Education Welfare Guide for Parents and Carers of Children with HAE

The majority of parents want the best for their children and having a good education is an important factor in opening up more opportunities in adult life. A child who misses a day of school per week misses an equivalent of two years of their school life.

Failing to attend school regularly means falling behind in work and creates a culture of dissent and can lead to disruptive behaviour. Children who miss school lose out on important factors of school social life, which can affect their ability to have friendships.

Figures have shown that 90% of persistent non-attenders fail to achieve five or more good grades of GCSE and around one third achieve no GCSEs at all.

As a parent or carer of a child or young person with HAE, managing the condition on a day to day basis whilst prioritising attendance at school can be quite a challenge.

What the Law says
The Education Act 1996 states that parents and carers must ensure that all children of compulsory school age (5-16) receive a full-time education that is suitable for their age, ability and aptitude and special educational needs.

Children must be educated from the commencement of the school term following their 5th birthday, until the last Friday in June of the school year in which they reach their 16th birthday.

The Local Authority has a responsibility to ensure that parents fulfill their legal responsibility and must also ensure that there are enough school places for all children to attend. As a parent you may be committing an offence if you fail to ensure that your child attends school regularly.

Once you have registered your child at a school it is your responsibility to make sure that s/he attends regularly and punctually.

If you fail to do so the Local Authority has a statutory duty to consider legal action to enforce school attendance. This may involve the issuing of a penalty notice, prosecution or application for an Education Supervision Order.

The role of the Education Welfare Service will vary in each Local Authority and the extent to which they are involved in your school will depend largely on the type of school and what services the school is paying for.

It is in your interests to find out the names and responsibilities of the key people involved in managing attendance at your child’s school and the Local Authority.
Who Authorises School Absence?
The Head Teacher authorises absence depending on his/her belief that the reason
given for absence by the parent/carer is justifiable and/or genuine.

Therefore, it is very important that you provide the Headteacher with as much
information about HAE as possible so that they have a clear understanding of the
condition and the effect on your child and your family. In addition to this you can:

- Report absences swiftly, providing as much detail as you can
- Where possible, indicate the expected length of the absence
- Involve the school nurse in discussions about your child’s health
- Involve the Education Welfare Officer in discussions about your child’s
  attendance
- Avoid taking holidays during term time
- Avoid making appointments, such as dental, during term time

Most schools will respond sympathetically and be supportive, but should you
find yourself in the difficult position of defending your decision to keep your
child off school, the following information may help you:

- Ask your Headteacher to provide a copy of the following documents, which
  are statutory and must be made available upon request:

  a. Home School Agreement
  b. Equality Information & Objectives
  c. Register of Your Child’s Attendance
  d. Complaints Procedure

  Other useful documents are:

  e. Attendance Policy
  f. Disability Discrimination/Equality Policy

- Check that your school recognises HAE as a disability and that they have the
  policies and procedures to deal with it fairly

- Keep a record of all conversations, telephone calls & correspondence.
  Include date, time & the name of the person you spoke to.

- Follow the school complaints procedure if you are not satisfied with the school
  response

- Remember that the Headteacher is answerable to the School Governors
- The school is responsible for educating your child while they are on roll (registered with them). This could mean being educated at home if the circumstances require it.

At the end of the day, everyone wants the best for your child. A well managed school will be able to reassure you by having the following in place:

- A detailed risk assessment, specific to your child and their needs
- A detailed Care Plan, usually prepared by the school nurse, in conjunction with the school and parents
- First Aid provision at all times, including before & after school clubs
- Clearly documented emergency procedures, specific to your child
- An up to date, signed Health & Safety Policy & Procedures

- Ask your school to ensure that any attendance initiatives such as a rewards scheme, use adjusted attendance percentages. This means that the school must exclude absences related to your child’s disability from any calculations. This will ensure your child is not treated unfairly.

- The same applies to any attendance punishments.

Failure to ensure this could lead to your child being bullied for reasons such as bringing the class percentage down, or exclusion from treats such as trips and certificates.