



You may have been given this information because your employee has Hunter syndrome, or is a carer for someone with Hunter syndrome. This is a rare genetic condition that affects many parts of the body. Symptoms present in childhood.

Carers or family members of those with Hunter syndrome may require flexible working arrangements to accommodate healthcare appointments or time for caring for unwell dependents.

Employees with Hunter syndrome will require adaptations to the work 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; these are known as neuronopathic (with cognitive impairment) and non-neuronopathic (without cognitive impairment). Both types experience the signs and symptoms that affect the body, but the neuronopathic type also has symptoms that affect the brain and nervous system, meaning that behaviour and development are also affected.

If your employee is a carer

People with Hunter syndrome have to attend many healthcare appointments, so the workplace may need to be flexible around appointments that fall within work hours. Those with Hunter syndrome may also be unwell more frequently than others, so carers may need to take time off work to look after their child if they are unwell.

Check the legal rights that carers have in your country; these may include flexible working or leave.






Visit Huntersyndrome.info to learn more





If your employee has Hunter syndrome

Hunter syndrome has a variety of effects on the body, which can advance over time, and are likely to necessitate adjustments to the work environment.

-  Hunter syndrome affects the skeletal system, restricting joint movement and causing mobility difficulties
-  People with Hunter syndrome may have carpal tunnel syndrome or curled-in fingers, which can affect hand function and fine motor skills
-  Vision and hearing may be affected by Hunter syndrome
-  People with Hunter syndrome are susceptible to ear infections and respiratory infections; this and other various problems may mean that the employee will be too unwell to work sometimes
-  Hunter syndrome requires regular healthcare appointments; your employee may need to work flexibly or take time off to attend these

Check the legal rights that employees with disabilities have in your country; these may include adjustments to the work routines and environment.

Find out more

The Equality and Human Rights Commission can provide information on legislation about adapting the workplace for disabled people:

www.equalityhumanrights.com

Your local or national MPS society may be able to give you more information about Hunter syndrome, and advise on ways you can support your employees

Visit Huntersyndrome.info to learn more

This resource is intended only to provide knowledge of Hunter syndrome health topics. This resource is not a substitute for medical advice, and should not be used in place of advice from a healthcare professional. Please contact a healthcare professional for advice. This resource is intended for an international audience outside of the USA and has been produced by Shire. This resource has been developed in accordance with industry and legal standards to provide information for the general public about Hunter syndrome health topics. Shire makes every reasonable effort to include accurate and current information. However, the information provided in this resource is not exhaustive.

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