will my ataxia progress?

The speed at which ataxia progresses varies between different types of ataxia and between individuals but it is usually slow and changes take place over many years. The age at which symptoms begin also varies between the types of ataxia, as some tend to start in childhood and others later on in life.

There are some types of ataxia that are not progressive.

It is important to note that there are very large variations in the severity of the symptoms. Some people are affected very mildly; for example, they experience slight balance problems, while others will need assistance.

Everyone experiences ataxia differently, and this includes their symptoms and the speed of change.

## Can anything help in living with ataxia?

Although there is currently no cure for the ataxias there are a number of treatments available to help with some of the symptoms. For example, medication is available to help with muscle spasms or tremors.

You can ask your doctor about other services that may help:

Physiotherapy and exercise such as swimming may prevent loss of strength and preserve mobility. Neurophysiotherapists are usually familiar with the problems that you may have.

Speech therapy can help with problems involving speech, swallowing, coughing and choking if needed. Speech therapists can also advise on the best communication aids and computer programmes to use.

Occupational therapy can be helpful for home adaptations and advice on techniques to assist daily living activities.

## Can I meet other people with ataxia?

Many people with ataxia say that it helps to meet other people with the condition, and realise they are not alone in what they are going through. Ataxia UK's network of local Branches and support groups help by running events, trips out, fun activities and chances to meet up and socialise. People also keep in touch via our online community with Health Unlocked at <http://ataxia-uk.healthunlocked.com> or the virtual support group, Virtual Ataxia.

Ataxia UK Helpline may answer any other questions you may have: [helpline@ataxia.org.uk](mailto:helpline@ataxia.org.uk)

# Ataxia UK and research

Ataxia UK is a national charity for everyone in the UK who is affected by ataxia. In addition to offering a range of support services we fund research into treatments, and are striving for a cure for the ataxias. We also support the opening of a number of Specialist Ataxia Centres around the UK for the diagnosis and management of ataxia. Based within the Centres are specialist neurologists and nurses who have expertise in ataxia investigation and symptom control.

## What research is being carried out?

Ataxia UK is committed to finding treatments and a cure for ataxia and therefore funds research projects throughout the world, including the UK, for many types of ataxia. This is our **2020 Vision** – our goal to find a cure for this generation.



You can find more about the latest research on Ataxia UK's website and in the quarterly Ataxia magazine which is available free of charge to those who become Friends of Ataxia UK.

## Further information

Ataxia UK produces a longer booklet about ataxia as well as a range of factsheets. See the website for details and downloads: [www.ataxia.org.uk/pages/information-publications.html](http://www.ataxia.org.uk/pages/information-publications.html)

You can contact Ataxia UK on 0800 995 6037 or [helpline@ataxia.org.uk](mailto:helpline@ataxia.org.uk) to ask any questions you have, obtain more information, or become a Friend, free of charge.

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