

SWALLOWING AND SPEECH

People with ataxia often have difficulties with swallowing and speech. This leaflet explains the reasons, and suggests how some problems may be alleviated.

PROBLEMS WITH SWALLOWING ('DYSPHAGIA')

Ataxia can affect the muscles needed for chewing and swallowing in the same way that other groups of muscles may be affected. They may be weak and their movements slow or inaccurate or mistimed. The type and severity of the problem varies enormously between individuals.

Dysphagia can involve problems with chewing, food sticking in the throat or difficulty moving the food back through the mouth.

Eating can become very slow, exhausting and messy. People may cough or choke during and after eating, which can be very frightening. Too much saliva can mean dribbling. These problems can combine to make eating stressful and unpleasant. People may also experience aspiration, where liquid and food from the throat trickle into the airways and down into the lungs. This may be a subtle process ('silent aspiration', where the person is unaware) and can result in infection and aspiration pneumonia. Persistent and repeated chest infections should therefore always be investigated further.

When detected, the symptoms of dysphagia can often be successfully managed to make swallowing easier. Diagnosis and treatment are a team effort, perhaps involving a radiologist to carry out a moving X-ray of the swallow, speech and language therapist, dietitian, the person with ataxia, their family and carers.

Early referral can help identify and even avoid later problems. It is important to have regular follow-ups.

STRATEGIES FOR SWALLOWING

Some practical changes can improve the ability to eat and drink more safely and comfortably.

Diet

- A softer diet requires less chewing; eating is not so tiring
- Avoid lumpy or very dry food; add gravy (for example) to drier food
- Pureed or liquidised food may be easier to manage
- Thickened drinks (add a cornstarch-based preparation) slows the flow, giving more time and control

When eating

- Alternate liquid with solid food – sip fluid during a meal
- Eat little and often through the day - less tiring than full meals
- If full meals seem OK, eat the main meal at midday when most people have more energy and strength, which makes swallowing safer and easier
- Drink a small amount of water at the end of a meal to remove any food that lingers in the throat; then clear your mouth by coughing deliberately

Posture and atmosphere

- Good posture: use comfortable, supportive seating; tuck the chin down towards your chest when swallowing to help close the airway and reduce the chance of choking
- Eat in a relaxed atmosphere; cut out distractions (talking or TV) to increase concentration
- Don't rush the meal: take time to chew well, allow time between swallows
- Remain upright for at least 30 minutes after the meal

Dietitians can give guidance on food preparation to make swallowing safer and on maintaining a balanced, nutritional, enjoyable diet.

People who need help with feeding should feel confident in their **carer(s)**. Carers should take their time and be particularly careful to make sure each mouthful is swallowed before offering more food or drink. Ideally, everyone caring for a person with ataxia should learn the Heimlich manoeuvre, a first aid treatment for choking.

PROBLEMS WITH SPEECH (DYSARTHRIA)

Ataxia can also cause difficulty with speaking, disrupting the smooth and efficient working of the lips, tongue, soft palate and larynx (voice box). Everyone is different but there are some recognised features of dysarthria that tend to occur in ataxia:

- some slurring of words (the most common symptom)
- rather slow speech
- distortion of vowel sounds
- difficulty in varying intonation

STRATEGIES FOR COMMUNICATING for people with ataxia

- Before you start a conversation with somebody new, explain that you sometimes have difficulty with your speech. Ask them to tell you if they don't understand. This usually helps to relax both speaker and listener; alerts the listener to pay extra attention; and gives them permission to say if they have difficulty understanding (otherwise they may keep quiet so as not to cause embarrassment).
- Talking face-to-face helps. Listeners watching a speaker's face gain extra help from watching the mouth and, if they are closer, will also be able to hear better.
- Reduce background noise if possible - switch off the TV, shut the door or move to another room
- Depending on how severe the dysarthria is, other tactics may help:
 - slow the speaking rate to give the tongue more time to get around words
 - reduce the amount to say by getting to the main point quickly
 - give a key word first – the listener will understand much better if they know what the subject is, even when speech is not very good
 - if you have to repeat, change the words slightly so that you are not just repeating the same thing

STRATEGIES for listeners

- Remind the person with ataxia of their communication strategies if they have a tendency to forget to use them.
- Allow plenty of time; talking with someone who is dysarthric always takes longer, and they'll manage better if they feel relaxed, not rushed.
- Be an active listener, giving the person with ataxia your full attention. This may well involve concentrating more and listening harder than usual.
- Be honest. If you don't understand, don't pretend to. Acknowledge what you do understand, so that the speaker doesn't have to repeat the whole message unnecessarily, then let the speaker try to fill in the gaps by repeating the missing information.

The other thing that can affect communication is frustration - on both sides. Accept that there are times when you get irritated and downright angry if communication isn't working. Mood, illness and general confidence can all affect communication too.

COMMUNICATION AIDS

If speech becomes too difficult, there is a wide range of communication aids – from simple alphabet or picture charts to very sophisticated technology – that may be helpful. It is important to get the right system for the individual and their present needs, which is where an assessment by a speech therapist comes in.

THE ROLE OF THE SPEECH AND LANGUAGE THERAPIST (SLT)

The SLT will carry out a full individual **swallow** assessment then advise based on that assessment, monitor and review regularly for changes. The main aim is to give the person with ataxia more control over their eating and drinking. Is it safe for the person to eat and/or drink? Is the person getting adequate food and drink? Everyone needs the right levels of nutrition (food) and hydration (liquid) for their well-being, to maintain strength and to fight infection.

A speech therapist may be able to offer a course of therapy and provide exercises to improve **speech**. This may include:

- advice about good posture
- exercises designed to improve muscle strength and accuracy
- articulating clearly, more slowly and with frequent pauses
- advice on how to focus on emphasis and intonation in speech
- communication strategies, such as making the most important points of what you want to say first
- control of breathing
- using amplifiers or other communication aids

If you wish to see an SLT for an assessment of your speech or swallowing, ask your GP to refer you to the local service. Or contact **The Royal College of Speech and Language Therapists, 2 White Hart Yard, London SE1 1NX, tel: 020 7378 1200.**

For children with ataxia, there are specialist paediatric speech and language therapists.

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**For more support or information please contact:
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We have a number of other publications on the ataxias available free of charge. In addition we publish a quarterly magazine called *The Ataxian* containing articles on research, living with ataxia and other relevant information. Our website also contains news of research projects.

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