



HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group
Registered Charity No. 1109398

Issue 29 – May 2013

HSP & FSP – Hereditary Spastic Paraplegia,
Familial Spastic Paraplegia & Strumpell-Lorrain Syndrome

HSP saved my life!!!



Mike Horsman (third left), an HSP sufferer, and his team after completing a charity ride from his Hertfordshire village, Tewin, to Edinburgh. Extreme left, fourth left, and extreme right are his sons Ian, Will and Graham. The team raised £17,000 for the British Heart Foundation and Cancer Research UK.

I joined the HSP Support Group a year or so ago and have greatly benefitted from email advice from Ian Bennett (who pointed me in the direction of FES stimulation, more about that later). I also benefitted from reading HSP Newslink which has given me important information about my condition and many inspiring stories by HSP sufferers

to which I can strongly relate. So I thought my own experiences might similarly be of use to someone; here they are.

I never knew I had HSP till I was 50 (I'm 63 now). As a boy I was a good long-distance runner and a keen cyclist. When I was 15 I did a 1,000 miles cycle tour with a friend during the school holidays.

Exercise got less as I got married and had children (3 boys) and, to be honest, in my thirties and forties I let myself go physically. My weight soared to 16 stone with my time taken up by a demanding and responsible desk-bound job combined with family responsibilities. I began to develop health problems like sleep apnoea and hypertension and had a heart scare but in my late forties I was still capable of walking more than 15 miles in a day.

However, I had always been a clumsy walker and began developing a noticeable limp. In 1999 HSP was diagnosed. Of course no-one could tell me how fast or far the disability would progress but it seemed time to take a turn to myself and stop making life difficult by lack of exercise and to attempt sensible weight control. I started attending Slimming World and lost four stone. I still eat too much and have slid back up to 13 and a half stone, I'm ashamed to say, but I've never gone back to the grossness I was demonstrating when I started to reform. The benefits of weight loss are enormous. HSP has indeed progressed. I now can't run and walk with difficulty, but if I had stayed at 16 stone I seriously doubt if I would now be walking at all. Weight loss also helped with the hypertension and got rid of the sleep apnoea. Reducing the stress in my life helped too. I took early retirement in 2003. There was a lot about my job I missed, but it was undeniable that retirement meant less stress and the chance of a less sedentary, desk bound life.

Even before retirement I had upped the exercise, particularly cycling, and in retirement I really piled it on. HSP was a motivator. I didn't know how mobile I would be for how long so get it in now! My disability means I am a slow and unpolished cyclist but I can do it much better than walking and developed good stamina. I cycled from Lands End to John O'Groats, Scotland side to side, England side to side, France end-to-end, Ireland end-to-end and side to side, Italy side to side, Vienna to Prague, Krakow to Budapest, etc, etc. Between 2003 and 2009 I cycled long-distance in 16 countries. I had many marvellous experiences, saw many fantastic places and made many new friends. Then, in

2010, I had a heart attack.

That's where HSP saved my life. HSP had driven me to exercise and get fit, partly to keep my mobility longer, and partly to get as wide a range of experience as possible while I was still able. But after my heart operation (an angioplasty and four stents) my cardiologist told me that the big exercise regime had probably saved me. My left artery was completely blocked but the vigorous exercise had prompted my body to drive little "collateral" arteries from my healthy right side to bypass the blockage and I finished up with no heart muscle damage. It's a remarkable thought that if I hadn't had HSP I would now have crippling heart damage or might indeed have departed this life altogether. It was just icing on the cake when I saw Professor Henry Houlden at the Institute of Neurology about my HSP and he said that my exercise regime was probably the reason that I retained as much function in my legs as I do.

So I'm back on the bike, over the Alps from Germany to Italy in 2010, undertaking a charity ride from my Hertfordshire home to Edinburgh with my sons and some friends in 2011 (we raised around £17,000 for the British Heart Foundation and Cancer Research UK). I'm declining as a cyclist, but the longer I go on the better, and I feel I have a lot in me yet. I've had much help from professional experts with the HSP, including FES which I find physically burdensome to use but which has undoubtedly improved and prolonged my walking. I've had even more support from my lovely wife, without whom it would be hard to soldier on, and from many good friends.

However, my message is it's up to you. The more effort you make, the more you do to help yourself, the more you will gain not only in relation to HSP but in your whole life. Don't lose heart. Don't let life get you down.

I'm far from perfect in this regard, I have bad days physically sometimes and very bad days mentally too, but keep positive! Shakespeare said it; "There is nothing either good or bad, but thinking makes it so".

Mike Horsman Region 3

Chairman's Column

I doubt anyone could have read the headline on the front page without being intrigued enough to read on. Thank you Mike for sharing this with us and thank you to all members who have contributed material for the Newsletter. Recently there have been some very interesting articles from members which are essential in making the Newslink an interesting read. Please keep this up and if anyone out there has an interesting story to tell, please put pen to paper, particularly if I haven't heard from you before.

Sarah Daniel, a physiotherapist with PhysioFunction has once again very kindly contributed to the Newslink. She has supplied us with some useful stretching procedures which should help us maintain joint movement and function. If you have any questions for Sarah regarding physiotherapy, please let me know and she has volunteered to answer them in future editions.

I hope you are able to join us at our AGM on June 15th. You'll read more about it in this Newslink and you'll notice we have three speakers. There will also be time to chat to old friends and make new ones. Please let us know if you are attending by returning the form that you have or will shortly receive to John Mason. Once again we have fixed the price at £7-50 per person which includes a buffet lunch and teas, coffees and cakes throughout the day.

Remember the AGM is your opportunity to get more involved and have your say. The committee work very hard on your behalf and any assistance would be welcomed. This could be on a casual basis or if you feel you have skills to offer, you can consider joining the committee. The committee doesn't have to be comprised of HSP affected individuals. Healthy partners, relatives and even friends can get involved, indeed anybody with a passion for our cause will be welcomed aboard.

I've recently enjoyed another good get together amongst many friends in Ashburton. We didn't have a speaker on this occasion but spent the afternoon chatting amongst

ourselves and making new friends. Twenty five of us stayed the night and enjoyed the friendly atmosphere and facilities of the Dartmoor Lodge Hotel, the staff of which as always looked after us superbly.

I look forward to meeting up with more of you at our AGM and other future meetings.

Ian Bennett

Useful Information

Flexyfoot Ferrules

A number of our members are now using these very clever ferrules and a number of people have asked me about them recently.

Flexyfoot ferrules provide:

- More grip than a standard ferrule to reduce slips and falls and install confidence.
- Improved grip in the wet
- Shock absorbency and reduced impact to reduce hand, arm and shoulder pain
- 360° rotation for full support and to reduce wrist twist

Full details can be found online at www.flexyfoot.com

or freephone 0800 0285 888.

HSP Group Funds

The HSP Support Group is now in a position to support research projects with a maximum grant of £10 000. Applications for such support are welcome. Please apply in writing.

Members' Letters

Dear all,

There have been many comments on questions of exercise and this is my own point of view.

We are each different but I am 70 (thanks to Merrille) and believe that we must each adapt and adjust as best we can to what I have heard described as a benign disease!

I have been doing a stretching routine just about every morning for the last 30 years. I have added new exercises and enjoy it. This takes about 30 minutes. I start on my back on the Lounge floor and finish on a chair with various rotations and then simple foot lifts which I find the most difficult. Back to the bedroom, where I start to dress and attach the Micro-Stim (c/o NHS Salisbury) which tends to tingle the muscles around the buttocks and part the knees. This takes about half an hour.

I have read various weighty books including Ulysses and War and Peace but am just finishing Civilization by Niall Ferguson and this should be read by everyone. It is an historical analysis of the last 500 years comparing the development of the East and the West.

My right leg is tending to collapse and feeling tired in the mornings has recently tempted me to go back to bed until 11.30 am. When I clean my teeth in the morning and evening this prompts me to hold the washbasin and bend both knees doing a sort of squat- 12. At bedtime I stand with knees tight together and do 20 arm flings, then 20 side to side arm stretches- double touching each knee, then arm rolls bending down and up.

I must admit that I walk very little and use the wheelchair when we go out.

The point is to do as much exercise as you can bearing in mind that the base of the spine is the focal point of our disability, so gently easing and stretching should be beneficial.

Please let me know what exercises you do.

Best regards,

Michael Jarvis Region 1

PS. Indoor bowling has been a fantastic help for me in "going out", gentle exercise, chatting to the other players and then dreaming of the bowls I played and trying to remember the game and the people. It tends to send you off to sleep!! For me a bowls wheelchair is now essential.

Dear Ian

I got your address on the internet and was thrilled to see there is a support group for HSP. My late mum had it which in those days

was diagnosed as M.S. I am now 63 and I only showed signs of HSP in my 40's.

I have had four minor strokes and my neurologist did a lumbar puncture and said my spinal cord is inflamed but not infected. This was in South Africa.

Being born in Chester in the UK I have now come back as I have a daughter in Camberley and two daughters still in South Africa.

I am also profoundly deaf and was lucky enough to receive a Cotelea Implant in Southampton eight months ago which has been like a miracle. I only went deaf three and a half years ago.

I find my ankles are getting very weak and have to wear supports. I walk with the aid of a four wheel walker.

I am also on a lot of medication and I find I get terrible bouts of depression.

It is so wonderful to hear of a support group and I hope I can be of some support to others.

Once again it is wonderful to know of a support group.

Hope to hear from you soon

Regards

Marilyn Lubbe Region 1

My scooter and me.

It was 2006 when I first came to the decision to use a walking stick. HSP had progressed and I now had a pronounced limp and was regularly veering to one side. It looked, to others as if I was drunk. Once I had started using the walking stick, I noticed peoples attitudes to me had changed. They did not now think I had just left the pub, but realised that I actually had a medical problem or such like.

I could still get around town, very slowly, but I could still walk a shortish distance. As time went by, my walking started to get harder. I progressed, slowly to two walking sticks, and then added crutches to my collection. These all helped me at the time and could still get out and about, visiting friends, meeting up for coffee and window shopping.

That started to become difficult too and I purchased a lightweight wheelchair from e-bay with the help of a grant from the HSP Support Group. Second hand. Good price though. :) I also, contacted the local wheelchair service, who assessed me, measured me and provided me with a steel wheelchair. Always good to have one in reserve and to get the correct measurements for when purchasing a wheelchair. :) I used it when Roger (hubby) and I went shopping or visiting places etc. Most of the time, when not using the wheelchair I would park near to where I needed to be, get out of the car, get what I needed from the shop, then get back in the car and go home. That was it really. My walking had become that bad.

Along with the Lightweight wheelchair, I purchased a small mobility scooter. This I found, after taking ages to actually get myself on it. As my pride was telling me, "no! It's not cool"! The scooter was quite an old model, it was very heavy. Roger could lift it, in and out of the car, but I could not. :(So, I was still having to wait for Roger or some able bodied friend to come out with me to do the lifting. I am not complaining, because (Zippy 1) gave me independence to go my own way, once we had got to the shops etc. Not that I don't like shopping with Roger. Women like to browse. You ladies will know what I mean. I must say Roger was happy about this also. He did not like me struggling and it makes him happy seeing me do my own thing, the best I can. :)

We moved home last July, to a better house for us to manage. This took a long time and caused me a lot of stress. Roger also. You don't know how stressed you are until it's over. Although, I do regular physio and find this keeps my muscles as supple as they can be, hence not too much pain. I have found that my legs are weaker and my balance is way off and I aim for walls and furniture to break my fall. This is not doing my wrists any good, as they take much of the force. I now use a walking stick and tray trolley walker around our home.

I had a long think about this over the past winter and applied for another grant from the support group, to hopefully acquire a very

lightweight scooter. One that I could take apart and put together myself. I have been very isolated during the winter and did get depressed. I felt my independence was diminishing a lot. :(

I was awarded a grant from the Support Group and started to shop around for a new scooter. I contacted friends who had various mobility scooters, went to mobility shops to try them. None of them, I could possibly assemble etc or lift at all! Feeling despondent I contacted a fellow HSP'r. Carrie has a Rascal Micro Balance scooter. She sent me a link. I looked at the specs and then decided it was, indeed, the lightest I had seen anywhere.

I ordered it. When it came, I found I could lift it in and out of the car. I practiced for a whole week before I took it out for a spin. It was and is a dream come true. :) It is brilliant. :) I now feel I have some of my independence back! I can go shopping, go for a spin in the fresh air when I want to, go meet a friend in town etc etc. I even used it in March, when I mentored this years candidates at RAF Cranwell, for Flying Scholarships for Disabled People (FSDP). No problem. It was hard work, exhausting even, but I enjoyed every minute of it.

(Zippy 2) Has made my year already. Without it, I would just be moping around the house. I would get depressed, I feel. Not good to be indoors all the time. We need to get outside now and again. Get some fresh air.

Don't be afraid of walking aides. They are there to make our lives easier. Give us some degree of independence.

I LOVE MY SCOOTER! :O) :O) :O)

Della Brookman region 3

Dear all

I need to start by saying that I feel like a different person now. I have a great night's sleep, wake up happy, always have things to do during the day, and even if I don't, I don't feel guilty or bad in any way to just chill out and watch TV, or listen to music! I'm so happy and I do love my life now! Hopefully you can compare this article with the last article I wrote for HSP in the last newsletter.

I believe my mood began to change during, and after, the FSDP (Flying Scholarships for Disabled People) selection meeting at Cranwell. I was really nervous about going, but knew I had to go. I went on the 24th March 2013. My partner went to Ireland that day with work for a week. If you remember, the weather was quite bad that day for driving with it being quite snowy.

Anyway, with my determination to get on with my life, I started to drive to Cranwell with my sat nav directing me there. I got about 30 minutes away from Cranwell, and I could see that the snow was getting quite bad on the roads. I was driving down a country road, when a car came slowly on the other side of the road, and the driver said to me that the snow was really bad further up the road, and he had decided to go back on himself, and to go a different way. Me being on my own and nervous anyway, decided to turn my car around and go back on myself, like the man in the other car was doing. So, I tried to do a three-point-turn, but my car got stuck in the snow!!! Luckily the man in the other car was still there and saw my poor little car, and so he and his son pushed my car out. I was so relieved that I had got out of that, and thought it would be a story to tell the others at Cranwell.

So I was on my way again to Cranwell. I was only about 20 minutes away by this time. I couldn't wait to get there! I was driving, maybe I wasn't going as slow as I should've been, and suddenly I wasn't in control of where my car was steering, and my car ended up wedged in the snow horizontal across both lanes, blocking all traffic. I was full of panic and just didn't know what to do. Luckily a lady who saw it happen came over to check I was okay and her husband said that he knew some mechanic people who he could call to help me. I think I was just a bit numb by this stage and just looked at him blankly. Anyway, after about 10 minutes or so another man came up to my Driver's Window, and said that he had a tow rope, so he could pull my car back. Me in my blank clueless state said "yes please". He tied the tow rope to some car thing at the back of my car, then tied it to his car, then pulled my car back. However, my car was now facing the wrong way for

Cranwell, but he said that if I got out of my car, he'll turn it around, and then I could follow his car to Cranwell. So I agreed, got out of my car, and remember I had been sitting down for about 2 hours, well as soon as I was standing up in the snow, I fell. So I got up feeling all embarrassed, but I fell again! I was so embarrassed!!! The man turned my car around, and asked me if I was okay. I said "I'm fine; my legs are always like that! Thank you for turning my car around". I followed his car for about 10 minutes, and then I saw we were at RAF Cranwell, and I saw the Guardroom which was the first place I needed to sign in. I did feel a huge sense of relief! I had made it!

By the end of the few days I had at Cranwell, I made some wonderful friends, and I felt that I could just be myself. Apart from the staff at RAF Cranwell, everyone who was trying to get a scholarship was in some way physically disabled. It was wonderful that I felt like the true Leanne had come back, I don't think Leanne has been there since my teenage years.

Since being there, my confidence has grown so much. I was lucky enough to get a flying scholarship; I'm so chuffed with myself! I know that everyone feels down at times, but please never give up. If something is that important to you, I strongly believe that you will get there. I'm not on about getting the flying scholarship, but my confidence is back, and the true person that I really am.

Leanne Piccirillo

Regional News

Region 9

Wow! What a good response. There were over thirty people who turned up to the meeting for Region 9 held at the Premier Inn St Helens South on Saturday 16th March. We had a talk from Sarah Wilkinson from Neurocare neurological physiotherapy team who managed to give friendly and helpful information without being too technical.

So, a big thank you to those who organised it all, a thank you to Sarah and a big thank you to all who came along and helped to make it

such a friendly afternoon. It was good to meet up with old friends, but equally good to welcome some new faces. As one of the 'old' friends, I am always pleased to know that important information gets to people recently diagnosed as well as updating us with some things we may have forgotten. As a carer, I know how difficult it can be for somebody with HSP to overcome the problems and make a journey to a meeting that may be a waste of time. So it was good to see the smiling faces that tell me that I wasn't the only one enjoying the afternoon.

I know that in his younger days, Terry would have loved to have been part of the organising team, but unfortunately that isn't possible now. However, I hope that somebody else will respond to Ian's request to carry on with these Region 9 meetings. They are so important to gather information, but most of all to just chat to others having similar problems. This quite often means finding out how they have overcome some of the problems and it always helps to have a fun afternoon.

I finish hoping 2013 is kind to all of you and that I will see many of you at the AGM in June.

Now a message to Ian – I am emailing this to you, but having just read the enclosed poem, I hope I manage to press the correct button and that this isn't the last you hear of me.

The computer swallow Grandma

The computer swallow Grandma
 Yes, honestly it's true!
 She pressed 'control' and 'enter'
 And disappeared from view.
 It devoured her completely,
 The thought just makes me squirm.
 She must have caught a virus
 Or been eaten by a worm.
 I've searched through the recycle bin
 And files of every kind;
 I've even used the Internet,
 But nothing did I find.
 In desperation, I asked Mr Google
 My searches to refine.
 The reply from him was negative
 Not a thing was found 'online',
 So, if inside your 'Inbox',

My Grandma you should see,
 Please 'Copy', 'Scan' and 'Paste' her,
 And send her back to me.

This is a tribute to all the Grandmas and Grandpas, who have been fearless and learned to use the computer..... They are the Greatest!

**WE DO NOT STOP PLAYING BECAUSE
 WE GROW OLD; WE GROW OLD
 BECAUSE WE STOP PLAYING.**

Pat Reed Region 9

Region 6 Summer Meeting

Our next meeting will be held at the Grand Pavilion Porthcawl on June 8th 2013 start time 2pm.

This will be a special meeting which will start with a concert by the Porthcawl Ukulele Band.

Most people think of George Formby when you mention the ukulele but he is famous for playing the banjolele which is a totally different sounding instrument. Many current pop groups now use ukuleles, the group Train being one of them, they also come in four sizes soprano, concert, tenor and base.

I have been involved with the band for the past nine months and enjoyed playing with them at many venues, some private functions, some charity functions and elderly care homes etc., but the one thing that impresses me most is the way it seems to lift people's spirits.

With this in mind I thought I could combine our meeting with the concert to hopefully raise some funds for the group, lift the spirits of our members and provide us with a good meeting place.

The concert will be held in the stage door function room of the Porthcawl Grand Pavilion which will seat 100 people in cabaret style

It will be open to the public for the first part of the afternoon and entry will be by ticket which will cost £6 each.

We shall have the usual raffle draw at the end of the show. The bar will be open to serve drinks and coffee, anyone wishing to have a

meal can do so in the upstairs (lift available) café bar before the show.

At the time of writing we have 33 seats sold, I know most of you reading this will be unable to attend but if you know of anyone who may be interested then please let them know.

Tickets are available from me Tel.: 07702477026 or from the Pavilion box office 01656 815995

Best wishes

Peter Bateman Region 6

Milford April 2013.

We were delighted to welcome Fiona Dorman, from the local Citizen's Advice Bureau. Fiona spent time preparing us for PIP (Personal Independence Payment), which will not affect most until 2015.

Some of the key points include:

- There is no automatic replacement of DLA with PIP. PIP will have to be applied for. A letter will be sent to everyone receiving DLA to initiate the process.
- Whether you can get PIP depends on an assessment of your ability to carry out daily living activities and mobility activities. There is a table which is divided into two parts for the ten daily living activities and the two mobility activities. Each activity within these groups has a list of descriptors. These describe different levels of ability to carry out the activity and how much help you need. Each of these activities has points attached to each descriptor. To achieve the standard payment you have to achieve 8 points, for the enhanced rate you need to score 12.
- As we have a degenerative disease we have to prove our level of disability. For some that will not be a problem, but for those that are still working and easily mobile by the time 2015 arrives, circumstance could have changed. Fiona recommended that a diary is kept, which shows the changes. This is definitely something I will be doing.
- For more detail visit the CAB website and select Personal Independence Payment. <http://www.adviceguide.org.uk/england/b>

enefits_e/benefits_sick_or_disabled_people_and_carers_ew/benefits_personal_independence_payment

Motability will also be affected.

Fiona guided:

....to be eligible the applicant must have at least 12 months qualifying benefit (higher rate DLA Mobility component or PIP enhanced rate mobility component) ahead, and Motability say,

"If you lose the allowance during your lease, we will make arrangements for the return of the car. However, you will only pay the cost of the lease until the car is returned, not for the remaining length of the lease. If you paid an Advance Payment, this will be refunded to you on a pro rata basis."

In conclusion anyone on a lifetime or indefinite award will not be affected by PIP until 2015.

VAT on building work

Fiona also guided on VAT payments when building work is carried out on our homes:

Certain building work that you have done may also be free of VAT.

Not all goods and services supplied to chronically sick or disabled people are eligible for VAT relief. In general, the items covered by the VAT relief are things that are of practical help to you because of your illness or disability.

Certain building work to a disabled person's private residence may also be VAT free. This is limited to:

constructing a ramp, widening an existing doorway or passage to help a disabled person enter or move about the building
installing, extending or adapting a bathroom, shower room, washroom or toilet where the work is necessary to suit the condition of a disabled person
installing a lift designed to help a disabled person move between floors within their home"

Best wishes,

Jane Bennett

Forthcoming Events:

Afternoon tea Regions 1 & 2

Sunday November 17th 3pm – 6pm
The Clockhouse Milford
Call Jane Bennett on: 020 8853 4089

Region 4 get together

Saturday October 26th 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

Region 6 Summer Meeting

June 8th 2pm
Grand Pavillion Porthcawl
Call Peter Bateman on 07702477026

Region 3 Meeting

August 10th 1pm – 4pm
The Orange Tree Public House
100 Stevenage Rd, Hitchin, SG4 9DR
Contact Della Brookman: 07710637941
or Ian Kitchen: 07540476735

HSP Support Group AGM

Saturday June 15th
Trident Technology and Business Centre
Leamington Spa

The Mobility Roadshow

Telford International Centre TF3 4JH
27th, 28th & 29th June
www.mobilityroadshow.co.uk

New Members

We welcome the following new members

Alan Brear
Bradford
Region 10

Michael Lyon
Aberdeenshire
Region 11

Murray Petray
Aberdeenshire
Region 11

Neil Brear
Bradford
Region 10

Victoria Paul
Newton Abbot
Region 4

If you are interested in contacting the new members listed, please contact the relevant area co-ordinator, or the membership secretary, who can then supply the necessary contact details

HSP Support Group 2013 AGM Details

Saturday 15th June

The Trident Technology and Business Park, Poseidon Way, Warwick, CV34 6SW

- 10.00 Coffee & Welcome.
- 10.30 AGM
- 11.00 Liz Redmond – Genetics Nurse Specialist National Hospital of Neurology
- 11.45 Break
- 12.00 Professor Henry Houlden – National Hospital of Neurology & Neurosurgery
- 1.00 Lunch
- 2.15 Alison Clarke - Clinical Specialist Physiotherapist - Sheffield Northern General
Dr Siva Nair - Consultant Neurologist - Royal Hallamshire Hospital
- 3.30 Coffee and open forum
- 4.30 Close

Stretching in HSP by Sarah Daniel

Consultant Neurological Physiotherapist, PhysioFunction

Regular stretches can be very beneficial in managing some of the symptoms of HSP. These can be either the direct or indirect symptoms such as spasticity, joint stiffness, reduced mobility and pain. Stretches can help maintain range of movement in the joints, retain or improve muscle function, contribute to the management of the spasticity.

Stretching programmes can be delivered in a number of ways with different intended goals. One goal of stretching maybe to try and increase the length of a particular muscle. This can then help to achieve an increase in joint range of movement to permit greater function. This type of stretch needs to be a static stretch held for a long duration. To achieve this type of stretch equipment such as splints or a standing frames are often used.

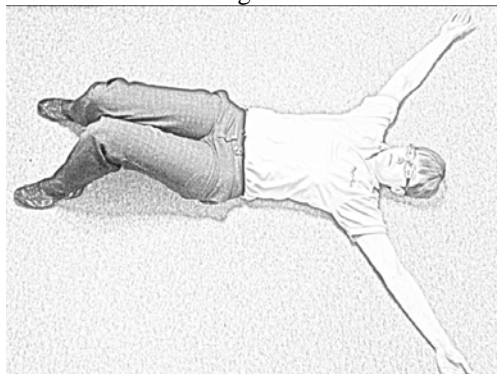
Another goal is to maintain a muscle length and to prevent shortening or loss of range at a joint. Maintaining function and preventing deterioration is key to independence with mobility and day to day activities. These types of stretches are usually ones that you can perform by yourself or with the help of another person.

Below are a few stretches that are aimed at the key muscle groups that are affected by HSP. PLEASE NOTE NOT ALL OF THESE STRETCHES ARE RIGHT FOR EVERYONE. Although these are low level stretches but it is important that you have professional advice to help devise a stretch programme that is right for you. When doing stretching exercises you may feel a 'stretchy-pulley' feeling but it should not be painful whilst doing them or afterwards. If this is the case stop and seek advice.

Stretch 1 – Mid Back and shoulders

Lying on your back with your knees bent. You may want to place a pillow or rolled towel under your knees. Place your arms out to the side in a crucifix position. You can increase this stretch by placing a small rolled towel down the spine. This will allow the shoulders to gently drop down either side of the towel to increase the stretch across the chest. This stretch is aimed to keep the mid back (thoracic spine) and shoulders mobile.

You can lie in this position for up to 20 minutes or as long as tolerated.



Stretch 2 – Inner Thighs

Lying on your back with your knees bent. Gently allow the knees to fall out to the side. Do not push them or try to push them out, gravity will place a big enough stretch on your muscles. You should feel a stretch in your inner thigh and groin.

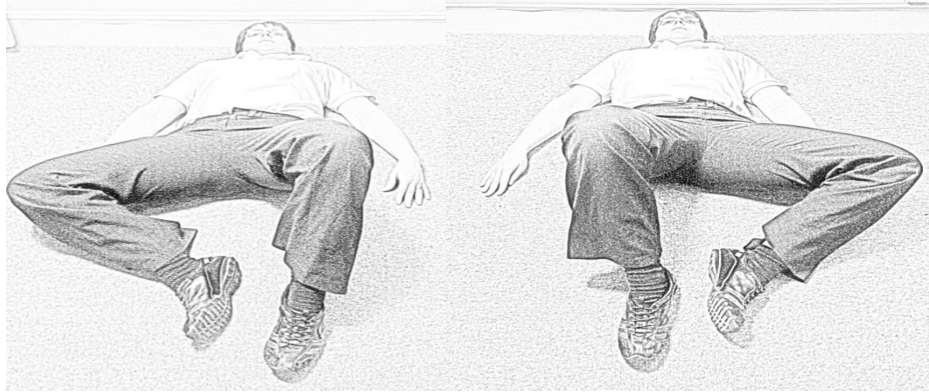
Hold the position for 30 seconds, slowly bring your knees together and repeat 3 times.



Stretch 3 – Single inner thigh

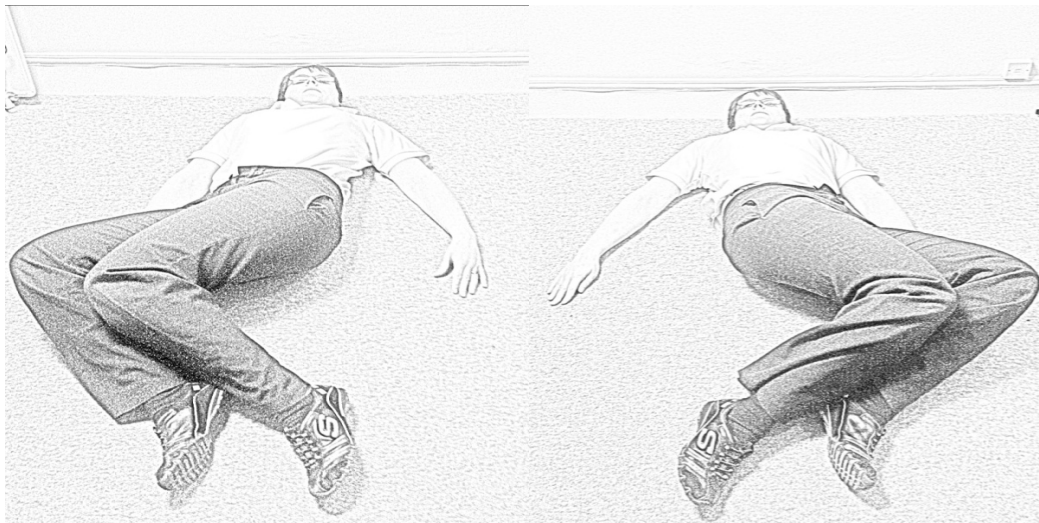
Repeat the stretch as in number 2; however only allow one knee to fall out to the side at a time. You should feel a stretch in your inner thigh.

Hold the position for 30 seconds, slowly bring the knee back to the centre and repeat on the other leg. Repeat 3 times each side.

**Stretch 4 – Low back rotation**

Lying on your back with your knees bent and feet on the bed. Keeping both knees together gently rock both knees to one side, slowly bring back to the middle and then take to the opposite side. You should feel a stretch down the side of your body.

Repeat 10 times in each direction.

**Stretch 5 – Prone Lying**

Try to lie flat on your tummy; this is to stretch out the front of the shoulders, across the chest, front of hips and the front and back of the thighs.

You can lie in this position for up to 20 minutes or as long as tolerated.



Stretch 6 – Low Back

Start by kneeling down; slowly reach forwards with your arms. Let your head lower gently so that there is no strain on your neck. To increase the stretches try to slide your hands out in front of you whilst keeping your bottom on your heels. You should feel a stretch down the spine and down your sides from your arm pits to your hips. Hold for 30 seconds and return to a comfortable position. Repeat 3 times.

**Stretch 7 – High kneeling thigh stretch**

Start kneeling in front of a chair, resting your hands on the chair for support. Try to keep your bottom tuck under and your tummy pulled in gently. Keep your weight over your knees. You should feel a stretch down the front of your hips & thighs. Hold for 30 seconds and return to a comfortable position. Repeat 3 times.

**Stretch 8 – Single thigh stretch**

Start kneeling in front of a chair, resting your hands on the chair for support. Step one foot in front and remain kneeling on the back leg. Try keep your bottom tuck under and your tummy pulled in gently. Keep your weight evenly over your back knee and front foot. You should feel a stretch down the front of your hip and thigh that you are kneeling on. Hold for 30 seconds and return to a comfortable position. Repeat 3 times on each leg.

