The Hereditary Spastic Paraplegia Support Group

Moving Forward Together

What is Hereditary Spastic Paraplegia (HSP)?

- A group of rare genetic conditions. At present, there are over 90 different types of HSP. Some people have a clinical diagnosis without a genetic diagnosis because not all responsible genes have been found.
- Progressive (gradually getting worse) neurological symptoms.
- Key symptoms are spasticity (muscle stiffness) and/or paraplegia (weakness) of the lower limbs.
- The age at which symptoms start, their ultimate severity and rate of progression can vary greatly between people.

The HSP support group.

The HSP Support Group is a UK charity supporting those with Hereditary Spastic Paraplegia. Their website is at hspgroup.org. They also have a YouTube channel, at https://www.youtube.com/@ukhsp-spasticparaplegia

Information about HSP can be hard to find. The HSP support group website has lots of information, including links to HSP support groups worldwide, professional and local organisations, and information about HSP.

The support group runs positive friendly meetings, both in person and online. Feedback includes: “The support group information was most useful”.

Many with HSP find life more isolating, and engaging with the support group or a similar community can be positive.

Symptoms of HSP.

Everyone with HSP is different. When symptoms start and their speed of progression varies from individual to individual, even in people in the same family with the same mutation. Most people (some 90%) with HSP have an uncomplicated form (sometimes called pure). This means that symptoms are typically confined to some (or all) of these;

- Lower limb weakness
- Involuntary spasms / cramps
- Increased muscle tone and stiffness (spasticity)
- Urinary problems – such as a frequent sense of urgency
- Fatigue
- Pain

There are a few other symptoms which can affect those with uncomplicated HSP. In addition, people can be affected by depression.

Some 10% of people have a more complex type of HSP (sometimes called HSP plus). In this case, the common symptoms are the same as uncomplicated HSP, but people have additional symptoms affecting other areas of the body.

Symptom management.

At present, there is no known treatment that can prevent, stop, or reverse HSP. The mobility symptoms of HSP can often be managed in a number of ways including:

- Muscle relaxants including baclofen, tizandine and botulinum (Botox) injections
- Regular physiotherapy or exercise
- Stretching
- Occupational therapy

Exercise is key.

Stretches are very important to prevent contractures (loss of range of movement) in joints and doing these regularly is important.
Pilates, Yoga and swimming are some exercises that people with HSP have found beneficial.
Other forms of exercise are beneficial, particularly those that a person enjoys as this increases motivation.

Treatments are also available for many non-motor symptoms. Your GP or neurologist can advise on options for these. Some people may need to use wheelchairs later in their HSP journeys and require modifications to their homes. Further information is available on the HSP patient journey at: https://www.ern-rnd.eu/patient-journey-hereditary-spastic-paraplegias-hsps/