

FACT SHEET

INFORMATION FOR SCHOOLS

What is Ataxia-Telangiectasia (A-T)?

A-T is a rare, genetic and degenerative condition, which causes severe multi-system disability. Children with A-T will have a short life expectancy and do not normally live beyond their early/mid-twenties.

The main symptoms of A-T are:

- Progressive loss of balance (Ataxia), leading to use of wheelchair
- Loss of coordination, body tremors, difficulty with gross & fine motor control
- Slurred speech
- Slow cognitive response
- Restricted eye movements
- Immune system deficiency, leading to constant infections and possible cancers
- Compromised lung function
- Chronic fatigue

Education, Health & Care Plan:

The A-T Society recommends that every child who has A-T has an 'Education, Health & Care' (EHC) Plan (Previously 'Statement of Special Educational Needs') put in place. This is because of the complicated needs of the child and the continuing deterioration of the condition. A full time 'Learning Support Assistant' is also recommended, not just for support in the classroom, but also in getting about the School.

Help that Children will need in the classroom:

- **Written and Practical Work:** Writing is very difficult because of the poor fine motor skills and involuntary movements.

It is also very tiring and physically hard work as well as being very slow and frustrating. The child should be encouraged to keep up with some writing if they wish to (for their own self esteem), however in time they would benefit from the use of an adapted laptop/computer and someone to scribe for them.

- **Extra time:** Children with A-T need extra time to answer questions, although there are no learning difficulties associated with A-T, there is a slowing down in response times. The child will often know the answer, but it takes a while for them to say something. Questions which require short or one word answers are helpful.
- **Reading:** Reading and the following of objects can be very difficult. Having an LSA to read to the child can help as can talking/audio books. Reading from a computer rather than a book may be easier, book stands can also be of use. Sitting the child at the front of class can also help. (When using printed worksheets, large print should be used).
- **Seating:** Special seating, with an assessment by an Occupational Therapist can help with correct positioning at the table. It is not advisable for the child to stay in the same seat all day, so transferring out of a wheelchair and the use of bean bags during floor time can also help.
- **Conversations:** These may be slow as there is a slowing down in thinking speed as the child gets older. The child may

give a blank look, (children with A-T have poor facial expressions) but this does not mean that they are not listening. You may need to repeat what you say a few times. However you will be understood and with patience the child will be able to respond.

- **Speech:** This is slow and slurred, so it is important to give the child more time to answer you and to avoid finishing sentences for them. (A few children use communication aids).

Help that Children will need in and getting around the School:

- Opening and closing doors
- Climbing up and down stairs (if walking)
- Propelling a wheelchair
- Carrying things such as books or schoolbags
- Changing clothes and shoes
- Eating and drinking, where they may need assistance
- Handling anything that needs balancing or can be spilled
- Playtime Supervision (although the child should be encouraged to join in with others)

Other Considerations:

- **Fatigue**
Children with A-T do suffer from chronic fatigue, which can impact on their overall health. Some children need a reduced timetable to cope with the School day, some need space for a quiet time and rest breaks and others finish School early.
- **Assessments**
Advice and assessments from Physiotherapists, Speech Therapists and Occupational Therapists in School can be very helpful. It is also advisable to design a specialist programme in PE to allow the child to participate as much as possible as well as an IT assessment for written work.

- **Emotional Support**

A supportive environment and understanding from the teacher and other pupils in the class is very helpful for a child's self-confidence and esteem. Although they may be unable to keep up with their peers they should be encouraged to try to do as much as they can. They may feel more self-conscious or clumsy in doing practical tasks, so a supportive friend or having a partner to work with is helpful. Tremors or involuntary movements of the arms, body and legs can be upsetting for the child, as can slurred speech and a difficulty in making themselves understood.

- **Eating & Drinking**

Children benefit from snacks/drinks during the day to keep up their energy levels and manage their fatigue. Some may have problems with eating, such as chewing & swallowing difficulties, which should be assessed by a speech and language therapist.

- **Communication**

Parents need to be kept informed of any infectious childhood diseases which occur in class (as the child with A-T may need special treatment) and they also need to liaise with class teachers to help coordinate catching up with School work due to absences.

Further Information

A-T is a very complicated condition and there may be other symptoms and issues which can affect the child's education. For further information and advice about A-T please contact us:

Tel: 01582 760733

Website: www.atsociety.org.uk

Email: support@atsociety.org.uk

