

From FRANCE: COPING WITH HSP

REGULAR BODY MANAGEMENT

Daily life is broken up into various sessions: *ie*, rehabilitation, physiotherapy, swimming pool. In this daily management, how can one pass from a standard medical treatment to a physical activity that specifically works for you?

Nobody can predict disease evolution. As for other neurological diseases, it appears now to the French rehabilitation therapists that a regular physical maintenance may delay or reduce evolution if physical efforts are moderate and practiced consistently (daily). The main objective is to obtain and maintain well-being.

So far, no universal and ideal method or any specific subscription can be proposed to reach a better life for people living with HSP. Foremost, the key element is the knowledge of your own body. Especially important is an accurate analysis and scoring of your disabilities by a rehabilitation therapist, muscle by muscle may be very helpful: if you know what and where is off-base, you could visualize during a walk to concentrate your efforts on contracting or on relaxing.

As our leg muscles become stiffer and stiffer, walking represents a real challenge. Given walking automatic responses are lost, every move requires a thinking about our gait, in order to avoid a fall. Walking must be consistently instructed by / relayed through the brain. Moreover the loss of adaptation to **stress** as well as the slowness of moving also requires a permanent awareness

of the full body. Of note, fitness varies from one day to another and no one can predict how tomorrow will go. Generally speaking, fatigue comes quickly in the day, reducing range of action rapidly. Reference centres advise us to remove stress and reduce any inner tension. Such evidence requires a subtle body-mind conversation in order to prevent the vicious cycle of muscular hyperactivity-spasticity.

Rule N°1: Whatever your degree of disability, an HSP person has to auto-manage herself in accordance with current abilities

The maintenance of physical activity targets 3 specific objectives:

- ✓ achieving daily movements (moving, bending down, standing up)
- ✓ preventing falls and their consequences
- ✓ slowing down any evolution of muscular deficiency.

In order to fulfil these objectives, a questionnaire of the French *ASL-HSP France* Association to HSP-affected people (n=90), yielded several non-exclusive approaches that may be practised according to your personal psychological behaviour and lifestyle as well as actual physical and mental possibilities:

- 1) Regular conventional physiotherapy and functional rehabilitation training sessions, including water-therapy
- 2) Guided self-rehabilitation according to a plan between a hospital medical physiotherapist and you
- 3) The Feldenkrais method with a liberal teacher,
<https://www.feldenkrais.com/>
- 4) Mindfulness, including sophrology,
<http://www.sophrologycenteronline.com/about-sophrology/what-is-sophrology/>

5) Chinese therapies

6) Human kinetics, *aka* Adapted Physical Activity (APA),

Parasports

2-1 Weekly physiotherapy and functional rehabilitation training sessions

Weekly conventional physiotherapy sessions usually focus on leg mobilization and repeated adapted stretching of contracted muscles.

Moreover, a session of functional rehabilitation once or twice a year is advised in order to slow progression and to keep as much autonomy as possible. These training sessions of 3-6 days are held in a hospital setting via either a daily training or complete hospitalization.

During these training days, the care team will propose a personalized coaching to each individual, including:

- functional rehabilitation: adapted walking without/with obstacle, strengthening of balance posture including moving from sitting to standing up, learning of best means for getting up from the ground.
- water-therapy
- relaxation, psychomotricity exercises, speech therapy
- Fitness restoration exercises to functional abilities up to the waist and physical effort
- Initiation to Adapted Physical Activity (APA)
- Guided psychological therapy

Back home, training rehabilitation can be done with the help of physiotherapist with a neurological education and who knows HSP as much as possible in relationship with the referred neurologist or the physical rehabilitation doctor.

A short stay in a Rehabilitation Service at hospital may constitute an option to test all necessary material to move (crutches, wheelchair), to consider all adaptation at home to be done as well as all social facilities with the help of an ergo-therapist and social assistant. Moreover this hospital session represents a real breathing space for the patient as well as the helper/carer.

Little by little, adapted HSP management has progressed in France.

A Trick

A motorized device MOTOMED Viva 2® passively mobilizes legs thanks to a crank gear with adapted speed. It allows increase of muscular tone during exercise. It has been recommended for Parkinson's disease to alleviate contractures. See www.mobilefrance.fr

Worth knowing

In each European country, it is advised to make a connection with rehabilitation centers dealing with neurodegenerative diseases, particularly those that specialize in ataxia and spastic paraplegia.

Testimony

*In 2012 I had a very bad fall that shook me: facial traumatism with a closed fracture of the nose. After that I was really distressed, I didn't dare walk in the street. So I decided to get a functional rehabilitation stay for one week at the Salpetriere Hospital, the French HSP Reference center, as follows: 3 physiotherapy sessions of 1 hour, 1 hour of Nordic walking, Yoga (1 hour), Relaxation massage (1 hour). This stay was very beneficial to me: for the next 6 months, I succeeded in being "balanced" for over 5 minutes, I stopped being scared to walk alone. Importantly, I did the exercises that I had learned in the hospital weekly in addition to my regular physiotherapy sessions. **Françoise***

2.2 Guided Auto rehabilitation

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Besides regular physiotherapy sessions once or twice a week, a daily self-training is very helpful. The approach is to treat individually each specific mechanism of impairment (paresis, muscle contracture or muscle overactivity), muscle by muscle, aiming to re-establish equilibrium.

For the most shortened and overactive muscles, a daily program of prolonged stretch is useful.

Physiotherapy potentially in conjunction with focal injections of nerve blocking agents (botulinum toxin, for example) by your doctor will help to lengthen and soften up the shortened and stiffened muscles in order to break the vicious cycle of Contracture - Spasticity - Contracture. To improve voluntary command of your weaker muscles, an intensive motor training program using unassisted large amplitude rapid alternating movements will gradually increase the capacity of your brain to command them more effectively. The final goal here is to break the cycle Paresis - Disuse – Paresis (from Guided Autorehabilitation, Pr Jean-Michel GRACIES, Mondor Hospital France) ([Link to Guided AutoRehabilitation Booklet](#)). In addition and importantly, an examination and measurement of the involved muscles by the Referred Medical Physiotherapist should occur. Thus you could visualize the muscles to train with the guidance and under the control of your physical therapist or your physician. From this examination, the Referred Medical Physiotherapist MD (RMP) can establish your own individualized profile and select, according to your needs, the most appropriate stretching and training exercises you may practice at home to go towards your guided self-rehabilitation. On this basis, a self rehabilitation contract is established that commits you and the RMP. This contract will be based on a daily realization of adapted postures that alternate long stretching (5-10 min) and immediate active mobilizations (30 to 60 sec.). These exercises target two goals: i)

maintaining muscle suppleness as well as muscular strength, and ii) initiating alternate bypass circuits of the deficient part of the spinal cord. Their repetitions (long stretching-active mobilizations) govern the benefit you can expect. You can keep track of it in a daily register book. This register enables you to gauge your own personal involvement and will power and the RMP can adjust the exercises to your individual possibilities. Postures and movements can be checked every 2 months in workshops and the RMPMD can perform a complete analysis of you with adapted tests twice or three times a year. Recorded test results are plotted in standardized curves that permit a close follow-up of personal improvements and to define new goals.

Guided self-training is exacting: it requires not only a great will from you but also a strongly motivated team of nursing staff.

Testimony

*The meticulous exam of the PMR MD led me to be conscious of my handicap, of the hyper-active muscles I have to consider. Enthusiastic at the beginning, little by little I let it go. Result: rapidly back to square one! Thus, pushed by my PMRMD, a real inflexible coach, I returned to alternate exercises. In the beginning, I needed a strong mental attitude, but I progressively got accustomed to do it regularly (without excuses!). So, now in a musical atmosphere, except the day of my physiotherapy session I **exercised** daily about 30 minutes, and I keep my register booklet up to date. If tired, minimal training. If I got very bad (flu, fever) I stop but knowing that I must come back quickly. If I stop more than 3 days, I feel myself slower; if I train too much I get tired and I can't perform. In brief, following two years of practice I know myself better. At last, this daily demanding activity is part of my life like my meals and shower! **Yann***

2.2 The Feldenkrais method

This method has the same goals as physiotherapy: stretching, strengthening, mobilization, but is itself a learning method of functional adaptation using movements, keys of consciousness of current mental and physical abilities.

The Feldenkrais method teaches:

- development of motricity activity and coordination
- effortless organization of body in movement *in gravity field*
- improvement of the quality of movement
- reduction of effort and pain *in aid of sensation*
- movement visualization before action in order to anticipate and avoid parasitic movements

As a result one can obtain a finer body consciousness, creating new motor scheme to move .

This method can be practiced by oneself or in a group. One must be careful about the experience of the teacher (to eliminate the “guru” and the “charlatan”). See <https://feldenkrais-method.org/fr/>

2.5 Adapted Physical Activity (APA)

This approach is often used as a complement to the medical rehabilitation center. It consists in improving the HSP person’s image in order to allow a better communication between mind and body so that the physical, psychological, cognitive and social abilities are optimized. APA teaching is absolutely different from rehabilitation in that you must express your physical, sportive or artistic *inclination to practice*. Indeed APA is essentially a developmental personal approach and the teacher has to adapt to the individual’s choice. Importantly APA displaces organic and physical situations to

emotion and feeling of self. APA must be fun with a large range of adapted activities: skiing, sailing, kayaking, cycling outside or inside, watching TV, trike, delta plane: www.sfp-apa.fr

Example: Aquatic activity

In a pool of at least 30°C (small pool for children or large pool) aquatic activity is recommended. This allows you to walk and do stretching exercises with free and creative gestures without any conformist judgment. Swimming or aquatic gymnastics in self-guided exercises focused on the legs. Movement in pleasant water gives a feeling of freedom.

Testimony

*At the start of the aquatic APA personal teaching, I was scared of the water. But rapidly I felt more confidence. Far from preventing me to swim, this experience sets me free and lets me gain back my body. Frankly, unconsciously, water lets me break my limits. **Marie-Christine***

2.6 Para-sports

Various sports such as hand bike, long distance swimming, fencing, kayak, ping-pong, para-sports allows you not only to surpass yourself but also to make fun social and friendly contacts. National Federations exist for many sports.

3. DEPENDENCE: CAREGIVER-CARE RECEIVER RELATIONSHIP

Handicap situations quite often induce dependence even with life actions we consider rudimentary. The handicapped person has to be helped by family: husband or wife, parents, children. Professional helpers can also intervene: a nurse, an auxiliary nurse. The caregiver-care receiver relationship requires continuous exchanges, a mutual understanding, confidence and respect. Such a situation often varies over time and can disturb the familial and social equilibrium. Indeed for the helper the slowness of the helped person, slow walking besides her, pushing a wheel chair, carrying heavy loads, adapting a slow motion, can make the helper tired. Conversely for the helped person to be dependent on others, to accept to delegate your own movements rapidly becomes burdensome. From both sides the “dominating-dominated” relationship has to stop. This relationship must be constantly questioned and analyzed by parents and maintain empathy for professional helpers.