

Cerebellar ataxia – frequently asked questions



This information is for general consideration and will not apply to all people with cerebellar ataxia.

Do I need more tests?

There are many reasons that doctors order tests, but most are for one of the following reasons:

- To try and find out what medical condition you have.
- To get a better idea of how your condition is affecting *your* health.
- To get an idea of your *current* health, so that if it looks like things are getting worse in the future we have something to compare to (often called *baseline* investigations).
- To get a better idea of whether your illness is getting worse or changing.

Do you see other people with this condition?

Although some conditions are very uncommon, some or many parts of those conditions may be found in many other cerebellar ataxias. Clinicians such as specialist neurologists and neurological physiotherapists, who see lots of patients with cerebellar ataxias, probably see lots of people with the same or similar conditions.

Will my condition get worse?

This varies for individual diseases and varies for the individual people. Not everyone with the same disease is affected in the same way. Reasons for this may include how severe (or not) your version of a given disease is; how old you were when the disease started; how quickly the disease is getting worse (if at all) and your general health. Often only time will tell if your condition will worsen, and if so, how quickly or slowly this will happen.

I am having difficulties swallowing

Ataxia means incoordination which may affect more than your arms and legs. The ability to swallow requires very coordinated muscle movements which can also be affected in ataxia. As a result of reduced coordination, it is possible that food and/or drink can go down the wrong way more easily, towards your lungs. If this happens frequently, it can cause a chest infection and sometimes more seriously, pneumonia.



Problems swallowing can present as coughing and choking when eating/drinking, particularly with thin fluids and flaky/crumbly/harder items of food eg biscuits, pastries and meat. You may find that you have to swallow a few times to clear the food, or it may take you a long time to chew and /or finish a meal.

If you are having any difficulty at all with your swallowing, or feel it is becoming problematic, please discuss this with your doctor. You may be referred to a Speech Pathologist for an assessment, and in certain cases a swallow x-ray (Videofluoroscopy) or Fibre-Endoscopic Evaluation of Swallowing (FEES) may be indicated. A Speech Pathologist can give advice on strategies and ways to make swallowing easier, and often solutions are quite simple. Swallowing, can however, decline as part of the ataxic progression, so a regular check-up is often recommended.

My speech sounds unclear

Ataxia can affect the clarity of your speech. This is due to reduced coordination of the muscles around your mouth, lips and tongue which help you articulate when you talk. As a result, speech may sound slurred, it can be more difficult and you may need more effort to articulate clearly. The sound of your voice may also change. Speech and voice production may be more difficult when you are tired or feeling unwell.

If you are having difficulties with the clarity of your speech or the sound of your voice, please discuss this with your doctor. You may be referred to a Speech Pathologist who can assess your difficulties and give you advice and strategies to help you manage your communication. In some cases, exercises may be beneficial.

Is it safe for me to drive a car?

Most people with a cerebellar ataxia are able to safely drive. It is the duty of someone who develops a cerebellar disorder to notify the road licensing authority in their state, to ensure that their driver's license is valid and that they are covered by their insurance. It may be necessary to undergo an on road occupational therapy driving assessment - most cerebellar patients are found to be safe to drive. This is often more affordable if arranged as part of a public hospital rehabilitation program. Car modifications (eg wheelchair carriage) may also be helpful.

Physiotherapists and occupational therapists should be consulted if there are any concerns regarding the safe use of public transport. Additionally, you may speak with your doctor to see if you are eligible for a half price taxi card. Hospitals and other services, such as municipal councils, may be able to arrange volunteer drivers to help with visiting a health service or doing other things such as the shopping.



Pain

Some cerebellar ataxia conditions can cause pain, for example in the legs. This is often nerve pain and is generally not best helped by regular pain medicines and may require treatment with special nerve pain medications. Your doctor or a specialist neurologist may be able to advise you on these medicines.

My legs seem to be too floppy (or too stiff)

In cerebellar ataxias, difficulty with movements may be due to more than incoordination (ataxia). Other causes may include muscle weakness, which may be part of your condition or because of lack of use. A specialist doctor or physiotherapist is often best situated to assess this. Muscle stiffness (called spasticity in medicine - different to what it meant in the playground!) may be part of certain cerebellar ataxias and may be helped by medicines and physiotherapy.

What treatment is there for cerebellar ataxia?

Unfortunately at this time only a few causes of cerebellar ataxia have treatments that can make the disease get better or stop it getting worse. Many researchers are working hard at finding effective and safe treatments.

While there are many claims for treatments that help cerebellar ataxia, most have not been proven to help. It is very important that any possible 'treatment' for a cerebellar ataxia has been researched to make sure that it is safe and that it has an ability to help.

One of the very few treatments that has been shown with good quality research to help people with cerebellar ataxia is intensive neurological physiotherapy. This generally means ongoing treatment with a special kind of physiotherapist, often found in specialist rehabilitation services.

Will my children or grandchildren get this?

Not all cerebellar ataxias are inherited, which means that the condition is passed down from one generation to the next. Even if your condition is known or thought to be inherited, it often boils down to a probability, or chance, that your child or grandchild gets a disease.

There are different types of inheritance and so, even where a condition is genetic, some people in the family may be at risk, while others are not (these people may be so called 'carriers' of the gene but are not themselves affected by it). A discussion with your specialist doctor



may find that referral to a genetic service for further information could be helpful.

Falls and broken bones

It is most important to avoid falls, but if there is a risk that you will fall (or fall again) then it is much better to fall onto stronger bones. Broken bones, particularly hips, can be very serious in older people or people with other illnesses.

Your doctor may recommend a scan to see how strong your bones are (DEXA bone densitometry) and many people with cerebellar ataxias may benefit from taking a calcium and vitamin D tablet. Those people who are found to have thinning of their bones are generally recommended bone strengthening drugs. Also, bones get stronger when they are working, so, where possible exercise is an important part of protecting bones.

How do I cope?

All illnesses have the potential to affect the way we feel, but when it is a condition that won't go away and changes our lives in BIG ways, we often need to make very big adjustments to living with the disease.

Things that can help people cope with the changes forced upon them by their illness include:

- Talking with others (especially people with similar conditions).
- Knowing about your illness and what you may expect to happen with your health.
- Seeing health professionals familiar with cerebellar ataxias.

It is very important that written information is relevant to your condition and is TRUE. This is especially important in the case of the internet, where there is a lot of information, much of which is probably not true for many of the people reading it. Patient support groups, such as Spinocerebellar Ataxia Australia Inc (www.scars.org.au) and the National Ataxia Foundation (www.ataxia.org) are very well regarded. Health psychologists are specialist psychologists that work with people who have physical diseases to help them better cope with the changes their illness makes to their life.

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