ATAXIA

Ataxia UK

ataxia: **what's that?**

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There are many different types of ataxia that affect people in a variety of ways. This booklet gives a general introduction to ataxia. There are also separate factsheets available for specific types of ataxia, including Friedreich's ataxia, gluten ataxia, episodic ataxia and some of the spinocerebellar ataxias. Contact Ataxia UK for free copies of the factsheets, or for more information on any of the topics in this booklet.

If you have any questions or concerns once you've read this booklet, please get in touch with our helpline using the contact details on the back cover.

From left to right:
Steph, Peter, Sam & Nigel

Disclaimer

We have made every effort to ensure that the information in this booklet is up-to-date, unbiased and accurate. We hope that this will complement any professional advice you receive. Please do continue to talk to your health and social care team, or contact our helpline if you are worried about any aspect of living with ataxia.

The medical sections of this booklet have been reviewed by ataxia-expert neurologists, Dr Paola Giunti (National Hospital for Neurology and Neurosurgery, London) and Dr Rajith de Silva (Queen's Hospital, Romford). We have also received input from a number of people who have ataxia.

ATAXIA

Ataxia UK

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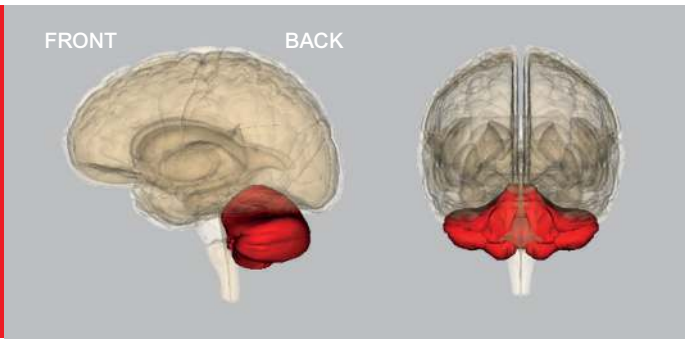
What is ataxia?

Ataxia UK

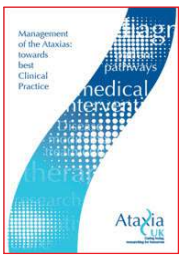
Ataxia means 'lack of order' and is used by doctors to describe problems with balance and coordination. In some cases, people get the symptoms of ataxia for short periods of time and then recover. However, the conditions covered in this booklet are mostly those in which the ataxia is permanent and, in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

Many types of ataxia are described as **cerebellar ataxias**. 'Cerebellar' means anything to do with the cerebellum, a part of the brain controlling movement and coordination. There are many different types of cerebellar ataxia and, often, they are hereditary. As a result, some types have been found in only a few families in specific countries, while others are more common and are found throughout the world. Some types of ataxia are not hereditary. There are well over 10,000 people in the UK who have a type of ataxia, so even though it is rare, it is not as rare as you might think.

The cerebellum *(illustrated in red)* is a part of the brain that controls movement and coordination. It is located at the base of the brain at the back, and at the top of the spinal cord.



You may find that many people, even some doctors, have never heard of specific types of ataxia, so it could be helpful to give them a copy of this booklet. You could also give your doctor a copy of Ataxia UK's guide for health professionals which is called ***Management of the ataxias: towards best clinical practice*** *(or the summary for GPs). Both publications are available free of charge from Ataxia UK (****www.ataxia.org.uk****)*



Who gets ataxia?

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

What causes ataxia?

Some people inherit ataxia via specific genes that have come from one or both parents. Some develop ataxia due, for example, to vitamin deficiencies, degeneration of the balance centre or prolonged exposure to high levels of alcohol. Others can develop ataxia as a result of damage to the brain, for example from a stroke, tumour, viral infection or head injury. In many people, discovering the cause of ataxia is complicated and involves a number of tests and scans. Sometimes it is not possible to find the cause of ataxia.

Is there a link between ataxia and other conditions?

Ataxia can also be a feature of other conditions, such as multiple sclerosis and cerebral palsy. However, most of Ataxia UK's services and information are only relevant for the group of progressive cerebellar ataxias. If you want to find out more about these conditions you may find it particularly helpful to get in touch with the organisation for the specific condition concerned.

Web: **www.mssociety.org.uk**
Tel: **0808 800 8000**
Web: **www.scope.org.uk**
Tel: **0808 800 3333**

What symptoms are experienced by people with ataxia?

People with ataxia have problems with coordination and balance. Often people first notice a problem when they realise they've been falling over more than usual, struggling to walk in a straight line or have become more clumsy. As the condition progresses walking may become difficult or even impossible, so people may need to use a wheelchair to get about some or all of the time.

Other common symptoms experienced by people with ataxia include:

- Slurred speech (also called **dysarthria**)
- Problems with swallowing which can cause choking or coughing
- Tremors or shaking, often of the hands
- Fatigue or tiredness
- Problems with sight, or blurred or jumpy vision due to difficulty controlling eye movements

Specific types of ataxia may also cause other symptoms, for example Friedreich's ataxia can sometimes be associated with heart problems (**cardiomyopathy**), diabetes or curvature of the spine (**scoliosis**).

In most people with ataxia, the ability to think and understand is not affected. However, there are emotional aspects of coming to terms with ataxia and these can vary from person to person. People with ataxia can experience mood disorders, such as depression, which are treatable. Some specific types of ataxia do affect mental function, but these are rarer forms.

Ataxia affects people in different ways. Some people are affected very mildly, for example they only experience slight balance problems and may walk using a stick. Other people experience symptoms more severely and require assistance from carers to carry out everyday living tasks. Although ataxia can affect people significantly, many people with the condition lead full and active lives, attending school, further education and training, working, bringing up families and travelling the world.

Does ataxia change with time?

Most types of ataxia covered in this booklet are known as **progressive**, which means they gradually get worse with time. How quickly this happens depends on the type and cause of ataxia, and on individual factors too. Ataxia usually progresses slowly, with changes taking place over many years, although this does depend on the person. Everyone experiences ataxia differently, and this includes their symptoms.

In some types of ataxia that are inherited, people carry the gene for ataxia but do not develop symptoms for many years. As a very rough guide, the earlier the ataxia starts generally the faster it progresses, but it is not possible to predict what will happen in a particular case. We need more research to find the answers to these questions.

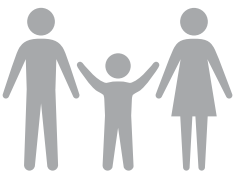
Some types of ataxia are not progressive. For example, disorders that involve malformations of the cerebellum that occurred before birth are usually non-progressive. When children get ataxia as a result of viruses, such as chickenpox, a full recovery generally occurs within a few months. People who get ataxia as a result of a stroke or multiple sclerosis can also make an almost full recovery from the ataxia symptoms. Ataxia due to traumatic brain injury is usually non-progressive. However, patients with ataxia due to brain tumours may either have a progressive condition or a non-progressive condition (once the tumour has been removed).

How is ataxia diagnosed?

It is sometimes difficult to get a diagnosis of the specific type of ataxia, as there are many different conditions that can seem very similar. A neurologist may need to do extensive tests to find out exactly what a patient has and this can take time. Investigations include:

Patient history: This usually involves your doctor asking you questions to help identify whether the ataxia is caused, for example, by a tumour or alcohol poisoning.

Brain scans: Magnetic resonance imaging (MRI) brain scans can give an image of the cerebellum and other parts of the brain that show whether they are damaged. The scans can sometimes be used to distinguish between multiple sclerosis and ataxia.



Family history: This helps to determine whether the patient has an inherited type of ataxia. If their parents and grandparents also have/had ataxia then it is likely that the patient has an autosomal dominant inherited ataxia (see page 15). If the parents are not (or were not) affected but more than one child has ataxia, it suggests that the condition is inherited recessively (see page 17). Even if no one else in

the family is affected, this does not necessarily mean that the ataxia is not inherited.

Genetic tests: These are available for some types of inherited ataxia and involve taking a blood sample. If the result is positive, then it can generally be considered a definite diagnosis. If the results are negative for all these tests, this may mean that it is a type of inherited ataxia for which the gene has not been found, or that a test is not yet available. Sometimes your blood sample may be stored for a long time so that if there are advances in research and new tests become available, further tests can be done.

Other laboratory tests: These may include testing for vitamin E levels in the blood or to see whether a patient has a genetic condition such as abetalipoproteinemia or familial isolated vitamin E deficiency. People with these conditions have low levels of vitamin E, and this can be treated with vitamin E supplements and a specialised diet. Another rare inherited condition that can be treated is Wilson's disease, which can be diagnosed by blood tests for copper and a protein that's called caeruloplasmin.

Pre-symptomatic genetic testing

If you are a close relative of someone with a known inherited ataxia and you do not show any signs of ataxia, it is possible to have a genetic test for yourself. The chance of developing ataxia or being a carrier depends on how the ataxia is inherited (as described above).

The decision to have a test or not is a very personal one and can be a difficult one to make. Some people prefer to have all possible information in advance, in order to plan for the future. Others may prefer not to know unless there is a cure. Test results can have a range of long-term consequences, affecting everything from whether or not to have a family to the ability to get insurance. Support in making this decision is available from clinical geneticists, who are experienced in talking to people about these issues. Tests are only generally available for adults (ie. people over 18 years old), but this may vary depending on individual circumstances. For more specific advice talk to your doctor.

Genetic counselling

The results of a genetic test can bring up some difficult questions and concerns about the future, so it is often useful to see a genetic counsellor or clinical geneticist before testing goes ahead, to talk about what the potential results might mean. For example, some types of ataxia have specific characteristics that make them distinguishable from others, eg. SCA7, which causes retinal degeneration leading to failing eyesight. If the neurologist suspects it is an inherited condition, they may make a referral for genetic counselling. This provides an opportunity to discuss what a diagnosis could mean for the person with ataxia and their family.

A doctor or neurologist can arrange a referral to a regional genetic centre (where genetic services are available) to explain the tests and the implications of the test results. Specialist Ataxia Centres also offer genetic counselling to their patients. For a full list of regional genetic centres in the UK contact the **Genetic Alliance**.

Web: **www.geneticalliance.org.uk/services.htm**
Tel: **020 7704 3141**

Are there any treatments for ataxia?

Some types of ataxia are treatable, which makes it so important for people to get a specific diagnosis of the type of ataxia they have.

If the diagnosis is of ataxia with vitamin E deficiency (otherwise known as familial isolated vitamin E deficiency) or of abetalipoproteinemia, these can be treated with vitamin E supplements and a specialised diet. Wilson's disease can be treated with zinc, or with a medication that helps to remove copper from the body. There are a number of other rare conditions, especially diagnosed in children, which are normally associated with deficiencies and are also treatable. Tests to diagnose these conditions should be carried out routinely.
The newly recognised disorder called 'cerebellar ataxia with coenzyme Q_{10} deficiency' may be treated with coenzyme Q_{10} supplements, and gluten ataxia may be treated with a gluten-free diet. Not all of these tests are appropriate for everyone, but this can be discussed with the doctor or neurologist.

What about a cure?

"Hearing about the latest research news always fills me with hope that we will one day have a cure."

At the moment there is no known cure for most types of ataxia. However, there are a number of clinical trials ongoing and these may result in treatments. In particular, there are many trials taking place testing medications for Friedreich's ataxia. There is also some evidence of benefit from vitamin E and coenzyme Q_{10} in Friedreich's ataxia (contact Ataxia UK for information).

In addition, although there may not be a cure, there are many ways to help people manage with some of the symptoms they experience (see page 22 onwards in this booklet for advice on living with ataxia).

Ataxia UK is committed to funding research into treatments and cures for ataxia. In addition to the research projects we fund, research into treatments for many types of ataxia is taking place throughout the world, including in the UK.

A lot of progress is being made in finding new genes causing ataxia, which will result in more people getting a specific diagnosis. There are also many promising new treatments that are being tested either in animal models of ataxia or in human trials, and may in the future be available to patients.

Find out more about the latest research on Ataxia UK's website and in our quarterly magazine ***the Ataxian***, available to Friends (our members).

Types of ataxia

"It's so good to meet other people, through Ataxia UK, with the same type of condition. It makes you realise you aren't alone."

Some types of ataxia are inherited (meaning they are caused by genes passed on by parents to their children) and some are not. When ataxia is not inherited there can be a number of different causes. The various types of ataxia are explained over the following pages.

Most of our individual characteristics - for example, the way we look and the way we grow and develop - are strongly influenced by genetic inheritance from our parents. Genes provide the instructions for making proteins, and proteins are fundamental to the essential processes that take place within the cells of every living organism. The majority of genes are located within the nucleus of each cell.

For most genes, each person inherits two copies of the gene: one copy from their mother and the second copy from their father.

Genes can be altered by a process called mutation, which is a source of human diversity. However, this process can sometimes lead to genes becoming faulty. The inherited types of ataxia are caused by faulty genes.

Different types of inherited ataxia are generally caused by changes in specific genes. These faulty genes are passed from parents to children through the generations in a number of different ways.

Inherited ataxia

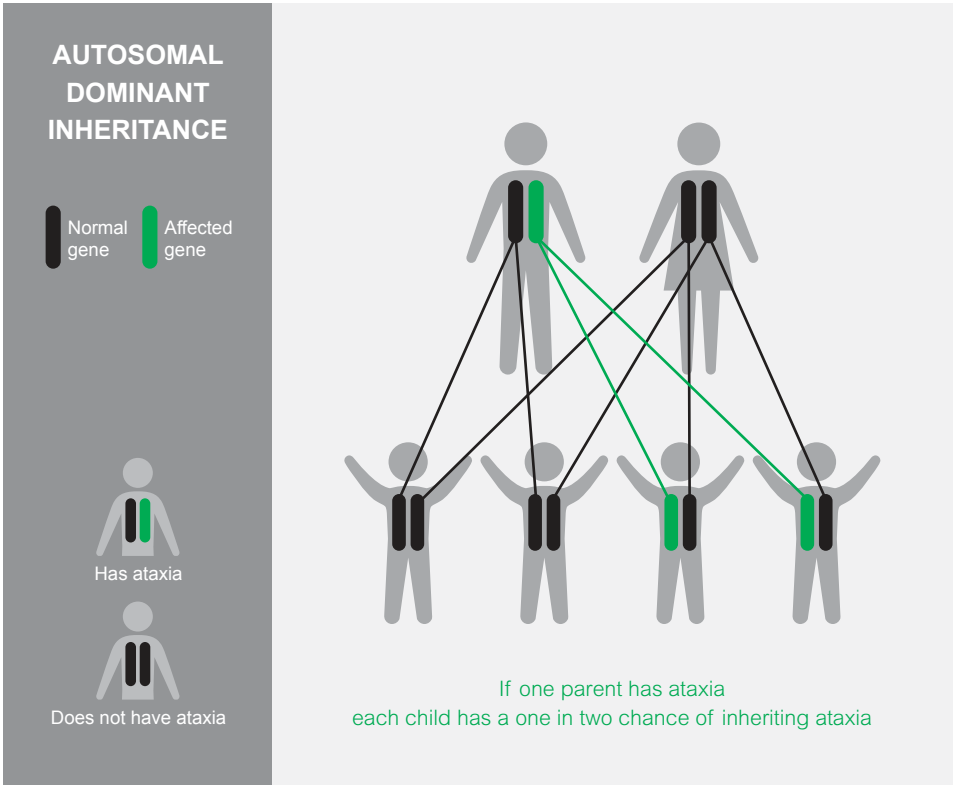
The inherited types of ataxia involve a fault in a gene or genes, which may then be passed on through the generations. They can be divided into four groups, depending on how they are inherited. These are:

- **Autosomal dominant:** meaning that the condition develops after a faulty gene is inherited from one parent only
- **Autosomal recessive:** meaning the condition is only passed on by receiving the faulty gene from both parents
- **Mitochondrial:** meaning you inherit ataxia from the maternal (mother's) line
- **X-linked:** in rare cases, ataxia can result from faulty genes that reside in the X chromosome, and in these cases either just men are affected, or men are more severely affected than women.

Autosomal dominant inheritance

In this case ataxia is caused by having one copy of the faulty gene, inherited from only one parent. In ataxia of this kind there is a one in two chance of passing the ataxia on to each child. A genetic counsellor or clinical geneticist can explain this further and discuss the implications of having children.

In some types of inherited cerebellar ataxia of autosomal dominant type, the condition becomes more severe as it gets passed down the generations, and the age of symptom onset gets younger. This is called **anticipation**.



Types of ataxia inherited in an autosomal dominant way include:

Spinocerebellar ataxia

Several spinocerebellar ataxias (also called SCAs) have been identified, all of which are caused by faults in different genes. As each gene is found, it's given a number; for example SCA1, SCA2, SCA3 and so on. Although each type is caused by a different gene, the SCAs are often very alike and sometimes it is only possible to tell the difference between them by doing genetic tests.

At present, we know of around 30 different SCAs. Genetic tests are not yet available for all of them. Specific tests are available for 21 SCAs, but only some of these are available routinely. Tests that should be routinely available include: SCAs 1, 2, 3, 6, 7, 12, and 17. In some cases, depending on individual factors and ethnic group, DRPLA is available too. A new technique known as 'next-generation sequencing' may make testing for a wider range of SCAs more accessible.

Factsheets are available for some SCAs from Ataxia UK and further information can also be found in ***Management of the Ataxias: towards best clinical practice*** for medical professionals.

Dentatorubral-pallidoluysian atrophy (DRPLA)

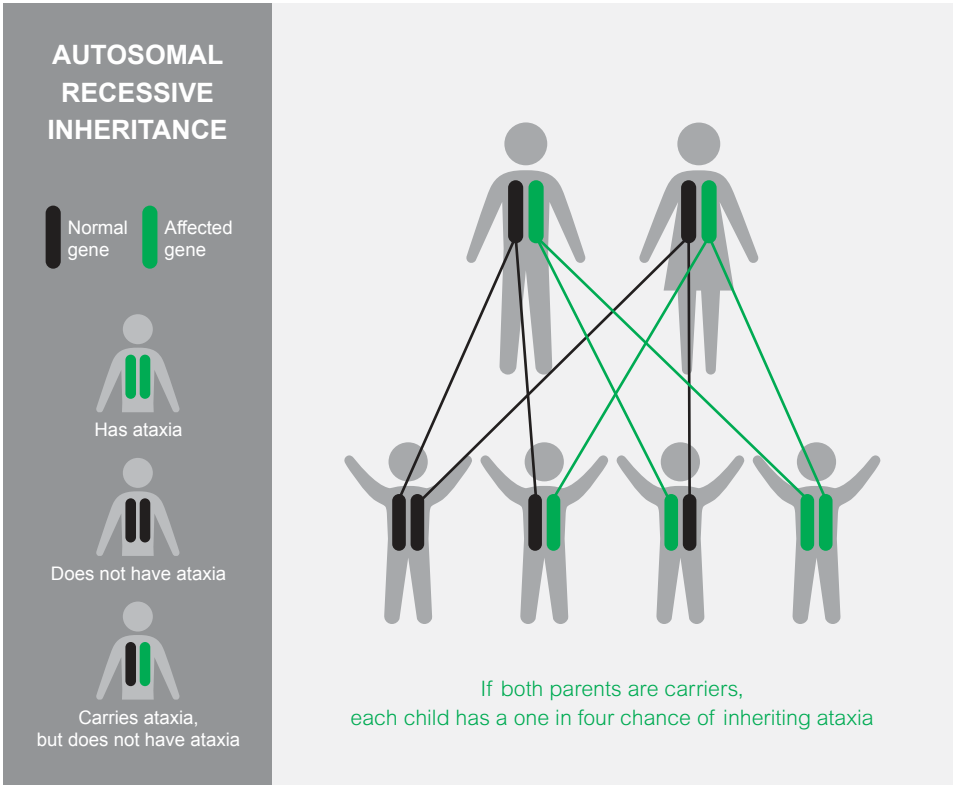
DRPLA has some similarities with Huntington's, another neurological condition. Symptoms of DRPLA include sudden muscle spasms and epilepsy. A factsheet is available from Ataxia UK.

Episodic ataxia type 1 (EA-1)

EA-1 is different from most other types of ataxia, because it involves short attacks in which people lose coordination and may slur their speech, generally for several minutes. EA-1 is usually not progressive, meaning it does not tend to get worse, except in some older people. Attacks sometimes happen spontaneously with no obvious cause, they can be triggered by a sudden shock or movement or by being tired, anxious or stressed.

Episodic ataxia type 2 (EA-2)

In EA-2, attacks of ataxia can last for hours or even days. The medication **acetazolamide** may prevent or lessen the attacks (or episodes) but the use of any medicines must always be discussed with a doctor. As stress often triggers attacks, stress management techniques may also help. EA-2 is caused by a mutation affecting the same gene as in SCA6 (which has a different type of mutation). This is also the gene involved in a form of inherited migraine, called familial hemiplegic migraine. There can be some progression in the symptoms of EA-2 over time.



Autosomal recessive inheritance

In these cases, ataxia is caused by having two copies of a faulty gene, one inherited from each parent. In other words, a child can be born with ataxia of this kind if both parents have one faulty copy of the gene. This means the parents are **carriers** of ataxia, although they don't have ataxia themselves.

If two parents are carriers there is a one in four chance of them having a child with ataxia, and there is a one in two chance of having a child who does not have ataxia but who also carries the faulty gene. If the child is a carrier, they may pass it on to their own children. There is also a one in four chance that a child will neither have ataxia nor be a carrier.

In this situation a clinical geneticist can advise on how these genes are inherited and the implications for other family members.

Ataxias passed on via autosomal recessive inheritance include:

Ataxia-telangiectasia

This is a type of ataxia that causes other symptoms and has its own charity, **The A-T Society**.

Web: **www.atsociety.org.uk**
Tel: **01582 760 733**

Friedreich's ataxia

Friedreich's ataxia (FA) is the most common type of inherited ataxia, mostly affecting children and teenagers; on average, the symptoms start at around the age of 15. Ataxia UK has produced a separate factsheet called 'Information on Friedreich's ataxia'.

Other recessively inherited ataxias

There are around 30 other types of ataxia inherited in an autosomal recessive way, some of which are only known to affect a few families worldwide. Some of the more well-known ones are listed here:

- Ataxia with oculomotor apraxia types 1 or 2 (known as **AOA1** and **AOA2**)
- Ataxia with familial isolated vitamin E deficiency
- Abetalipoproteinemia
- Cerebellar ataxia with muscle coenzyme Q_{10} deficiency
- Early-onset cerebellar ataxia with retained tendon reflexes
- Infantile onset spinocerebellar ataxia
- Marinesco-Sjogren syndrome
- Autosomal recessive spastic ataxia of Charlevoix-Saguenay (known as **ARSACS**)

Mitochondrial conditions

These types of ataxia involve changes (or **mutations**) in the genes that code for proteins in mitochondria, the energy-producing compartments of cells. As each person inherits their mitochondria and mitochondrial genes from their mother, this type of condition can only be passed down the maternal line, ie. from the mother. Women who have such a condition are at risk of passing it on to their children (male or female).

Most of the genes found in the mitochondria are involved in the production of energy, so generally mitochondrial disorders are caused because cells can't produce enough energy, which prevents them from carrying out their normal functions. As muscles and the brain need a lot of energy to function, they are the most likely parts of the body to be affected by mitochondrial disorders. Some mitochondrial disorders have ataxia as a main symptom.

Examples of mitochondrial ataxia conditions are:

- mitochondrial encephalomyopathy, lactic acidosis with stroke-like episodes (**MELAS**)
- myoclonic epilepsy with ragged red fibres (**MERRF**)
- neuropathy, ataxia, and retinitis pigmentosa (**NARP**)

X-linked inherited ataxias

Every cell in the body has 23 pairs of chromosomes - long stretches of DNA containing many genes. In humans, gender is decided by one of these pairs, known as the X and Y chromosomes. While women have two X chromosomes, men have one X and one Y. This can mean that some conditions with faulty genes on the X chromosome are more likely to affect men (and on the rare occasions that females are affected, it is generally much more mildly than in men). Females can be carriers of a faulty X chromosome gene, and pass on a condition to their sons. Haemophilia is an example of a condition that is inherited in this way, and some forms of ataxia can also be X-linked.

Non-inherited cerebellar ataxias

Some people who have ataxia have no history of ataxia in the family. However, they may still have a type of ataxia that can be inherited. It could be that they are the first member of the family to have developed a mutation in a gene causing an inherited ataxia or their parents may have passed away before developing signs of ataxia. Alternatively, they may have a non-inherited form of ataxia.

If the ataxia is not inherited it is sometimes called **sporadic cerebellar ataxia**, and if the cause of the ataxia is not known it is sometimes called **idiopathic cerebellar ataxia**. For example, a number of people are diagnosed as having idiopathic late-onset cerebellar ataxia, which means that the condition occurs later on in life and its cause is unknown. People can be diagnosed with this if there is lack of evidence of a genetic or other cause. It often progresses slowly and has few additional symptoms.

Examples of non-inherited ataxia include:

Multiple system atrophy with cerebellar features (MSA-C)

This is a condition that occurs later on in life. It is a progressive cerebellar ataxia and has its own support charity, **Multiple System Atrophy Trust**.

Web: **www.msatrust.org.uk**
Tel: **020 7940 4666**

Gluten ataxia

Researchers have found that some people with idiopathic ataxia have sensitivity to gluten (protein found in grains such as wheat and barley). This may be the cause of their ataxia, and a recent trial has shown that a gluten-free diet may be helpful. Before making any change in diet, a specific diagnosis of gluten ataxia is necessary. For more information contact your doctor or neurologist.

Ataxia due to cerebellar malformations

Ataxia can also be caused if the cerebellum (a part of the brain, see page 5) is not formed properly. This usually occurs before a baby is born.

The symptoms start in childhood and are normally non-progressive. There are many different types of this condition, some inherited and some caused by external factors.

Examples of cerebellar malformations are the Dandy-Walker malformation and Arnold-Chiari malformation. For more information contact **Shine** (formerly the Association for Spina Bifida and Hydrocephalus).

Web: **www.shinecharity.org.uk**
Tel: **01733 555 988**

Living with ataxia

In this section you will find information on the practical aspects of day-to-day living with ataxia. There are many different ways to improve quality of life when living with ataxia.

What can help in living with ataxia?

Although there is currently no cure for ataxia, there are a number of treatments available to help with the symptoms people experience. Medications are available, for example, for muscle spasms, tremors, bladder problems, abnormal eye movements and depression. Cardiac problems seen in Friedreich's ataxia are also treatable.

We recommend that people with progressive ataxia be seen regularly by a neurologist (at least annually) who can monitor the condition and provide help with any new problems that may have emerged. It also gives you a chance to benefit from any new medical advances. Ataxia UK supports the opening of Specialist Ataxia Centres around the UK. Based within the Centres are specialist neurologists and nurses who have expertise in ataxia investigation and symptom control. See our website **(www.ataxia.org.uk/pages/ataxia-centres.html)** to find out about your nearest Centre.

Physiotherapy and exercise such as swimming may prevent loss of strength and preserve mobility. A speech and language therapist can help with problems involving speaking, swallowing, coughing, choking and, if needed, communication aids, such as some computer programmes. An occupational therapist can also be helpful, for example with home adaptations, teaching strategies for daily activities or wheelchair assessments.

Many people with ataxia say it really helps them to meet other people with the condition and realise they are not alone in what they're going through. Ataxia UK's network of local Branches and support groups helps by running events, trips out, fun activities, and chances to meet up and socialise. Others keep in touch with one another through our online health community forum or virtual support group.

Dee was diagnosed with cerebellar ataxia when she was 28 years old.

Your rights

The Equality Act became law in 2010 and has replaced the Disability Discrimination Act which had been in place since 1995. The new act continues to make it unlawful to discriminate against disabled people in various areas of their lives, including work, education, travel and leisure. Sex discrimination and race relations are also covered by the Equality Act.

Under the Equality Act, disabled people are protected against direct and indirect discrimination in access to goods and services, as well as in employment. The Act also protects people (whether or not they themselves are disabled) from harassment or victimisation arising from disability. Service-providers are required to think ahead and make reasonable adjustments to improve access for disabled people.

If you or someone you know feel you have been treated unfairly or discriminated against because of disability, you might want to make a complaint or take legal action. How you proceed will depend on when the event/s occurred. If it was before 2010, the Disability Discrimination Act will still apply.

The Equality Advisory Support Service can give information and advice on making a direct complaint, seeking help from a mediator to resolve any dispute or making a claim in a court or tribunal.

Web: **www.equalityadvisoryservice.com**
Tel: **0808 800 0082**

You can also contact the Ataxia UK Helpline for guidance.

Counselling and emotional support

We are often contacted by people affected by ataxia who would like to talk to a counsellor or therapist to discuss some of the issues ataxia has brought up for them. Counselling may be available on the NHS with a referral from your GP, but you might also like to look into other options such as a paid private counsellor. There are also many charities, such as **Anxiety UK**, offering counselling services in particular areas, often at a lower cost. The Counselling Directory helps you find a counsellor or psychotherapist in your local area.

Web: **www.anxietyuk.org.uk**
Tel: **08444 775 774**

Web: **www.counselling-directory.org.uk**
Tel: **0844 8030 240**

Being a carer

Increasingly, more support is available for carers looking after a family member or loved one. It is vital for carers to take time for themselves so that they are refreshed and rested and their own health doesn't suffer. Many carers of people with ataxia find it very helpful to come to Ataxia UK meetings and events to get some support for themselves.

As well as Ataxia UK's helpline, there are many charities offering information about support for carers, including benefits, breaks, and carers' rights.

Web: **www.carers.org**
Tel: **0844 400 4361**

"Since we found Ataxia UK, I've got so much information and made so many friends. I don't feel so alone now!"

Education

Although schools vary as to how accessible they are, in general, modern facilities can accommodate pupils with physical impairments, and improvements are continually being made to accessibility. Such information can often be found in a school's accessibility plan, a copy of which must be given on request. The local council and current school should both be helpful in advising on accessibility issues in relation to post-school education.

SKILL (the National Bureau for Students with Disabilities) is an organisation that provides information for young people who are over 16 and in education or looking for work.

Web: **www.skill.org.uk/youth**
Tel: **0800 328 5050**

Disabled students may be able to get Disabled Students' Allowances, which are grants given to cover the extra expense of studying due to disability. They can be used for specialist equipment, a note-taker and extra travel costs required. Application forms are available from the local council or you can go to **www.gov.uk/disabled-students-allowances-dsas** for further information.

Employment

*"To get to work, I pay the equivalent of what public transport would cost and **Access to Work** pays the extra cost of a cab."*

Many people with ataxia continue to work after their diagnosis and hold down jobs for many years. There are a number of schemes to help with this, including **Access to Work**. Most jobcentres have a specialist Disability Employment Advisor you can speak to, and there are also charities such as the **Shaw Trust** who find work placements for disabled people.

Web: **www.gov.uk/access-to-work**

Web: **www.shaw-trust.org.uk**
Tel: **01225 716 300**

Housing adaptations

Some people need to make adjustments to their home when they develop ataxia. An occupational therapist with social services can advise on the home adaptations required. Local authorities can give different kinds of grants to private sector owner-occupiers and tenants. Council tenants can also apply. These include grants to make properties fit to live in and to cover improvements and adaptations. You can get a list of housing associations specialising in housing for disabled people from your local authority.

Ataxia UK regularly awards Cornberg Equipment and Adaptation Grants. They can be used to buy specialist equipment and home adaptations. Contact the Helpline to find out more about who is eligible.

Planning a family

Many people with inherited types of ataxia have children. Some people develop ataxia after they have had children, and others may do so while knowing that they have ataxia. Every person with ataxia will have a different view on whether to have children. It is always a deeply personal decision.

If someone has a known recessively inherited ataxia (eg. Friedreich's ataxia) and they wish to start a family, it is possible for their partner to be tested to see if they are likely to be a carrier of the same type of ataxia. If he/she is not a carrier, then their child is highly unlikely to develop that type of ataxia.

Walking aids

When considering the use of a walking aid, it is best to consult a GP or occupational therapist for help and advice. Disabled living centres offer a range of equipment as well as advice and information. For details of the nearest centre, contact **Assist UK**.

Web: **www.assist-uk.org**
Tel: **0161 832 9757**

Both walking sticks and frames are suitable for those who have some ability to stand and walk but need help keeping their balance. A walking frame offers more stability and support and many have additional features such as wheels, brakes or a seat for resting. The **Disabled Living Foundation** offers factsheets on the various aids and equipment available for disabled people.

Web: **www.dlf.org.uk**
Tel: **0300 999 0004**

Other forms of mobility aids include gait trainers, which have a frame and provide more support than a standard walker, and scooters, which may be used as a form of transport over a longer distance. Many of these aids are available through the NHS, via a physiotherapist or occupational therapist.

Chris has been a wheelchair-user since he was 15 years old.

Manual and electric wheelchairs

Although not everyone with ataxia uses a wheelchair, many people find it makes life easier. Some people can walk short distances or stand for a short period; they may use a wheelchair for the rest of the time.

Diversity in manual and electric wheelchairs is growing all the time. Technological developments mean chairs can be made stronger, faster, and lighter than ever before. There are many different types of manual and electric wheelchairs, including sports wheelchairs, standing wheelchairs and transport wheelchairs.

Factors such as age, need and ability are all important when finding a suitable wheelchair. The cost can vary from hundreds to tens of thousands of pounds, depending on what the chair is made of and whether it has been made to measure.

Manual wheelchairs are often available through the NHS, though these are usually older models. It is best to be assessed by an occupational therapist to find the most suitable wheelchair for your needs and requirements.

The main advantage of using an electric wheelchair rather than a manual wheelchair is that it is less physically demanding. All operating is done by battery, and you do not need to rely on assistance to move.

"At first I felt embarrassed being in a wheelchair, but my friends and family were a great source of strength."

Go Kids Go! is a charity that runs practical, fun courses to train children in the skills they need to become independently mobile.

Web: **www.go-kids-go.org.uk**
Tel: **01482 887 163**

Assistance dogs

"My dog is amazing - he can even help me empty the washing machine! He really helps me to live independently."

Assistance dogs are specially trained to help disabled people carry out everyday tasks that they would otherwise find difficult. People with ataxia sometimes find that having an assistance dog helps them to retain their independence in addition to the dog being a wonderful companion to have.

Dogs can be trained to carry out a variety of tasks in order to help people live as comfortably as possible. Tasks can include opening and closing doors, reaching up to shop counters, carrying a shopping basket or even emptying the washing machine.

Assistance Dogs UK is a group of charities working to train dogs to help disabled people live independently. The charities include **Support Dogs**, **Canine Partners**, **Dog Aid** and **Dogs for the Disabled** and applications are made to the individual organisations. For more information about how and where to apply:

Web: **www.assistancedogs.org.uk**
Tel: **01844 348 100**

On the road

Learning to drive is a great way to get mobile. Although the minimum age for learning to drive is normally 17, if you are receiving the mobility component of Personal Independence Payment at the enhanced rate, you can drive at 16. Many people with ataxia may be eligible for the Blue Badge Scheme. This gives parking concessions for drivers or passengers who have problems walking. It allows badge-holders to park close to their destination. To apply for this concession contact the social services department of your local authority.

Or to find out more information, you can visit:

Web: **www.gov.uk/apply-blue-badge**
Tel: **0844 463 0213 (England)**
0844 463 0214 (Scotland)
0844 463 0215 (Wales)

If you drive, you must inform the Driver and Vehicle Licensing Agency (DVLA) as soon as you are diagnosed with ataxia. This does not automatically mean you have to stop driving. For some people with ataxia, their condition means they need adaptations to their car to carry on driving and eventually may decide to give up driving. For more information on this, contact Ataxia UK.

Web: **www.gov.uk/contact-the-dvla**
Tel: **0300 790 6801**

QEF

Other useful organisations

Other useful organisations include: **Queen Elizabeth's Foundation for Disabled People (QEF)** which offers advice and gives training and assessments for those wishing to drive adapted cars and personal mobility vehicles; **Motability** helps people to lease cars, scooters and powered wheelchairs; The **Disabled Motorists Federation (DMF)** gives advice on suitable vehicles and other aspects of travel, including planning holiday travel.

Web: **www.qefd.org**
Tel: **01372 841 100**

Web: **www.motability.co.uk**
Tel: **0845 456 4566**

Web: **www.dmfed.org.uk**

Ataxia UK
Annual Conference 2014

Getting out and about

Most cinemas, especially multiplexes, offer good facilities for people with ataxia and other impairments. Details of these can be found on their websites. There is a **Cinema Exhibitors' Association** scheme in which supporting cinemas issue a free ticket to carers accompanying a disabled person. You can apply for a card online at **www.ceacard.co.uk** and it lasts for one year.

In recent years much public transport has been made accessible for people with mobility impairments. You may find that people with ataxia are eligible for reduced rates such as the **Taxi Card Scheme** in London and the **Disabled Persons' Railcard** nationally. These allow people who are unable to use other kinds of public transport to travel at a cheaper rate using taxis or trains. **Disability Rights UK** have produced an extensive guide to access on public transport for people with mobility impairments. It's called 'Doing Transport Differently' and is free to download from their website.

Web: **www.taxicard.org.uk**
Tel: **0845 415 4156**

Web: **www.disabledpersons-railcard.co.uk**
Tel: **0845 605 0525**

Web: **www.disabilityrightsuk.org**
Tel: **020 7250 3222**

Many local areas also provide community transport services for disabled people. Services can include dial-a-ride, door-to-door, shopmobility, wheels to work and community car schemes.
The **Community Transport Association UK** has a website you can search to find your local provider.

Web: **www.ctonline.org.uk**
Tel: **0161 351 1475**

Most rail, bus, and airline companies will allow assistance to be booked in advance if you need some help to travel, for example to change trains. Contact the individual firm for more information.

Women's wheelchair.
London Marathon.

Sport and leisure

Many sports can be adapted to allow people with conditions like ataxia to take part. This is reflected by the increase in the range of sports at the Paralympics. **Wheelpower** is the national organisation for British wheelchair sport.

Web: **www.wheelpower.org.uk**
Tel: **01296 424 171**

If you enjoy watching sport, many sporting venues in the UK accommodate wheelchair users. To find a sporting venue in your area, visit **www.disabledsport.co.uk** which gives information on local facilities or contact your local council for venues in your area.

The **English Federation of Disability Sport** can give you information on local events. Alternatively, contact the local council for clubs in your area specialising in disability sports, or ask individual venues about their accessibility and if they have sessions especially for disabled people; for example, many swimming pools offer this service.

Web: **www.efds.co.uk**
Tel: **01509 227 750**

Marie was diagnosed with cerebellar ataxia when she was in her 50s.

Getting online

Many people with ataxia find that going online can be a great way to keep in touch, arrange travel and get their shopping done. Most websites and internet browsers have accessibility options that allow the font size to be changed or show a text-only view, and so on.

A keyboard and mouse can be adapted for ease of control and there are also various communication aids that can help with computer use, such as voice recognition software. The computer desktop and settings can also be customised to make them more accessible.

Mobile phones can also be adapted for easier use, and some (such as the iPhone) offer voice recognition apps at a fraction of the price.

Useful organisations include AbilityNet and Microsoft.

Web: **www.abilitynet.org.uk**
Tel: **0800 269 545**

Web: **www.microsoft.com/enable**

There are several well-used chatrooms and message boards on the Internet for people with ataxia, including **www.livingwithataxia.org**, Ataxia UK's own virtual support group **www.virtualataxia.org.uk**, and social network community **www.healthunlocked.com/ataxia-uk**. You can also find Ataxia UK on Facebook and Twitter.

There are many other ways of using technology to improve daily life, for example different options for when you struggle to sign your name or type in a PIN number to pay for goods and services.

Get in touch with Ataxia UK for some helpful ideas and suggestions.

Holidays and travel

Most holiday services have accommodation for people with impaired mobility, and can offer extra facilities for those with additional needs. For more information, ask the holiday operator to give details of accessibility. Tourism for All can provide information on accessible holidays, including accommodation, transport and visitor attractions in the UK (and for some destinations abroad).

Web: **www.tourismforall.org.uk**
Tel: **0845 124 9971**

What next?

Although there is no hiding the fact that ataxia does affect people, it does not have to prevent people from having a full, active, and enjoyable life. Ataxia UK is here to give support, so do contact us if there is anything that we can help with. It is free to join Ataxia UK, which offers:

- Regular events and chances to meet up such as at conferences and seminars
- A dedicated website with information at **www.ataxia.org.uk**
- Publications and factsheets - please contact us for a full list
- A quarterly magazine full of information, stories, news, and research
- A helpline and advocacy service on **0845 644 0606**
- Equipment and adaptation grants to assist the mobility of people with ataxia within their homes
- A network of more than 65 local Branches and support groups around the country

Join Ataxia UK - become a 'Friend'

Joining Ataxia UK is free of charge and allows you to access all our services and resources. Just go to our website (**www.ataxia.org.uk**) and click on **Join us**.

DisabledGo

Other useful links

Contact a Family is a UK charity that campaigns to improve the circumstances of families with disabled children and for their right to be included and take part in society.
www.cafamily.org.uk

The Council for Disabled Children brings together a range of organisations including the Transition Information Network which aims to improve disabled young people's transition into adulthood.
www.councilfordisabledchildren.org.uk

DisabledGo is a website that provides detailed information about access to local healthcare, education, jobs, services and places of interest.
www.disabledgo.com

The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the UK, using a Radar NKS key.
www.radar-shop.org.uk

Rica is an independent consumer research charity providing information for older and disabled people on products such as family cars, mobility scooters and washing machines.
www.rica.org.uk

Shape is a disability-led arts organisation that develops opportunities for disabled artists, and works to improve access to arts and culture for disabled people.
www.shapearts.org.uk

For further information, contact Ataxia UK on **0845 644 0606**

We hope you have found this booklet useful. Your feedback is always welcome. Help us improve the next edition by telling us what you think:
www.surveymonkey.com/s/whatisataxia

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ATAXIA
2020 VISION

ATAXIA
Ataxia UK

Ataxia means 'lack of order' and is the term given to a group of neurological conditions that affect balance, coordination and speech.

In some cases, people get the symptoms of ataxia for short periods of time and then recover. In many cases ataxia is permanent and progressive (ie. symptoms get worse over time).

More than 10,000 people in the UK have been diagnosed with a type of progressive ataxia.

Ataxia UK is the national charity that supports everyone affected by ataxia.

Ataxia UK
12 Broadbent Close
London
N6 5JW

Helpline
0845 644 0606
helpline@ataxia.org.uk

Office
020 7582 1444
office@ataxia.org.uk

Online
www.ataxia.org.uk
www.healthunlocked.com/ataxia-uk

Follow us on
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PEER REVIEW AUDIT 2011

The Helplines Association
Member

Ataxia UK works across the whole of the UK
and is a charity registered in Scotland (No. SC040607)
in England and Wales (No. 1102391)
and is a company limited by guarantee (4974832)

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