



# A Handbook for Schools Understanding Childhood-Onset Hereditary Spastic Paraplegia (HSP)

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## What Is HSP?

Hereditary Spastic Paraplegia (HSP) is a group of rare, genetic neurodegenerative disorders that primarily affect the long motor pathways in the spinal cord.



***While HSP primarily affects movement, some students may also experience differences in learning, processing, or attention.***

- The hallmark feature is progressive lower extremity spasticity and weakness.
- HSP is not a single condition. More than 90 gene types (SPG types) have been identified. Each gene impacts cellular function differently, resulting in wide variability in symptoms, severity, and progression. Even individuals with the same gene type may present differently.
- Because different pathways are involved, HSP is best understood as a spectrum condition rather than a single clinical picture.
- Symptoms may evolve over time and vary significantly between individuals.

### Possible Motor Features

- Lower extremity spasticity
- Gait abnormalities / toe walking
- Muscle stiffness
- Weakness
- Fatigue
- Balance challenges
- Contractures
- Bladder and bowel dysfunction
- Hyperreflexia

### Possible Complex Features

- Speech differences
- Fine motor challenges
- Differences in learning, attention, or processing
- When fatigued: behaviour regulation
- Seizures (in some gene types)
- Vision or hearing differences

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**Suggested Accommodations:** \_\_\_\_\_

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***Please, be sensitive to diagnostic disclosure wishes***

## Key Messages

- Walking long distances or navigating busy spaces may require more time or energy.
- Fatigue can impact both movement and cognition.
- Increased effort required for movement can impact physical education and long schooldays.
- Written work may take more time due to motor effort or fatigue.
- Long written assignments may require additional support or alternative formats.
- Physical and cognitive fatigue may increase throughout the day and impact focus and/or participation.
- Output may not reflect understanding.
- Processing time can vary.
- It can impact on bathroom readiness.



## What Educators Should Know

- Although learning pathways may be different, with the right accommodations, students can access the curriculum and thrive.
- Support should be individualised as needs vary greatly from student to student and can vary day to day.
- A student's performance may not always reflect their true ability, especially where fatigue is a factor.



## Support Strategies That Help

- Extra time between classes and reduced walking distances.
- Elevator access, rest breaks, and locker placement near classrooms.
- Typing instead of handwriting.
- Extra time on tests, assignments, and everyday work.
- Adapted physical education to support participation.
- Supports may be provided through a 504 Plan or IEP (in the US), EHCP in the UK and other equivalents in each country.
- Physiotherapy for mobility and strength, supportive therapies (such as occupational therapy, mobility aids if needed and speech therapy). These adjustments help conserve energy and enable full participation in school life
- Provide wait time, offer multiple response formats.
- Consider seating for accessibility and social inclusion.
- Provide access to devices, flexible deadlines.

## Mobility Can Vary. Students May:

 Walk independently  Use orthotics.  Use mobility devices



## Participation & Inclusion

- Students can participate in a wide range of activities.
- Schools should take a flexible, individualised approach, making necessary adaptations to ensure inclusion.



## Confidence & Future Outcomes

- Encouragement should focus on what students can do.
- Independence, problem solving, and self-advocacy are important.
- Connecting with others with HSP or physical disabilities can be powerful.
- Students with HSP pursue a wide range of paths — including careers in science, technology, the arts, advocacy, and more.
- With the right support and opportunities, their future is wide open.

**Scan the QR code for a more comprehensive view of Childhood-Onset HSP, and how learning is impacted.**

**Different pathways. Limitless potential.**

