A guide for schools
And other carers

A guide for those who look after children and young adults diagnosed as having
Alpha-1 Antitrypsin Deficiency
This guide explains what Alpha-1 Antitrypsin Deficiency is and what you need to know if you have a student who has this genetic condition.

The name is long and difficult to pronounce and so the condition is often abbreviated to AATD, while people who have the deficiency usually refer to themselves as Alphas.

What is Alpha-1 Antitrypsin Deficiency?

AATD is a rarely diagnosed genetic condition, primarily featuring an abnormally folded version of the alpha-1 antitrypsin protein produced in the liver.

This abnormal protein gets stuck in the liver and cannot pass to the bloodstream, where it shields the lungs from inflammation when the body’s natural defence system is triggered, such as during infections or in the presence of irritants. The lungs of most Alphas are affected by this condition, and problems with breathing can start as young as twenty. Later in life they may also have problems caused by the accumulation of abnormal protein in the liver.

Some Alpha children are born with liver damage already apparent. Modern medicines may be able to treat some children. In some cases, however, the best treatment is to perform a liver transplant.

What does this mean for you?

Your student is a child with a genetic condition. They may have no health problems at the moment. However, it is also likely that they will have to have more medical checks than normal and may take special medication. Listen to the parents and if you still have questions get more information from medical experts.

Because the liver is affected, an Alpha student may have to be careful in what they eat. Some Alphas have special dietary requirements which will be documented by a dietitian or other specialist. If this is the case for your student, the parent will provide you with the information that they have been given.
Alphas of all ages need to avoid smoke and fumes since these aggravate their vulnerable lungs. Certain chemicals used in cleaners and paints can pass through the skin and affect the liver and although this is unlikely for a teacher to use, you should be aware of this danger.

Relationships with other children

Being marked out as different in some way can make it difficult for students to build friendships at school. This is particularly likely if the student has frequent absences from school.

Schools can help by:
- Ensuring that Alpha children participate in as many activities as possible.
- Watching for signs that a student is having difficulties forming relationships or is being bullied.
- Discussing any problems with parents.

School staff can also play a role in helping to remove any stigma that may be associated with a genetic condition. However, to protect the privacy of the student, school staff should consult with the student and the parents about how much information should be told about the condition.

What do schools need to do?

Alpha students vary in their need for support and each Alpha’s needs change over time.

All school staff should be aware of the individual needs of an Alpha student.

Recommended steps include:
- An initial briefing to explain the student’s needs and to agree how these can be met.
- Healthcare plan, including what to do and whom to contact if the student is unwell.
- Education plan to minimise the impact of AATD on the student’s education.
- Regular liaison to keep everyone up to date.
For more information please visit:
www.alpha1.uk

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