

# Physiotherapy

## A qualitative study of people with Hereditary Spastic Paraplegia (HSP) around diagnosis and treatment.

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<b>Abstract:</b>	<p>Abstract</p> <p><b>Aim</b> Identify what benefits people with HSP at diagnosis and explore the impact of physiotherapy on self-management.</p> <p><b>Method</b> Insider research, as the researcher also has HSP and is a physiotherapist, provides a unique perspective. An online questionnaire with a mixture of open and closed questions was completed by 101 people with HSP, and nine semi-structured interviews were conducted.</p> <p><b>Results</b> Only 16% of questionnaire participants had any awareness of HSP prior to diagnosis, and the information provided at diagnosis was very limited, with 24% reporting being given no information. Several factors were found to influence self-management for people with HSP: knowledge of the condition, emotional state, physiotherapy input and exercise. Exercise was reported as beneficial for symptom management by people with HSP, and stretches were reported to be the most beneficial type of exercise. Sociable exercise, part of a community, and people enjoying it were important for motivation. Finding appropriate exercise classes is important, with instructors who take time to understand the problem and adapt the exercises. Those who did this were valued by people with HSP. There were many factors that limited people's exercise routines. Time, energy, perception of capability, emotional state, understanding of exercises, motivation and support all played a part in whether people were participating in exercise or not.</p>

# Cover Letter

My name is Estelle Marshall, and I am a retired physiotherapist. I worked in the NHS in a wide variety of areas, within hospital and community settings, between 2002 and 2023. I was diagnosed with HSP (SPG 7) in 2018, with no family history of the condition. Due to the condition's rarity, before receiving the diagnosis, my knowledge of HSP was limited. Since receiving the diagnosis I have done a lot of reading and networking to increase my knowledge.

I conducted research on HSP for a Master of Science at the University of Lancashire to identify what benefits people with HSP at diagnosis and explore the impact of physiotherapy treatment on self-management in the long term. A questionnaire was completed by 100 people with HSP, and 9 interviews were conducted. I am currently a trustee in the UK HSP support group, the UK representative for Euro HSP, run a monthly zoom meeting for all UK members, and an associate lecturer at the University of Lancashire.

March 2026 I published a self-help book called living well with HSP, explaining the medical terminology in easy to understand ways. This book has a large focus on exercise and gets people to identify what changes they are able to make to their own lives. I am currently in the process of writing a book about HSP for health professionals. The research article highlights the need for increased awareness of HSP.

# A qualitative study of people with Hereditary Spastic Paraplegia (HSP) around diagnosis and treatment.

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EM: Conceptualisation, Methodology, Investigation, Writing-Reviewing and Editing

## Key Words

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Approved by the University of Lancashire Ethics Committee.

## **Abstract**

### **Aim**

Identify what benefits people with HSP at diagnosis and explore the impact of physiotherapy on self-management.

### **Method**

Insider research, as the researcher also has HSP and is a physiotherapist, provides a unique perspective. An online questionnaire with a mixture of open and closed questions was completed by 101 people with HSP, and nine semi-structured interviews were conducted.

### **Results**

Only 16% of questionnaire participants had any awareness of HSP prior to diagnosis, and the information provided at diagnosis was very limited, with 24% reporting being given no information.

Several factors were found to influence self-management for people with HSP: knowledge of the condition, emotional state, physiotherapy input and exercise.

Exercise was reported as beneficial for symptom management by people with HSP, and stretches were reported to be the most beneficial type of exercise.

Sociable exercise, part of a community, and people enjoying it were important for motivation.

Finding appropriate exercise classes is important, with instructors who take time to understand the problem and adapt the exercises. Those who did this were valued by people with HSP.

There were many factors that limited people's exercise routines. Time, energy, perception of capability, emotional state, understanding of exercises, motivation and support all played a part in whether people were participating in exercise or not.

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## **Contribution to the paper**

This paper adds a deeper understanding of the emotional impact of receiving a rare genetic, progressive neurological condition.

This paper reinforces the importance of exercise, particularly stretches, for the management of HSP.

## **Key Words**

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## **Introduction**

Hereditary Spastic Paraplegia (HSP) is an umbrella term for a collection of progressive, rare neurological diseases. The HSP group of conditions is divided into uncomplicated and complicated. Uncomplicated HSP is characterised by lower limb spasticity and weakness of varying magnitude and is typically accompanied by urinary urgency. Complicated HSP also includes one or more additional neurological symptoms [1]. The age of onset and the speed of progression vary greatly among individuals, even within families with the same gene mutation [1].

Treatment for HSP is currently limited to symptom management [1]. The available evidence regarding the effectiveness of physiotherapy for people with HSP is quite limited [2]; although, people with HSP and professionals widely report the benefits of physiotherapy [3], and there are some studies that do highlight the benefits of physiotherapy, five of which focused on the use of exercise for treatment. A case study involving a 10-year-old male involved stretches, strengthening and cardiovascular exercise and found improvement in the sit-stand, 10m walk and 1 min walk test, and these were maintained one year after treatment [4].

A case study of a 47-year-old female involved education about the condition, a stretching program, fatigue management advice and exercises for posture and balance. Outcome measures showed reduced spasticity, reduced fatigue, reduced work of walking, and reduced frequency of falls [5]. A pilot study with 16 participants examined the use of the Nintendo Wii Plus as an intervention for individuals with HSP, finding improved balance and a reduced frequency of falls [6]. A study

examining the efficacy of hydrotherapy found an 11% increase in gait velocity following treatment, attributed to increased cadence and step length [7].

Due to the limited available research on HSP, the impact of receiving a diagnosis and self-management has been looked at for other neurological conditions. Self-management is the ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle choices inherent in living with a chronic condition [8].

A paper by Topcu et.al reviewed thirty-seven papers in a meta-synthesis of qualitative papers with people with MS on this topic [9]. Key themes emerged: for example, all the studies found that people with MS experienced considerable emotional upheaval, with many challenges and disruptions experienced around the point of diagnosis; this can threaten people's sense of self and meaning. The paper identified that after receiving the diagnosis of MS, people went through a period of grief, often experiencing denial. Lack of knowledge about MS and the lack of information provided at diagnosis were issues raised in fourteen of the papers looked at, and [9] further identified the importance of people having access to various support resources, information and advice to aid the adjustment process, identifying that as information and advice is fundamental for people's ability to adjust [9].

Ten adults in the UK with progressive neurological conditions were interviewed about self-management, identifying a sense of self as important for those living with a progressive neurological condition, and expressing that they wanted to be valued as a person and not defined by their conditions [10]. Having a good knowledge of their condition facilitated the effective management of day-to-day activities, and as people learned to understand the nuances and triggers of their condition, they were able to make more informed decisions on their lives and take control [10]. It has been suggested that the best prediction of life satisfaction was found to be acceptance of disability [11].

### **Method**

Ethical approval was sought and granted in line with UCLan policy for post-graduate research. Permission was gained from the HSP support group, which distributed the invitation to participate in the research to all the members. Being a physiotherapist and having HSP positioned the researcher as both an insider and an outsider in relation to the subjects of this research study. As an insider researcher, it has been important for the researcher not to assume that they understand the lived experience of others with HSP and to remain impartial when conducting and analysing the research [12]. To aid with this, a reflexive diary was used by the researcher both before, during the conduction of the research and during the data analysis phase as advised by [13]. The fact that the researcher also had HSP contributed to the positive response rate, as people were keen to help 'one of their own.'

An online self-administered mixed questionnaire and interviews were conducted. The invitation for both was distributed via email to all members of the UK HSP support group and put on the UK HSP Facebook page. The inclusion criteria for the questionnaire and the interviews were people living in the UK, aged over 18, diagnosed with HSP (clinical diagnosis or genetic diagnosis), with access to either a smartphone or a laptop, able to read and write in English and able to provide informed consent. The questionnaire was on Microsoft Forms and contained questions on consent, diagnosis, information, exercise, and physiotherapy treatment, and looked at all the objectives. There was a mixture of open- and closed-ended

questions; apart from the consent questions, none of them were compulsory, although most participants completed all of them.

The interviews focused on gaining insight into the participants' experience of physiotherapy since diagnosis and looking at the self-management of physical symptoms; this led naturally into exercise and their feelings towards exercise and their exercise routines. The interviews were all conducted by the researcher in a relaxed conversational style. There were nine interviews conducted over two weeks, arranged at times to suit the participants. There were four women and five men with an age range from 30 to 82.

The information gathered from the open-ended questions was analysed using mind maps. A few key quotes were chosen, and themes were pulled out from the mind maps. The data from the interviews were analysed using a systematic six-step thematic analysis. Several quotations have been carefully selected, and these illustrate the findings while respecting the participant's confidentiality. This work was financially supported by the HSP support group with no involvement in the study.

Interviewees have been given pseudonyms to protect their anonymity.

## **Results**

### **Questionnaire**

The questionnaire was completed by 101 people. Four main themes emerged from this.

#### **Diagnosis process**

30% of the participants in the questionnaire described the diagnosis process as lengthy and 31% difficult, with visits to multiple health professionals. Misdiagnosis and not being listened to were issues raised by 14% of participants in the questionnaire.

Those with a known family history tended to have a more straightforward diagnosis process. However, this was the minority as only 16% of participants had any awareness of HSP before receiving the diagnosis.

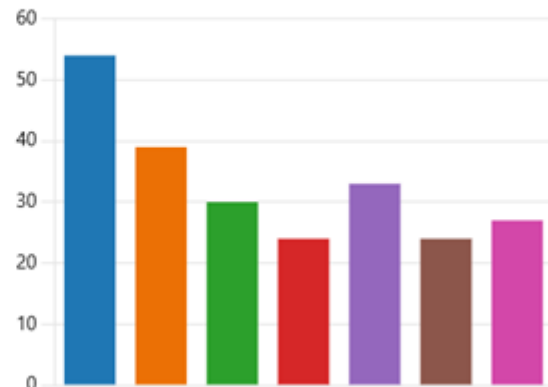
The data collected indicates that the experience and impact of the diagnosis process varied greatly from one individual to the next. A positive experience was described by 14% of participants, which included describing staff as being friendly, sympathetic and professional.

### **Table 1**

### 13. What information on HSP were you given at diagnosis?

[More Details](#)

● Explanation of what HSP is.	54
● Explanation of mode of inherita...	39
● Explanation of variation of symp...	30
● Advice on symptom managemen...	24
● Symptom progression.	33
● None	24
● Other	27



At diagnosis, the information provided was very limited for most people, who then had to find out about the condition themselves. The support group played an important role for people when they were diagnosed, and only one question was asked about the support group, but 35% of participants mentioned the support group when asked, 'Since diagnosis, what information or advice have you found useful?'. One participant said 'The information gained from the support group has been amazing and has been a lifeline to me. I have felt supported and no longer alone'.

#### **Impacts of the diagnosis.**

Feelings around receiving the diagnosis were often conflicting, with an element of relief expressed by 26% ('Good to have a name for it') and validation that they were right to fight for the diagnosis. There was also relief that it was not something life-threatening, with overlapping symptoms to many other conditions; 'I was expecting a motor neuron disease diagnosis, so although upsetting, it was a relief'. Negative emotions were expressed by 49% of participants, and even those who expressed some relief also expressed worry and sadness at receiving the diagnosis. One participant described their feelings thus: 'mixture, first was validation. loss and bereavement. Worthless'; while another said, 'It was a relief to know there was an answer, but huge dismay that "nothing can be done" a life sentence really'. 9% of participants expressed fear of the future for themselves and/or their children.

For those with family members with known HSP, the overall emotion expressed was that of sadness. Often, having watched a family member deteriorate, they had more awareness of the prognosis. Some expressed fear at the deterioration that they knew would happen, and how it would impact their life. One participant said: 'Seeing the decline in others is a reminder of the decline ahead. It's very real and very scary'.

The group of people that the diagnosis impacted the least were those who had lived for a time with a misdiagnosis, such as MS (Multiple Sclerosis) or CP (Cerebral Palsy). The diagnosis also provided some positive impacts and 10% of participants expressed that the diagnosis assisted with understanding, reaching acceptance, planning for the future, or facilitating getting the support that they needed. One participant said: 'It helped me get the support that I needed, such as a neurophysiotherapist, mobility aids, etc'. 6% of participants expressed finding it difficult to take in the information provided at diagnosis due to the emotional reaction

to receiving the diagnosis , for example, “What I was told went straight out of my head. I had to ask him to write it down. (I was Scared). The information was too much to take in”.

Some people recognised going through the grieving process. Loss was expressed by 10% of participants. The loss of the future they had planned was frequently expressed. As it is a progressive condition, people become more physically limited and experience more loss as it impacts more parts of their lives. Depression, feelings of worthlessness, worry and anxiety were expressed by 15% of participants. One participant said, 'Devastated failed my exams cos I was so depressed, altered the whole course of my life' and another 'Plunged me into a deep depression' 'Absolutely traumatised, devastated and totally suicidal'. With the progressive nature of the condition, people often went through the grief process more than once.

### **The impact of Physiotherapy.**

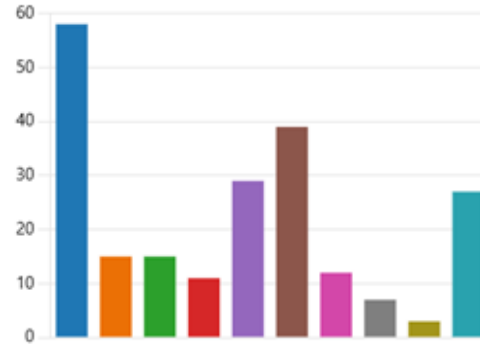
Most people were aware of the importance of physiotherapy, and 50% of people received treatment from a physiotherapist in the first year after diagnosis, with 55% of those seen being by a neuro physiotherapist. A positive experience of physiotherapy was expressed by 29% (useful, provided motivation, improved quality of life, helped understanding) and 18% describing negative experiences (awful, inconsistent, unrealistic goals, limited, lack of knowledge), 11% described a mixed experience, one participant said 'you get good physio's and not so good physio's I remember the one's that explained things as they have been going along' and 4% reported not having received any physiotherapy. Good communication was key to positive experiences of physiotherapy. The physiotherapy treatment that people received and found useful varied (See table 3), but stretches were by far the highest, with 62% and the next highest treatment that was found useful was the provision of walking aids by 42% of people.

### **Table 3**

19. Since diagnosis what physiotherapy treatment have you found helpful?

[More Details](#)

● Stretches	58
● Gait education (improving walki...	15
● Advice on spasticity management	15
● Pelvic floor exercises	11
● Balance exercises	29
● Advice/provision of walking aids	39
● Fatigue management (pacing)	12
● Advice on exercise groups	7
● Expert patient programme	3
● Other	27



One participant explained how physiotherapy provided her with the skills to be able to help herself: 'I knew I must do something to help myself. When I met this neuro physiotherapist, it opened the way to start moving'.

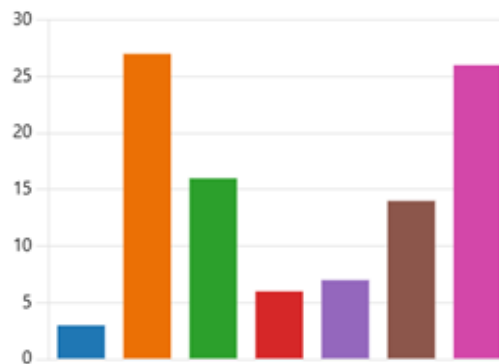
**Table 4**

20. How often do you do an individualized exercise program provided by a physiotherapist?

[More Details](#)

[Insights](#)

● More than once a day	3
● Daily	27
● Weekly	16
● Monthly	6
● Less often than monthly	7
● Have but don't do.	14
● Never been provided with one.	26



**Exercise.**

**Table 4**

## 22. Do you do any exercises regularly?

[More Details](#)

[Insights](#)

● Yes	67
● No	32



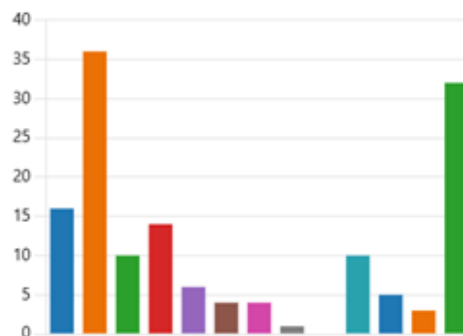
Exercise is important for the symptom management of HSP [6], and many people with HSP do embrace exercise. People reported that exercise helped them to keep mobile; 68% (table 4) of participants exercise regularly, and 47% of participants described exercise as beneficial, both physically and psychologically. When asked what exercises they found helpful 43% reported stretches. Although 5% of participants reported increased pain with exercise, it is unknown which forms of exercise these participants had tried.

**Table 5**

## 23. Have you done any exercises in the community since diagnosis?

[More Details](#)

● Pilates	16
● Swimming	36
● Cardiovascular machines	10
● Yoga	14
● Aqua-aerobics	6
● Tai Chi	4
● Dancing/Wheelchair dancing	4
● Racket sports	1
● Football	0
● Weights	10
● Walking groups	5
● Other sports	3
● Other	32



Enjoyment of exercise can increase motivation, and 26% report that they enjoy exercise. 30% of participants reported that doing the exercises at home was 'boring' and being with other people helped motivate them.

Negative emotions towards exercise decrease motivation, and this was expressed by some.

People's emotional state impacts motivation, with one participant saying: 'I want to (exercise) but depression is holding me back'.

People participated in a wide variety of exercises, and 67% exercised regularly.

### **Experiences of physiotherapy.**

Participants all described mixed experiences of physiotherapy. There were several examples of physiotherapy impacting long-term self-management, and people reported that they were continuing with exercises years after being shown by a physiotherapist.

One of the main differences between a perceived positive and a negative experience of physiotherapy was communication.

Five of the interview participants have accessed physiotherapy privately.

### **Exercise**

Eight out of the nine participants interviewed participated in exercise regularly. Responses to exercise advice varied. Cristal, initially daunted by the lack of a 'magic pill,' now views exercise as essential. Ben, who has always been active, taking part in competitive sports, continues to exercise despite physical decline, treating it as his 'work.' Support from exercise instructors is highly valued, enhancing motivation and adherence to exercise routines.

People reported difficulty in motivating themselves to do exercise at home and reported that a sociable exercise environment increased motivation, and finding exercise that they enjoyed was important.

All participants, apart from one, were doing stretches regularly as part of their exercise routine.

### **Quality of life.**

There were many factors that impacted the participants' quality of life. The physical limitations of disability affected individuals' lives differently. For example, Tom was restricted by the fatigue levels, and this had prevented him from going out.

Acceptance of disability had an impact, particularly with regard to the use of aids;

Doreen's embarrassment caused her refusal to use walking aids, limiting her life, whereas Philip describes his wheelchair as his best friend and talks about the freedom it provides. Support and being part of a community were expressed as important by the participants. Early retirement frequently occurred, and many people found new ways to use their skills, such as setting up support networks or engaging in community activities. Financial resources were identified as being able to improve quality of life in many ways, such as enabling access to better equipment and accessing services privately. Hobbies, voluntary work and adapted activities play a significant role in maintaining a fulfilling life, and people are involved with a wide range of activities.

## **Discussion**

The findings highlight the emotional impact of the diagnosis process and the need for emotional support at this difficult time, in line with [9], who highlighted the need for emotional support for people diagnosed with MS.

The lack of knowledge of HSP by healthcare professionals was an issue seen, in line with previous research by [14], highlighting a training need within the NHS. The research also found a link between knowledge of the condition and self-management, in line with [8] who found that having a good knowledge of the condition facilitated the effective management of day-to-day activities, and as people learned to understand the nuances and triggers of their condition, they were able to make more informed decisions on their lives and take control over their condition.

The research found that stretches were the type of exercise that people had the most benefit from, and this is in line with previous research [2].

There is the potential of recruitment bias due to convenience sampling, as all the participants for both the questionnaire and the interviews were recruited through an invitation on the HSP support group. More proactive people with HSP may be more likely to respond to the invitation.

The research highlighted the need for emotional support for people going through the diagnosis process and those recently diagnosed with HSP, as well as the need for increased awareness of the condition and the need for increased information provided at diagnosis. The importance of exercise for long-term symptom management is highlighted, particularly stretches which were identified as beneficial by 58% of questionnaire participants, and the use of exercise groups with social interaction was found to be an important factor in motivating people to exercise.

## **Conclusion.**

Many participants experienced significant delays and challenges in getting diagnosed. This led to confusion, anxiety, and frustration. A minority (16%) had a known family history, and these people generally had a quicker diagnosis process. Receiving the diagnosis of HSP had an emotional impact that profoundly impacted all areas of individuals' lives, including self-management strategies.

Physiotherapy is widely recognised as important by people with HSP, and useful treatments include individualised exercise programs and walking aids, with stretches being identified as the most beneficial by 62% of participants. Positive physiotherapy experiences equipped individuals with essential skills for symptom management, and this was the case in six of the nine participants interviewed.

Exercise was recognised as crucial for managing HSP symptoms, and 68% of participants reported that they exercise regularly, with 47% who reported finding it beneficial both physically and psychologically. Common exercises include stretches, yoga, and swimming, which help reduce stiffness and pain.

## **Abbreviations**

CP Cerebral Palsy

HSP Hereditary Spastic Paraplegia

MS Multiple Sclerosis

Ethical approval was obtained from the University of Lancashire's ethics department.

Funding for this work was gained from the UK HSP support group.

There is no conflict of interest.

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