Ataxia after brain injury

This publication is part of Headway's *Effects of brain injury* series. To browse through our publications on a range of issues relating to brain injury and download these free-of-charge, visit www.headway.org.uk/information-library.

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Introduction

This publication is about ataxia after brain injury. Ataxia is the name of a group of disorders in which movement is affected. Various conditions can cause ataxia, including brain injury.

This publication explains what ataxia is and how it can affect different aspects of life. It also offers tips for coping with ataxia and guidance on getting professional support with this issue.

Words in **bold and underlined** are defined in a glossary at the end.

The information in this publication does not replace clinical guidance. You should always seek advice from a suitably qualified professional on managing the effects of brain injury. Your GP may be the best starting point for this.

You can also contact our nurse-led helpline for information and advice on living with brain injury.

What is ataxia?

Ataxia is the name for a group of disorders in which the brain's ability to control muscles becomes disrupted. This can affect the body's movement, co-ordination and balance.

Ataxia can cause difficulties with:

- Walking
- Vision
- Speech
- Swallowing
- Continence (bladder and bowel functions)
- Using one's hands for activities such as eating, dressing or writing

Ataxia can be caused by a range of conditions. Experiencing a brain injury can cause a type of ataxia called acquired ataxia.

There is an area of the brain called the **cerebellum**, which is responsible for the balance and coordination of muscles. Damage to the cerebellum as a result of trauma, stroke or deprivation of oxygen, can affect muscle control and movement, therefore causing ataxia.

Vision also relies on movement of muscles around the eyes. Even when we think our eyes are still, they are constantly moving back and forth to process the world around us. A brain injury can affect the control of these muscular movements, which can cause a range of visual problems that contribute to ataxia.

Similarly, speech, swallowing and continence are all functions that rely on muscular control. If parts of the brain responsible for controlling these muscles get injured, these functions can be disrupted. For example, some people experience dysarthria, which is a difficulty with speech, and/or dysphagia, a difficulty with swallowing.

Ataxia can cause muscles to **spasm**, which can be uncomfortable or painful to live with.

Impact of ataxia

Emotions

Living with the effects of a brain injury can be challenging. Life can change very suddenly, and in many different ways. Emotions such as frustration, anger, sadness, depression, anxiety or a sense of loss and longing for the ‘old life’ are very commonly felt by many brain injury survivors.

If ataxia, or any other effects of brain injury, are having an emotional impact on your life, remember that **help is available**.

Our nurse-led helpline can offer information and guidance on living with brain injury and can offer a listening ear to anyone affected by brain injury who wants to talk about their feelings. Contact 0808 800 2244 or email helpline@headway.org.uk.

Find out about other ways that Headway can help by visiting our website at www.headway.org.uk/supporting-you.

You should also talk to your GP if you are having a difficult time with your emotions. They may be able to prescribe medication or refer you to helpful services such as talking therapies or **neuropsychology** services.

More information on coping with anxiety and depression after brain injury is available in our publications *Anxiety after brain injury* and *Depression after brain injury*.

Returning to work

Many people find it difficult to return to work after brain injury. Ataxia can interfere with many work-related skills such as being able to move around safely, manual handling, speaking, reading and/or typing/writing.

If you have a disability, you are entitled to 'reasonable adjustments' to be made within the workplace to help you with your role. Employers are legally obliged to make these adjustments, which could include things such as:

- providing specialist equipment
- improving accessibility around the building
- re-locating an employee to be nearer to required facilities such as toilets
- adjusting working hours to make them more suitable for the employee
- adjusting responsibilities to make them more suitable for the employee

These arrangements may be helpful for brain injury survivors with ataxia.

More guidance on this topic is available in our publication *Returning to work after brain injury*.

Driving

Various muscles are used simultaneously when driving a car, such as using muscles in hands to steer the wheel and using muscles in legs to operate the foot pedals. Muscles in the eyes are also used to see the route, the road and hazards when driving.

Ataxia can affect the control and coordination of these muscles, interfering with a brain injury survivor’s ability to drive. The survivor may no longer be able to drive, or may need vehicle adaptations to be made to continue driving safely.

It is a legal duty to report any illness or injury that may affect driving to your vehicle licensing agency. Failure to do so can result in heavy fines and license points, as well as carrying a serious risk of injuring or hurting someone.

A **fitness-to-drive test** may be needed to assess a survivor’s safety and suitability to continue driving.

After the test, it may be decided that the survivor can carry on driving. This may be on the condition that they use adaptive vehicles that make it safer or more comfortable for them to drive, such as hand steered or automatic cars. Other survivors may no longer be considered safe to drive. They may lose their driving license or have it temporarily suspended. This can be very upsetting and may cause practical challenges, but it is very important to recognise that this decision is made to keep the survivor and others safe.

More guidance on this topic is available in our publication *Driving after brain injury*.

Activities of daily living

‘Activities of daily living’ refer to everyday activities that form many people’s regular routines, such as washing, dressing, brushing one’s teeth and hair, shopping, eating, etc. Being able to carry out these activities relies on many different muscles working together. Ataxia can therefore affect someone’s ability to carry out these activities independently or safely.

In many cases, it is the family and/or partner of the brain injury survivor who takes on a caring role to help the survivor with completing such activities. If it is difficult for family or partners to do this, the survivor’s local adult social care team can be contacted to find out about how they can help.

They may be able to provide support for carers, arrange for professional carers to support the survivor with these activities, or provide adaptive equipment or home adaptations to help.

More guidance on the help available for carers and contacting adult social care teams is available in our publication *Caring after brain injury*.

Socialising

Many of the skills needed to communicate and socialise with others rely on muscle control and movement. Talking to friends or others might be difficult due to issues such as slurred speech. It may be difficult to access certain places if the brain injury survivor's balance or walking are affected. Hobbies or activities that the survivor enjoyed with friends or family may no longer be safe or comfortable for them to do.

Friends, family, colleagues and others should consider making adjustments so that the survivor can continue to take part in social activities, such as changing the types or location of activities to make it easier and safer for the survivor to get involved.

Researching the accessibility of places beforehand, or availability of toilets nearby, can also help with planning social events.

If crowded places are especially problematic, consider contacting places in advance to find out when their quieter hours are.

It can also be helpful to remember that many people are not aware of what a brain injury is and how it can affect someone. Being open and honest about how your brain injury has affected you can help others in your life to understand how they can best support you, which may help with social activities.

Headway's network of charities and volunteer-led branches offer opportunities to socialise with other brain injury survivors. For more information, visit www.headway.org.uk/supporting-you.

Writing

Ataxia may affect the ability to write, and it may be necessary for brain injury survivors to use alternative methods of writing where needed. Fortunately, there are many digital alternatives available nowadays such as typing, recording or text-to-speech functions. There are also adaptive pencils, pens or styluses that may make writing more comfortable.

There are different procedures in place for people who cannot sign legal documents due to a disability, depending on the type of legal document, such as signing a will or a deed. You should seek advice from a legal representative in these instances.

Cooking and eating

Cooking

Handling objects such as knives or hot pans while cooking can be dangerous with ataxia, as the brain injury survivor may lose control and accidentally hurt themselves. Adaptive equipment in the kitchen can help to keep the survivor safe. Recipes can also be chosen carefully to minimise risk of harm. Ready chopped ingredients may be a helpful option.

Occupational therapists might be able to advise on techniques and equipment that can make cooking safer for brain injury survivors with ataxia.

Eating

Ataxia can affect the ability to bring food up to the mouth, which can make eating difficult. A brain injury survivor might be at risk of burning themselves if they spill hot food, or may need to frequently clean or change their clothes. **Occupational therapists** might be able to advise on adaptive cutlery or equipment to help.

We also use our muscles to chew and swallow, so ataxia can put survivors at risk of choking. **Speech and language therapist**s can devise modified diet plans that can minimise the risk, for example including only soft foods in the survivor's diet.

Travelling

The processes of planning a holiday and travelling after brain injury can be made easier by researching in advance, planning and arranging for support where needed.

Many holiday providers offer support, packages, or accommodation for people with disabilities, while several disability specific holiday organisations also exist. There are also many websites available to help you with understanding the accessibility of different holiday destinations.

It might be necessary to notify rail line, coach, ferry or airline companies in advance of any adjustments or special assistance needed with travel.

Remember to notify any travel insurance providers of ataxia or any other circumstances related to your brain injury that might affect your cover. You might need to specify to them that you have acquired ataxia, as opposed to other forms of ataxia.

More guidance on this topic is available in our publication *Holidays and travel after brain injury*.

Communication

There are many muscles involved in the process of speech (i.e. talking). Ataxia can cause problems with controlling these muscles, which can in turn affect communication.

Speech might become slurred, or it might be harder for the brain injury survivor to form words that they want to say. The survivor may struggle to join in with conversations, or express their preferences or opinions. Trying to make themselves understood can be tiring, upsetting and frustrating. It can also be difficult for others communicating with the survivor if they are unable to understand what the survivor wants to say.

Speech and language therapists can help brain injury survivors by suggesting strategies and exercises to improve speech.

Communication aids such as letter boards or **Augmentative and Alternative Communication (AAC) devices** may be helpful.

Sometimes, with practice, people who spend a lot of time with the survivor can learn to ‘tune in’ to their speech over time.

For some types of ataxia, ‘**voice banking**’ may be considered.

More guidance on this topic is available in our publication *Communication problems after brain injury*.

Professional support

Professionals may be able to help by either offering **rehabilitation** exercises or suggesting ways to adapt to life with ataxia. Some of the professionals that may be able to help are as follows:

- **Physiotherapists** - to help with movement issues
- **Speech and language therapists** - to help with speech and swallowing issues
- **Occupational therapists** - to help with accessing and using adaptive equipment and learning adaptive ways of completing activities
- **Nurses** - to administer and monitor medication
- **Continence specialists** - to help with continence (bladder and bowel function) issues
- **Neuropsychologists or clinical psychologists** - to help with the emotional, cognitive or behavioural impact of brain injury

You may already have contact with these professionals through your treatment and rehabilitation programme, or you may need to speak to your GP about getting referrals. Many of the above professionals are also available in private practice.

If your ataxia is causing difficulties with day-to-day living, your GP or neurologist may be able to refer you to an Ataxia centre, clinic or a professional specialist in ataxia. More information on these is available on Ataxia UK's website at www.ataxia.org.uk/healthcare-professionals/ataxia-centres-specialists.

General tips for coping with ataxia after brain injury

The term 'ataxia' covers a wide range of different issues related to movement and balance. Different coping strategies will therefore be needed depending on the type of difficulties a brain injury survivor with ataxia has. Our range of publications on the effects of brain injury discuss some of the difficulties caused by ataxia in more detail and offer specific guidance for these, such as…

- Balance issues and dizziness after brain injury
- Communication problems after brain injury
- Continence problems after brain injury
- Visual problems after brain injury
- Fatigue after brain injury

Visit our website at www.headway.org.uk/information-library to browse through our full list of publications.

General tips for coping with the impact of ataxia include:

- **Get support** - for instance, professional support, support from agencies to help with aspects of your life that you are struggling with, and/or support from charities such as Headway and Ataxia UK (www.ataxia.org.uk).

- **Keep walkways clear** to avoid tripping. Consider installing grab rails for safety.

- **Speak to your GP** about symptoms of ataxia that you are struggling with. They may be able to prescribe helpful medication or provide referrals to relevant services. For instance, there may be specialist clinics nearby that your GP can refer you to, such as spasticity clinics, continence clinics or pain clinics.

- **Consider deep breathing exercises** to help with calming the body. The NHS website has guidance on deep breathing for stress, but this advice may also be helpful for a range of conditions including ataxia: www.nhs.uk/mental-health/self-help/guides-tools-and-activities/breathing-exercises-for-stress.

- **Explore adaptive equipment** that can help you with managing day-to-day life, such as mobility aids, adaptive kitchen equipment or walking aids.

- **Discuss helpful exercises** with a **physiotherapist** to help with balance and **gait** issues.

- **Explore adapted activities**, such as accessible holidays or adapted sports.

- **Be honest with others in your life about how you are feeling**, as they may not understand how your brain injury has affected you, especially if your symptoms are not visible to others. Talk to others about your experiences, your feelings, and how they can best support you.

- **Avoid drinking alcohol** if possible, as this may worsen ataxia issues such as balance, speech and **gait**. Alcohol is generally discouraged after brain injury as a brain injury can reduce one's tolerance to it. More guidance on this topic is available in our publication *Alcohol after brain injury*.

Glossary

Augmentative and Alternative Communication (AAC) devices - technology devices that can help people with speech difficulties to communicate.

Cerebellum - a part of the brain largely responsible for processing balance, coordination and movement, also involved in memory. It is located at the back of the brain and looks like a smaller, smoother brain.

Fitness-to-drive test - a test done by professionals to assess if someone is safe to continue driving after an illness or injury.

Gait - a person’s way of walking, which can be affected by ataxia.

Neuropsychology - a branch of psychology specialising in how brain injury can affect cognitions, emotions and behaviour.

Occupational therapist - a professional that assesses and advises on adapting everyday activities to make them safer and more comfortable for people with disabilities.

Physiotherapist - a professional that assesses and offers exercises for movement issues after illness or injury.

Rehabilitation - a set of therapies designed to facilitate recovery and reduce disability after illness or injury.

Spasm - a condition in which the muscles tighten, causing a squeezing, tightening or stiffening sensation.

Speech and language therapist - a professional that assesses and advises on speech and language issues, as well as issues with chewing and swallowing.

Voice banking - a process whereby someone’s voice is recorded and saved in a ‘bank’, which is then computer generated if they gradually lose the ability to speak themselves.

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As a charity, we rely on donations from people like you to continue being able to provide free information to those affected by brain injury. To donate, or find out how else you can get involved with supporting our work, visit www.headway.org.uk/get-involved.

If you would like to leave feedback for this publication, please consider completing our short survey at www.surveymonkey.co.uk/r/hwpublications or contact us at publications@headway.org.uk.

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