You may have been given this information because a child in your care has Hunter syndrome, a rare genetic condition that affects many parts of the body, and in 7 out of 10 cases, also impacts cognitive and learning ability. Children with Hunter syndrome will require adaptations to the learning environment, which may need adjusting over time with the changes in symptoms.

Introduction to Hunter syndrome

Hunter syndrome, also known as mucopolysaccharidosis type II (MPS II), is a rare genetic disease almost exclusively affecting boys. Hunter syndrome is one of a number of lysosomal storage diseases (LSDs). It is estimated that the condition is present in 1 in 162,000 live births. Hunter syndrome can affect any part of the body and causes a number of signs and symptoms. Hunter syndrome is progressive, so symptoms advance over time.

There are two types of Hunter syndrome patients; these are known as neuronopathic (patients with cognitive impairment) and non-neuronopathic (patients without cognitive impairment). Both types of patients experience the signs and symptoms that affect the body, but the neuronopathic patients also have symptoms that affect the brain and nervous system, meaning that behaviour and development is also affected.

Symptoms usually show between the ages of 2 and 4 years in the neuronopathic type, whereas the non-neuronopathic type generally presents later in childhood.

Absences

Children with Hunter syndrome have to attend many healthcare appointments, so the school may need to be flexible around appointments that fall within school time. Children with Hunter syndrome may also be too unwell to attend school more frequently than other children; they are susceptible to ear infections and respiratory infections (coughs and colds).

Symptoms that may particularly affect the educational environment

- Hunter syndrome affects the skeletal system, restricting joint movement and causing mobility difficulties
- Some children with Hunter syndrome may have carpal tunnel syndrome, curled-in fingers, or problems with the nerves, which can affect hand function and fine motor skills
- Children with the neuronopathic type of Hunter syndrome often have developmental delays, including delayed speech
- The neuronopathic type of Hunter syndrome can also cause behaviour such as hyperactivity, obstinacy, and aggression
- Hunter syndrome's effects on the skeleton can lead to difficulties with opening the jaw and chewing. An enlarged tongue can contribute to problems with swallowing
- Vision may be affected by Hunter syndrome, in both the neuronopathic and non-neuronopathic types of the disease
- Nearly all children with Hunter syndrome experience hearing loss

Visit **Huntersyndrome.info** to learn more

Special educational needs

Some children with Hunter syndrome will be able to attend mainstream school, whereas others will benefit more from being in a school for children with special educational needs.

Children with Hunter syndrome may have a statement of Special Educational Needs or need an Individual Education Plan (IEP) with regular reviews.

The UK MPS Society has made the following recommendations for adapting the educational environment for children with neuronopathic Hunter syndrome:

- Having a varied and flexible curriculum tailored to the child
- A change of activity may be required every 5–10 minutes
- Giving one-to-one support
- Having familiar people and routines
- Focusing on activities that the child enjoys
- Having a soft play area or outdoor area

Your local or national MPS society may be able to offer further support and information.