

Hippotherapy in the management of hypermobile Ehlers-Danlos syndrome

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Accepted 24 October 2024

SUMMARY

Hypermobile Ehlers-Danlos syndrome (EDS) is an inherited condition marked by joint hypermobility, instability, chronic pain and fatigue, significantly impacting quality of life and autonomy. Management focuses solely on symptom alleviation. After experiencing a rapid decline in functional abilities, a patient in late adolescence with hypermobile EDS underwent hippotherapy rehabilitation (30 hours). She saw substantial improvements in fatigue, chronic pain and regained walking abilities. Hippotherapy played a crucial role in refining her postural balance, motor skills, proprioception, muscle function and endurance. It also positively affected her cognitive and emotional regulation by stimulating sensory inputs that activate neural pathways, providing relief from pain and fatigue. Notably, the patient transitioned from wheelchair reliance to walking with crutches, and then greatly enhanced both gait quality and speed. These findings demonstrate the relevance of hippotherapy for the rehabilitation of hypermobile EDS, reducing the need for pharmacological interventions and fostering a proactive approach to future challenges.

BACKGROUND

Ehlers-Danlos syndrome (EDS) encompasses a spectrum of genetic disorders characterised by various symptoms, including hyperextensible skin, joint hypermobility and impaired wound healing.^{1,2} As a result of the numerous deficiencies, quality of life (QoL) in people affected by EDS is severely impaired and the psychological burden of the condition is significant.³⁻⁶ Hypermobile EDS is one of the most prevalent subgroups, accounting for 90% of EDS cases and affecting 1 in 3000–5000 people.⁷ However, as this is the only subgroup that cannot yet be detected by genetic screening, the prevalence of hypermobile EDS may be underestimated.⁷ Hypermobile EDS is responsible for chronic pain, kinesiophobia, joint instability and joint hypermobility.⁸⁻¹¹ The QoL of the patients and their caregivers is significantly affected, mainly because of the chronic pain and great fatigue experienced by them. Because of their joint hypermobility, people with hypermobile EDS also have impaired walking, involving ankle and knee flexion, as well as foot placement during the stance phase.^{10,11} There is no known treatment for hypermobile EDS other than symptomatic management. These approaches are multidisciplinary, ranging from pharmacology for chronic pain, to physical therapy to apprehend all the symptoms involved.^{8,12,13} While therapeutic approaches to perform rehabilitation are highly

heterogeneous, they all seem to bring some relief in terms of pain and proprioception, as well as in patients' functional abilities.¹⁴ Indeed, the evidence suggests that therapeutic exercise and motor function training are effective methods for treating individuals with hypermobile EDS. However, there is weak evidence for other interventions such as adaptive equipment, manual therapy and functional training. The lack of guidelines and consensus on physical therapy interventions poses a challenge for clinicians, highlighting the need for further research to determine effectiveness and dosage.¹⁵⁻¹⁷ As a result, there is an overall improvement in the QoL of people affected by hypermobile EDS.¹⁴ However, there are few therapeutic approaches specifically targeting walking, which can be severely impaired and disabling for hypermobile EDS patients.^{10,11}

Hippotherapy is a specialised rehabilitation approach, performed on a specially trained horse via its movement at a walk, by a team of accredited health professionals (eg, physicians, psychologists, physical therapists, occupational therapists, psychomotor therapists and chiropractors) and equine specialists to lead the horse.¹⁸⁻²⁶ As the horse's walking movements are biomechanically similar to human walking movements, they enable micro-adjustments to be made to the patient's postural balance, global and fine motor skills, as well as strengthening sensorimotor control.^{27,28} Given that a horse's walking cadence is around 100 steps per minute, and that the average riding session lasts between 30 and 40 min, the patient performs between 3000 and 4000 postural microadjustments, involving between 3000 and 4000 contractions of the various muscles of the postural apparatus (the human body has over 600 muscles, many of which play a role in maintaining posture). Additionally, through multimodal inputs (sensory, exteroceptive, proprioceptive, interoceptive and emotional), hippotherapy has a direct action on the individual's motor capacities, as well as on her cognitive and emotional spheres.^{21,24,25,29-33} During hippotherapy, the specific execution and repetition of a task are key elements of learning/strengthening/promoting a function and a robust evidence-based rehabilitation/neurorehabilitation backbone.^{18,20,24,26,27,29,30,32-36} Its relevance has been shown in the rheumatology domain including hypermobile EDS.³⁴⁻³⁷ The present case study provides additional evidence to expand the knowledge base on the relevance of the approach in the rehabilitation pathway of patients with hypermobile EDS. Indeed, hippotherapy offers a multidisciplinary approach aiming to work on numerous physical and functional areas, such as balance, posture and walking. Additionally,



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To cite: Viruega H, Loriette C, Quignon M, *et al.* *BMJ Case Rep* 2024;**17**:e261605. doi:10.1136/bcr-2024-261605

Case report

hippotherapy also targets the individual's cognitive faculties and emotional regulation.^{19 24 27 29 33 38 39}

In this article, we study the effects of hippotherapy on a patient with hypermobile EDS. The patient underwent five programmes for a total of 30 hours of rehabilitation through hippotherapy. Improvements were observed in fatigue and chronic pain. Most of all, the patient started walking again and then improved substantially her speed and gait quality over the sessions.

CASE PRESENTATION

Patient history

The patient was a woman in late adolescence. She was initially diagnosed with hypermobile spectrum disorder, then, the diagnosis of hypermobile EDS was given a few months later.⁴⁰ There was no known history of hypermobile EDS in the family. Her condition was characterised by diffuse musculoskeletal pain, recurrent subluxations (shoulder, maxilla, phalanges) and ankle sprains, proprioception disorders, dysautonomia, dysbiosis and chronic fatigue. Her treatment was mainly symptomatic. Non-drug treatments consisted of abundant hydration (2.5 L of water per day to keep urine clear), hypersodic diet, regular movement of limb extremities, physical exercise at least three times a week (walking with Nordic-style walking sticks, exercise cycling, swimming, yoga, Pilates, etc), adapted physiotherapy (twice a week) including isometric and proprioception work (spine, trunk, limbs, feet), transcutaneous electrical nerve stimulation, analgesic massage, the wearing of compression stockings and gloves, adapted orthopaedic insoles (arch support, medial retro-capital support and posterior pronator wedge), ankle stabilisers, sacroiliac and hip stabilisers and stabilisers for hypermobile joints, ergotherapy sessions (once every 2 weeks), mesotherapy sessions (once every 2 weeks), psychological sessions (once every 2 weeks). Subluxations and sprains were managed through the orthotic devices and decreased significantly until they no longer occurred. Pharmacological treatments consisted of supplements, analgesics including opioids and lidocaine-based local anaesthetic.

Initial clinical observations

The patient arrived in an electric wheelchair. She wore compression clothing (compression belt) and multiple bilateral orthoses (wrists, knees, ankles). She experienced chronic fatigue (persistent feeling of emotional cognitive and physical exhaustion⁴¹) and daily pain rated 7–8 in the Visual Analogue Scale (VAS) mainly in the outer part of both ankles and in the lumbar region. She had stopped walking for the last year and a half before starting hippotherapy. When standing with the help of an antibrachial walker, she unevenly distributed her body weight: more weight to the right and a right-tilted pelvis with trembling legs. She relied heavily on her forearms to relieve the weight on her legs, as the load accentuated her instability and pain. When trying to walk, she compensated a lot with her arms, blocking the mobility of her upper body and both legs were trembling uncontrollably.

INVESTIGATIONS

The diagnosis of hypermobile EDS was confirmed by the medical staff of the hospital where the patient was being followed up—a member of the Orphanet network—according to the 2017 criteria⁴²: the Beighton score was 7/9 (criterion 1); 5 out of 12 clinical signs were present (criterion 2 feature A), although no family history was found (feature B) and musculoskeletal involvement was 3/3 (feature C); for criterion 3, all the

prerequisites were met. In the absence of a confirmatory genetic test for hypermobile EDS, genetic testing ruled out other conditions with a similar clinical presentation.⁴²

TREATMENT

The hippotherapy sessions took place at the Equiphoria Institute, a specialised rehabilitation clinic located in the South of France. The hippotherapy exercises on the horse focused on diverse entangled health functioning processes including reinforcement of global postural balance and fine-tuning of postural responses, strengthening of different muscle groups, enhancing upper limb fine motor skills and coordination, improving movement fluidity and psycho-corporal relaxation, reinforcement of the body schema and body image,⁴³ and employment of breathing techniques and visualisations. Attention was given to body and emotional awareness, working memory and executive functions. The therapy also aimed to bolster notions of success, pleasure and disinhibition, as well as social and cognitive flexibility. Additionally, it stimulated proactive postures, involvement and motivation, while fostering self-esteem and self-transcendence. Therapeutic work also included addressing post-traumatic stress disorder and the creation of a new life course meaning.⁴⁴

A minimum set of equipment was essential, including a helmet meeting European standard EN-1384, a specialised multi-belt for emergency manoeuvres. The horse's equipment and preparation ensured patient's safety. Equipment consisted of a specially designed leather saddle pad that enhances comfort and facilitates transmission of the horse's movements and heat. Stirrups were omitted to preserve pelvic mobility. The patient was continuously supervised and accompanied by a team of three staff members (two health professionals and one equine specialist leading the horse) for safety assurance and quality of care throughout the session. For the safety of the patient and staff and comfort of the horse, a mounting ramp was used for mounting and dismounting.

The therapeutic programmes consists of 1 hour of hippotherapy per day during 5–10 days. The patient completed five programmes separated by 3–4 months. The first three and the last programmes lasted 5 days, and the fourth programme lasted 10 days. Based on our clinical experience over the past decade, our programmes have traditionally spanned 1 week. However, on careful consideration of the patient's potential for consolidating functional gains, we advocate for extending the programme duration to 2 weeks. Overall, she performed 30 hours of hippotherapy. The session of hippotherapy planned for the patient was as follows: a mounted period of 35–50 min depending on fatigue and type of session, a walking session lasting 5–10 min from the mounting area to the grooming area and a grooming session by the horse of 5–10 min. Specific exercises on and by the horse were designed to improve the physical, mental and emotional spheres according to the patient's needs and therapeutic goals identified at the beginning of each programme by the multidisciplinary staff (therapists and equine specialists). Depending on the patient's progress, certain previous exercises are reintroduced and enhanced to further bolster functional improvements. The programme is entirely tailored to the individual patient, ensuring a patient-centred approach throughout.⁴⁵

OUTCOME AND FOLLOW-UP

The walking tests were conducted on both the first and last day of the programme, preceding the riding sessions.

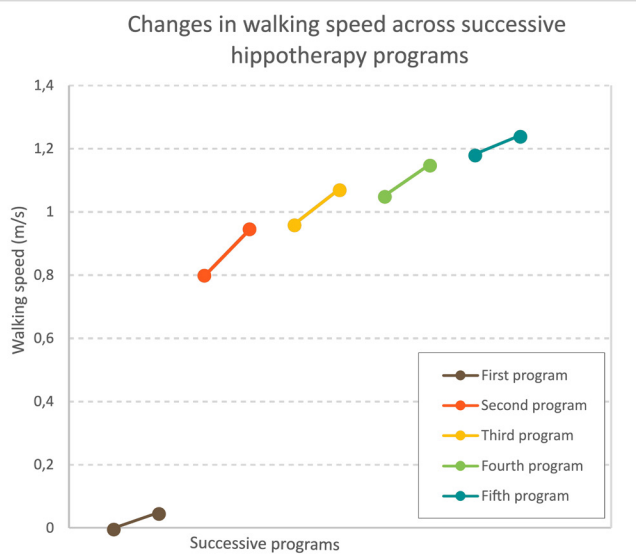


Figure 1 Changes in walking speed during different hippotherapy programmes. Each line represents the evolution over the course of a programme, the first point corresponding to the gait speed during the test on the first day and the second point to the gait speed during the test on the last day of the programme. As the patient was unable to walk on the first day of the first programme, the gait speed was set to 0. The figure is an original work from the authors.

The first important result is the recovery of her walk. In fact, as of the first 5 days programme, she demonstrated her ability and willingness to walk. On the last day of this first programme, we invited the patient to walk without braces with her antebrachial walker. She was able to walk for 3 m, controlling her knees and ankles. She rested on her forearms but was standing straighter, with more freedom of her shoulders and torso, and a symmetrical support. During the first programme on the horse, she developed strategies to relax and to accept the horse's movement more freely. Doing so, she refined her perception of body movements and balance and found greater confidence and pleasure in her physical sensations. During the programme, she reported not feeling as much pain as usual.

During the second programme, she was able to perform a 1 min walking test with her antebrachial walker. On the first day, she was able to cover a distance of 47.9 m (0.80 m/s, figure 1), with a shift of her weight to the right. When standing, the right foot showed an internal rotation and the left foot an external rotation. On the fifth day of the programme, she covered 56.7 m (0.94 m/s, figure 1), with a more homogeneous weight transfer, but still with the same foot rotations when standing with her walker. At the end of the 5 days programme, the patient tried to swap the walker with crutches and was able to cover 12 m. Surprisingly, when standing using crutches, the feet were perfectly aligned, and no rotation was observed.

During the first day of the third programme, the patient was able to cover 57.8 m on the 1 min walking test (0.96 m/s, figure 1). She now had the appropriate walking posture, looking straight up. She showed fluidity while walking and symmetrical paces. She had a close to normal gait pattern. Also, her feet were aligned. The last day of the programme, the patient was able to cover 64.5 m on the 1 min walking test (1.07 m/s, figure 1). With the improvement of postural alignment, tonus, stability, endurance and balance on the horse, the patient was able to focus on experimenting with exercises/techniques to deal with the pain

Table 1 Patient-Reported Outcome Measures through the assessment of the quality of life using the Short Form Health Survey-36 patient-reported questionnaire before the hippotherapy programme and at the end of the last session

Dimensions	Before	After
Physical functioning	5%	50%
Role limitations due to physical health	0%	100%
Role limitations due to emotional problems	33.3%	100%
Energy/fatigue	10%	60%
Emotional well-being	36%	84%
Social functioning	25%	75%
Pain	0%	55%
General health	15%	65%
Health change	50%	100%

Scores for each domain range from 0% to 100%, with a higher score defining a more favourable health state.

associated with the weight support and ankle joint movement while standing and walking.

When the patient came for the fourth programme, she had started to remove the orthotic help on her knees and wrists. She was wearing a new orthotic device shifting from full leg support to just ankle support. She reported being now able to walk for longer distances with less ankle pain. On the first day, the patient was able to cover 63.2 m (1.05 m/s, figure 1) on the 1 min walking test. On the last day, she was able to cover 69.2 m (1.15 m/s, figure 1) on the 1 min walking test. This programme mainly focused on her emotional sphere, which was an important step towards letting go and opening herself to express her feelings. According to the patient's testimony, this process facilitated the release of long-standing tensions and frustrations, ultimately restoring an inner equilibrium conducive to embracing new experiences with heightened enthusiasm. Consequently, she found herself able to pursue her interests with renewed vigour. These outcomes were documented by the patient in the QoL questionnaire Short Form Health Survey-36⁴⁶ (see table 1).

During the fifth programme, the first day, the patient was able to cover 71.0 m on the 1 min walking test (1.18 m/s, figure 1). She had a symmetrical stride length, she rolled out the stride well and leaned much less on her arms than during the last programme. Her trajectory was straight, and the walking speed was within the norm. The last day of the programme, the patient was able to cover 74.6 m on the 1 min walking test (1.24 m/s, figure 1). Compared with the first day, the gait was more assertive and unbound. After the test, the patient tried to walk with two simple canes with ergonomic handles and was able to cover 10 m. She adapted well and even felt more stable with these canes than with the crutches. She was encouraged to walk looking straight ahead. Indeed, thanks to her improvements she was able to walk with a regular rhythm with the simple canes while trusting herself. During this programme and thanks to what she learnt during the hippotherapy sessions about the management of the effort and pain, she rated her pain between 4 and 6 on the VAS depending on the effort.

Concerning the management of pain, during these five programmes, pharmacological treatments were reduced. After the first programme, opioids were replaced by paracetamol with codeine if needed. After completing two programmes, lidocaine-based local anaesthetic was stopped. These changes are important because they show the efficacy of hippotherapy in reducing the patient's pain. In addition, opioids can cause considerable side

effects and tolerance.⁴⁷ Reducing them, in conjunction with a reduction in the sensation of pain, is therefore a major step forward for the patient's health.

As of the fourth programme, the patient reported a reduction of her chronic fatigue (see [table 1](#)).

DISCUSSION

Hypermobile EDS is a group of connective tissue disorders characterised by joint hypermobility, joint instability, muscle weakness, chronic pain and fatigue, among other symptoms.⁷ Individuals with hypermobile EDS often experience difficulties in walking due to joint hypermobility, musculoskeletal instability and chronic pain. Joint hypermobility, a hallmark feature of hypermobile EDS, can lead to abnormal gait patterns, decreased proprioception and increased risk of joint dislocations or subluxations during weight-bearing activities such as walking.⁴² Additionally, chronic pain, which is prevalent in hypermobile EDS patients, further exacerbates mobility issues and may lead to fear of movement (kinesiophobia), thereby perpetuating a cycle of reduced physical activity and functional impairment.⁴⁸ Pain in hypermobile EDS is multifactorial and can result from musculoskeletal abnormalities, joint instability, soft tissue injuries and neuropathic or central sensitisation processes and is associated with regular use of analgesics.⁴⁹ These challenges in walking and pain management significantly impact the QoL and daily functioning of individuals with hypermobile EDS, highlighting the importance of comprehensive multidisciplinary interventions tailored to address these complex needs. In this article, we report the improvements observed in multiple aspects of a patient with hypermobile EDS managed by hippotherapy.

The first and most significant result observed is the shift of the patient from an electric wheelchair to walking with crutches after 30 hours of hippotherapy. Along the different programmes, we observed a substantial and continuous improvement in the quality and the speed of the walk. The rapidity with which the transformation occurs with the patient should be outlined. After being stimulated by the horse's movement at a walk for only 5 hours (first programme), she shifted from not being capable of reproducing a gait pattern to actually initiating that pattern. Hippotherapy improves dynamic postural balance and gait in individuals with neurological, musculoskeletal and osteoarticular conditions.^{27 34 50-54} Hippotherapy engages patients in a multisensory setup leading to an improvement in motor function, postural control, stability and gait through neuronal plasticity mechanisms.^{18 51 55} It leverages the rhythmic and three-dimensional movement of the horse to stimulate postural reflex mechanisms.⁵⁶ This stimulation reinforces balance and coordination, contributing to the development of strength, muscle tone, flexibility, relaxation, body awareness and motor coordination.⁵⁷ The rhythmic oscillation of the horse's back particularly targets postural reflex mechanisms, promoting balance and coordination in the patient.^{24 33}

The movement generated by the horse's locomotion and simulator's motion induces a forward-backward motion, prompting anterior and posterior pelvic tilt. This movement stimulates trunk stability by engaging both flexor and extensor muscles. Furthermore, the lateral movement triggers the reciprocal activation of trunk's lateral flexors, further enhancing stability. The rotational component of the movement induces trunk rotation, likely activating the lateral flexors.⁵⁸

It has been stated that movement plays a crucial role in alleviating joint pain.^{59 60} Hippotherapy offers a distinctive trirotational movement that contributes to these

improvements.⁶¹ Some studies observed that older adults experienced enhanced core strength following hippotherapy sessions providing muscular support to the back and hips.⁵⁶ Furthermore, significant reductions in pain reported posthippotherapy may lead to sustained engagement in exercise regimens over time.⁶² In the context of other studies,³⁶ the decrease in pain observed could be linked to increased range of motion (ROM) and potentially improved muscle strength. For individuals with hypermobile EDS, this helps to support unstable joints and improve posture leading to motor enhancement. Also, the rhythmic movement of the horse at a walk promotes muscle tone regulation which increases the ROM in joints. This is beneficial for individuals with hypermobile EDS who often experience joint stiffness and limited mobility. Musculoskeletal and osteoarticular pain often trigger kinesiophobia which can impede functional recovery exacerbating pain perception and disability.^{63 64} Recent studies further underscored the impact of kinesiophobia on pain severity and functional impairment across various musculoskeletal conditions including hypermobile EDS.^{9 65 66} Rehabilitation aims to mitigate kinesiophobia, by integrating motor tasks like reaching, bending, sustained trunk loading, trunk stabilisation exercises and pelvic tilts. These interventions frequently incorporate sensory-based stimuli such as visual, acoustic, haptic and motion feedback, with hippotherapy being one of the finest examples of such an approach.⁶⁷

Finally, hippotherapy also has a significant impact on the mental and emotional well-being of patients. The multisensory experience and rhythmic movement of the horse provide a unique therapeutic environment that reduces stress and anxiety while promoting emotional regulation and motivation.^{68 69} Studies have shown that hippotherapy leads to improvements in mood, self-esteem and overall QoL.³¹ Similarly, improvements in emotional regulation, self-confidence, social cognition and social communication in children with autism spectrum disorder following a hippotherapy programme were reported.³⁸ These findings highlight the holistic benefits of hippotherapy in addressing not only physical but also mental and emotional aspects of patient well-being.

Hippotherapy as a therapeutic option for the relief and rehabilitation of patients suffering specifically from hypermobile EDS has received some attention in the scientific literature^{34 35} confirming on-field observations. The field of physical therapy for individuals with hypermobile EDS presents both challenges and opportunities. While therapeutic exercise and motor function training show promise in improving function and well-being, the lack of consensus on effective interventions poses a significant hurdle for clinicians. Managing the complex symptoms experienced by individuals across different age groups requires a comprehensive understanding of the condition and its impact on physical function. The current evidence base, though limited in size and quality, underscores the need for further research to determine the efficacy, feasibility and safety of various rehabilitation interventions. By addressing these challenges through rigorous research and multidisciplinary collaboration, clinicians can better meet the diverse needs of individuals with hypermobile EDS, ultimately improving their QoL and functional outcomes. Hippotherapy confirms its relevance for the management of hypermobile EDS.

Patient's perspective

I have Ehlers-Danlos syndrome, a connective tissue disorder that produces chronic pain and hyperlaxity joints. Before I started hippotherapy, I hadn't walked for a year and a half. I couldn't even stand up or walk. I saw a lot of effects at the end of the first week as I was able to take a few steps and my legs weren't shaking at all, and since then, after each new week of hippotherapy, I have seen a lot of progress.

I've been able to walk again with a walker and with crutches. Now, I use the walker all the time at home and outdoors. During an hippotherapy session on the horse, I'm much calmer than when I do a classic rehabilitation session. The movement of the horse enables me to move my arms rhythmically, which helps me to walk. Unlike a conventional rehabilitation centre, which didn't work for me, I feel listened to, my pain is taken into account and my feelings are not questioned.

Learning points

- ▶ Hippotherapy enables a hypermobile Ehlers-Danlos syndrome patient to walk again after more than a year of being unable to walk.
- ▶ Hippotherapy reduces the patient's need for painkillers, particularly decreasing the opioid load.
- ▶ After completing five hippotherapy programmes, the patient's autonomy improves, giving her the strength to take on new challenges. Hippotherapy empowers her to move forward.
- ▶ The patient and her parents report that the effects of hippotherapy are sustainable and positively impact her daily living activities.
- ▶ Functional global Patient-Reported Outcome Measures from the Short Form Health Survey-36 questionnaire before and at the end of the last programme support these assertions.

Contributors The following authors were responsible for drafting of the text, sourcing and editing of clinical images, investigation results, drawing original diagrams and algorithms, and critical revision for important intellectual content: HV, CL, MQ and MG. The following authors gave final approval of the manuscript: HV, CL, MQ and MG. HV is the guarantor.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Consent obtained from parent(s)/guardian(s).

Provenance and peer review Not commissioned; externally peer reviewed.

Case reports provide a valuable learning resource for the scientific community and can indicate areas of interest for future research. They should not be used in isolation to guide treatment choices or public health policy.

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