



HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 49 – May 2020

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

David Pearce - A very special man



Lorraine Saupé presenting David with a glass tankard at a Milford Meeting to thank him for all his hard work on behalf of us all

Our former chairman, David Pearce was a very special man. You may remember reading in the September 2018 newsletter that very sadly, David had passed away. David was extremely passionate about the HSP Support Group and the work we do and because of this, he remembered us in his will. In fact, he left an extremely generous bequest for us and we're keen to ensure that we use this wisely and, in a manner, that David would have fully approved of.

David was chairman of the Group when I joined in 2003 and he held this role until the 2009 AGM. He was very enthusiastic about the future of the charity and I know he'd be delighted about the way things have moved forward. He loved speaking to members as chairman and always did it with a big smile and a very friendly approach. I know his ambition was for our Support Group to become a significant charitable organisation that made a big difference to the lives of

individuals with HSP. I honestly believe that we're well on our way to achieving this and I'm confident that David is looking down on us with a big nod of approval.

From the beginning of his term as chairman, David realised how important regional meetings were and he was a key figure in getting local, informal meetings up and running. I remember him helping me to get the West Country Group together and he attended the first two meetings in Exeter. When you consider his limited mobility and the fact that he lived in Ilford, you can see what a dedicated, pro-active individual he was. He regularly attended the Milford meetings until illness and mobility issues got the better of him. With this in mind, we have decided to use some of his money to cover the cost of refreshments and room hire for future regional meetings.

On the subject of meetings, remembering how much David appreciated them, we agreed to make the AGM this year free to attend. However, due to the covid 19 pandemic affecting this year's event, we will carry it over to next year when there will be no charge for attending our AGM. It will be interesting to see if this attracts any more members, and this may be useful to know when planning future events. I'm sure David would have given this the thumbs up.

Some of you may remember that David was a big fan of the Calvert Trust. On the front of the August 2006 newsletter David wrote an article about how much he enjoyed a short stay with the Calvert Trust. For those of you who don't know, the Calvert Trust is an organisation with three locations around the UK, where they provide many exciting challenges for disabled people. These challenges include horse riding, kayaking, sailing, archery, cycling and abseiling to name but a few. I can remember David telling me what an incredible experience this was and he'd be delighted to know that some of our members have recently discovered for themselves how much fun and uplifting a Calvert trust break can be. For this reason, we have decided to pay half the cost of a Calvert Trust experience for any member. We will limit this to one holiday per member

every two years. We have allocated a certain amount of money for this and when it's gone, it's gone.

The committee recently agreed that it's very important that we recognize the great work that people do on our behalf. I remember David being very appreciative of some of the hard work and fundraising that individuals did for us. As a result of this, beginning at this year's AGM, we will be presenting two special awards in David's name. You'll read more about this in Adam's column.

The trustee's have agreed to use the bulk of David's bequest for research purposes and I can assure you that your committee go through detailed procedures to ensure that we select the research projects that we believe will provide the highest benefit to our members.

Over the years, I got to know David very well and I'm confident that he'd be very satisfied with how we spend our funds. In his time as chairman, it's something that he put a lot of time and thought into and I strongly believe that we're still very much on his wavelength.



Our former Chairman, David Pearce

Many of our members will remember David and I'm sure they share my thoughts. David, and our former treasurer, Mike Fawcett worked closely together and formed a very strong working relationship. When I got involved with the Group in 2003, I soon got used to the pleasure of working with the pair of them and I learnt a lot from each of them.

We'll never be able to thank David enough for all he did for our HSP community, he was a large building block in our development.

Ian Bennett

Chairman's Column



Hello everyone. As I write this we are in full Lockdown, with potential relaxation of this coming soon. I hope that you're all coping well with this unusual situation, keeping in touch with people and making sure that you follow the advice given.

Excuse the length of my column this edition, its been a busy time and I have lots of things to share with you, so I have used my engineer head and numbered them!

1. Coronavirus

I know that there is a lot of uncertainty around who should do what. I have been keeping an eye on the Association of British Neurologists advice and interpreting that for HSP, and have run this interpretation past Henry Houlden and Evan Reid.

There are two things to note – firstly, the majority of people with HSP should have a low risk of complications should they get coronavirus, but note that this could rise to a moderate or high risk if your HSP is significant and/or you have issues which affect your breathing. Secondly, we are working in an evidence free zone – the advice is opinion rather than evidence based. If you are not sure, be more cautious. Whatever, follow the government advice. I have put some further info on my blog: <https://hspjourney.blogspot.com/>

As you will have seen from the letter I sent in March, we have decided to postpone face-to-face meetings until after the lockdown restrictions have been lifted. We will next physically meet when; the advice from Government indicates that we can, and when this is in line with the advice from the Association of British Neurologists on social distancing.

2. Virtual Meetings

Early in May we held a successful set of test meetings using the Zoom platform to try out how it works for members. These were very successful, and it was good to have chats between the fifteen members who took part. These meetings give us a good way of keeping in touch during lockdown and help reduce isolation and improve wellbeing. We will run more similar test chats, and have more organised meetings going forward. Thanks to everyone who dialed in!

3. AGM

Now that we have had successful test virtual meetings it has come to the decision point on the AGM. It is our view that even if lockdown restrictions have started to be lifted by 4th July, we feel that it would be inappropriate to hold a physical AGM on this date. As the Zoom meetings were successful, we have decided to hold our AGM virtually. Since we are just starting our virtual meeting path the AGM for 2020 will just cover the business side needed for the charity – principally reporting our activities for the year and electing trustees. Please see the enclosed AGM notice.

I know that many of you enjoy the AGM, so I will be happy to leave the Zoom meeting open for as long as anyone wants to discuss things after the AGM. We will not be having technical presentations this time, but you will be pleased to know that most who we had asked to talk

are also happy to do an on-line version of their talk. We will schedule these using Zoom over the summer.

Whilst I know that some of our regular AGM attendees will be disappointed that there will not be a physical meeting this year, this new approach gives the opportunity for other members to try out their first AGM. I look forward to seeing many of you on-line.

4. Grants

Members should remember that they can apply for grants from the group. Whilst this has generally been used for mobility aids the scope is wider than that and we would be happy to consider applications for grants from members for accessories to help them get on-line, improve their wellbeing and join in the virtual meeting world.

5. David Pearce Bequest

You may recall that David Pearce left the group a donation in his will. You can read more about David on the front cover, but I wanted to give you some more details about the bequest now that the various paperwork has finished. The amount we gratefully received was just short of 87 thousand pounds. We have decided to use the bequest in a number of ways:

- One of David's passions was meetings, so we have enhanced our policy on meetings to cover refreshments at meetings as well as room hire costs.
- We were going to make this year's AGM free of charge, however that decision was taken before coronavirus, and this decision gets rolled over to next year instead.
- We are starting up two annual awards in his name, which you can read about below.
- We have set aside money to pay half of member booking costs when booking at Calvert Trust.
- We have agreed to raise the maximum research grant application from ten thousand to fifteen thousand pounds

We made these decisions based on our understanding of David's passions and interests within the group. Our decisions help both members and the wider research community.

6. Awards

We have decided to set up two annual awards in memory of David Pearce, to be presented at the AGM. There is the David Pearce Fundraising Award and the David Pearce Award for Raising Awareness of HSP. We are happy to consider nominations for either award from members, so do drop me a line soon if you wish to nominate someone.

The fundraiser of the year award can be for any aspect of fundraising – funds raised, noteworthy activity undertaken, completing a personal challenge, persistence over time, or any other reason.

The award for raising awareness of HSP can be for any person who improves awareness of our group, of any aspect of HSP, of any information relevant to members. Awareness can be raised in any way – appearances in the media, talking to important people, actively participating in events, strong on-line presence, or any other reason. The award is principally focused around raising awareness to a new/wider audience.

7. Committees

Since the last AGM we have agreed to start up committees to help get the work of the charity done. So, if you fancy helping the group but didn't want to be a trustee then this gives another way of doing that. The first four committees set up are:

- membership – to deal with welcoming new members and pointing existing members in the right direction for information.
- meetings – to run our excellent series of meetings across the UK and to provide a network of support between those meeting organisers.
- research – to deal with applications for research grants and to keep up to date with HSP research that is going on.
- fundraising – to give a more co-ordinated approach to our fundraising, and to seek out new ways of fundraising.

We would be happy to hear from any people who wanted to get involved in any of these areas and get more involved with helping the group. There are also a few specifics we are looking for in "Help needed", below.

8. Trustees

Since the last AGM Mitesh Patel has put himself forward to be a trustee. We have met with him and all agreed that he has the right qualities to be a trustee. The existing trustees made him a trustee at our February 2020 meeting, and he will be up for election at this AGM.

In addition, John Mason and myself are up for re-election as trustees, which marks the last of the unusual 'shorter' terms which started with the new constitution at the 2018 AGM.

9. Research Grant Applications

The newly formed research committee is in receipt of three applications for research funding. These have all used our new application process, and allow us to give the new process a good trial. The process makes our decision-making process as transparent as possible. Once we get to June we are in the next funding cycle and we will consider further applications in the next cycle. By the AGM I should be able to report the outcomes of the first three applications.

10. Help needed

Whilst John Mason is up for re-election this year we need to sort out a succession plan so that when he chooses to step down from his current roles we are able to hand-over to someone new. John has two key roles:

- Treasurer – we will need a new treasurer. This must be someone with experience in financial management, and this position requires you to be a trustee.
- Database management – The membership database is a MySQL database, and we need someone with MySQL database knowledge to carry on managing the database. This does not require you to be a trustee, but you would be on our membership committee, who are responsible for the database.

In addition, look at any of our new committees and see if you could help there. I am happy to share more details about any of the committees. If you can think of someone else who might be suitable then drop me a line and I'll ask them!

Adam Lawrence

Editor's Column

Who'd have thought our lives would have changed so much since we read our last newsletter earlier this year. I hope you're fit and healthy and coping well with the social isolation that we're all experiencing. At least things are now improving and we're slowly moving in the right direction for returning to normal life, but I expect it'll be a long time before we're as we were.

I mentioned in the last edition that I've just become a grandad. One of the hardest things for me has been not being able to give my grandson regular hugs. At least I've managed to see him as he's only five houses down the road. We've all been going for walks together (me in a wheelchair) although my daughter's household stay on one side of the road and we stay on the other. We chat from across the road so the locals must wonder what all the shouting's about. Hopefully it won't be too long before I can give him a huge hug.

I've just mentioned some of my recent wheelchair activity. I've actually been going out most days and doing two or three miles and recently I've been incorporating a couple of hills. I always use fit4change while doing this, so that every mile I do raises 5p for the HSP Group. It may not sound a lot but it all adds up.



Believe me! It's steeper than it looks

I've also been doing other exercises during the lockdown to get myself a little fitter. I've been watching my diet too and making sure

my weight remains below my acceptable maximum. I'm certainly no saint though, I've been having at least one alcoholic drink every day and sometimes more.

I live with my wife and half sister and we've been playing a lot of card games and watching a lot of films. Often the winner of the card game was the one who chose the film. My gardener has been unable to visit during the lockdown, so my other main activity has been gardening. We've been really lucky with the weather and it's enabled me to do small jobs most days. In fact I've surprised myself what I've been able to achieve and my garden has rarely looked better.

I've managed to find a way of recording my weekly radio show from home which gives me a great project to work on. In fact, that is one of the positives to come from this situation, as I doubt I'll ever go to the radio station again to record my show, even when this is all over, saving me energy and fuel. Currently, it may be hard to envisage, but I'm convinced that many positives will come out of this coronavirus pandemic. We'll certainly all appreciate each other more.

It may sound like I've been coping well, but like many friends that I've spoken to, I've had a few lows. I really miss all the local live music gigs that I regularly attend and I also miss going to local pubs and restaurants. It also seems odd not regularly going to football matches. The high point there is that my team were struggling and maybe this will save them. Perhaps that's wishful thinking.

I hope that you and your friends and family have all kept clear of the dreaded virus and long may that continue. I've heard from some people who've been getting a bit fed up and lonely but hopefully you've found ways of coping with the lockdown and been able to keep in touch with your own friends and family. I'm always on the end of the phone line or social media platforms if you'd like a natter. Thank goodness for Facetime, Zoom, Skype and other similar platforms that have enabled us to keep in touch with friends and family.

Ian Bennett

Spreading the word about HSP

It's been a busy time since January and fortunately we got a lot in before the Covid 19 lockdown

Wednesday 26th February

To mark the international Rare Disease Day, Genetics Alliance again held the annual reception at the House of Commons, and I attended.

Jennie Harries was there on the podium. You will have seen her as the deputy medical director England, standing with Boris at the daily Covid 19 briefing. It was rather amusing to see this grand lady (shes quite nice really) standing by an air conditioner that blew her hair so it was standing on end as if she was connected to electricity!! The aircon was quickly switched off!!

Covid 19 dominated most proceedings. But one patient strongly made the point that it was important for doctors to listen to patients with a rare disease as usually the patient knows more. She promoted the acceptance of ALERT CARDS, which are voluntary at present but bring forward such things as medicine allergy. By chance her consultant was available to stop the routine administration of a drug which would have killed her. She has not got HSP but some patients may suggest things that need being made known.

There is an All-Party Parliamentary Group (APPG) for rare diseases and I am aware of condition related APPG so that a particular condition can be promoted.

Saturday 29th February

Newcastle held their annual event to mark Rare Disease Day which is a public Genetics Matters afternoon where patients meet researchers and have delicious cakes.

This year for the first time the university made a room available for HSP Meeting. We hope they will do the same next year and we can be more definite as to what is available and where. We have been building interest in the North East over the past few years. The

university is going through reorganisation and if the format is reasonably the same, I hope to be one of the speakers.

Newcastle is the home of the computer system where registries of rare diseases are maintained and unlike the Genome Project this is a national database used by NHS England. Its head is Mary Bythell Head of Rare Disease Registration (England)

Mike Cain

Fundraising News

Please read this!

Since I publicised

[Easyfundraising.org.uk](https://www.easyfundraising.org.uk) at our 2019 AGM, we now have 46 individuals raising funds for us using this facility and we have raised nearly £500.

We have nearly 400 members, and no end of friends, so we should easily be able to attract many more than 46 supporters and raise significant funds for HSP with Easyfundraising. If you ever shop online and are interested in supporting the HSP charity, please register for this or get in touch. It's so easy to do. There is no catch: it really is a no brainer. For example, every time we do our supermarket shopping online with Sainsbury's, 50p goes to HSP. This alone raises £25 a year for HSP and I'm sure many of you do your supermarket shopping online. Other retailers pay us up to 3% of the value of purchase and even my eBay purchases earn the HSP Group 0.5% of the price I pay. We've just renewed an insurance policy on a car and if we'd realised that if we'd navigated to the insurers website, via the easyfundraising site, £10 would have been donated to the HSP Group.

There are thousands of retailers who support this including Amazon, Groupon and eBay, not to mention most high street stores. Use the following link and follow instructions:

<https://www.easyfundraising.org.uk/causes/hspsupportgroup1/>

As I said, any problems, give me a call but it's proving to be a great way of raising funds, we

simply need to get more members and friends involved, and it really is simple.

Many thanks to the 46 people who have already signed up to this great facility.

Ian Bennett

HSP Group Grants

Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier. The maximum grant available is currently £750. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from the Secretary Dave Harris, details at the end of this newsletter.

Members' Letters

Oh. The Joys of 'Lockdown'!

I thought 'Lockdown', introduced by the Government on the 23rd March 2020, would give me a chance to catch up with many things I wanted and needed to do. However, knowing one has so much time on ones hands I often put off jobs to the next day. (Sounds familiar? I can't be the only one, surely?)

Anyway I decided to try to adopt a routine. Like many with HSP I continued with my leg muscle stretching and balance exercises. I did these in a variety of ways including on my exercise bike which I store in the sun-lounge. I also did a lot of reading, mainly of natural history and environmental, magazines. The one I particularly like is the 'Countryfile' magazine. I love the accompanying TV programme on Sunday too. However, I, like many with our condition find it very frustrating when they emphasise the go for a 'walk' message. Despite being in self-isolation, I have managed occasionally to go out to my local woods on my mobility scooter. This venture is for my daily exercise, though in my case, it is more an exercise of the 'mind' ie

being able to gain some sounds of nature and be out in the local environment. In addition, conscious of my ever-growing hair and no barbers open, I ordered some hair clippers online. Practising doing a DIY haircut was quite a challenge, especially when everything is round the opposite way when you look in a mirror. With this in mind I warned some local neighbours that if I looked like I've adopted a Mohican-style hair cut they will know why!

Plus there is always my garden, which has received more of my attention recently. Indeed, probably due to less human activity in countries like Spain and France, the spring migration of birds, for example, from Africa has benefited from the virus. The world environment in general and climate change in particular, has gained from our present health emergency.

I am absolutely determined not to get tempted to watch day-time TV. However, I must admit my only exception is to see 'Escape to the Country', on BBC1 at 3.00pm. It features so much of our wonderful varied British countryside that we often take for granted. In retirement it was one of my ambitions to move with my wife to Devon or Somerset. However, this was not to happen. One can always dream! The programme does, though, give me some form of escapism. Though, I find myself on occasions shouting at the TV when I see steps, steep staircases, houses totally isolated and located near potentially over-flowing rivers, etc. We never know 'what is round the corner' in life, so I think some of the programme's potential house buyers may be taking a risk.

Anyway, that's my take on 'Lockdown'. However, as I write this England is going into a new phase with 'Stay At Home' advice being replaced by 'Stay Alert' (10.5.20). We'll have to assess the wisdom of this advice in the coming days and weeks.

Finally, I must admit that if I have any time when I don't know what to do next, I default to putting the kettle on for a good old cup of tea. Plus, the biscuits come out of the cupboard. **I know my priorities!**

Gary Cliffe

Our Lockdown

I feel we have been very lucky during the lockdown because none of us has been ill and we have a garden and also live in the country so that we can see trees and fields through the windows. A partridge nested successfully under our hedge this year which was a joy. It must be so much harder for people living in flats in the cities. Our son is shielding so my husband and I have hardly left the house either, but this hasn't been a problem because this period has been the perfect opportunity to catch up on jobs, to fit in lots of physio and to make contact with old friends. So, for me the lockdown has been a very positive experience so far. I'm desperate for a haircut, though!

Hilary Croydon

My Experience of the Covid-19 Pandemic.

My gut intuition was telling me very early on when the Pandemic hit Spain and Italy how serious this was and that it would have a huge impact in the UK

I work at the HQ of the largest Building Society in the UK - with approx. 5000-6000 employees at our large office. The building has and is still going through a refurbishment so we are very familiar to the world of 'hot desking' and smaller desk sizes.

We were all asked to do a two-day test run, working from home 11th and 12th March, so knew that soon this would be asked of most employees. I did declare my HSP when I joined the company two years ago and glad I did – as a result of this, they had me registered as one of their 'vulnerable employees' and I am also glad I enjoyed the Employee Disability Network too.

I am trying to remember from memory but all vulnerable employees received an email advising the business would like us to work from home for 12 weeks from 23rd March – I

think we were given an option to do so a couple of weeks before, I felt guilty to do this and also my manager had the belief it was business as usual until the 23rd March.....which at this point – every employee was to work from home.

I am single, live on my own in a coach-house flat, my HSP does not affect my mobility to a great deal currently, just advised to use walking sticks, as had recent falls (not alcohol induced either sadly). I have SPG4 and SPG6 (very rare – Nat Neurology Hosp only seen 3 people with it). My HSP is complex, it also affects my upper body – only part that is not affected is my upper right quarter of the body, Main issues are increasing spasticity...pain – peripheral neuropathy, digestive issues – bowels badly affected – one of my biggest symptoms and hard to deal with and manage and my wonderful bestie as I call it.....Fatigue 😊

I work full time, which I am finding ever more difficult and initially when working from home, not sure if it was just myself or other people felt that way – that I should be doing more work because I was at home. I loved that fact that my alarm no longer went off at 5.45am – my daily travel time on buses each day is usually 2hrs 30 mins – on top of an 8-hour working day.

Having to walk 5 mins 'to start work' was great. I was at a busy time of year work wise and trying to train a new colleague – which we were now having to do via MSFT 'Teams'. So, we all became technical/systems gurus overnight and I feel this will permanently change how we work in future and working from home.

I've always loved being a social butterfly – at work and with friends etc, I am a people person - also love my own space and my flat is my calm sanctuary. So initially it was ok working from home – but then I got peeved as my 'sanctuary' was becoming an irritating place to be as I could no longer 'not take my work stress home'. Then reality kicked in I would say two weeks later...am I vulnerable –

am I high risk, do I register as this on the Gov.UK site- do they mean people with rare conditions are high risk. I still feel it was confusing and still is - some HSP'ers have been advised they are high risk – whilst others haven't. I've classed myself as quite vulnerable 😊 – the last time I had a cold, even after having the flu shot – I had shortness of breath and breathing issues and on top of antibiotics to clear chest infection – had to use an inhaler.

So, I worked silly hours at first from 8 am until 6 pm trying to get all the work done and trying to train someone via a video screen, so the stress was building from that alone, I had the tv on all the time...it was shocking. My mum was confused as to whether she was vulnerable – advised she was as over 70 but also doubly as she had HSP – we argued about this for a couple of days...and finally she twigged – she lives on her own too. So I was worried and concerned about her – we are close and always see each other and are a support system to and for each other - how was she going to cope.....I am so relieved I suggested she got a Smart Phone earlier this year....teaching her how to do a WhatsApp Video call early on in the pandemic - gave both of us a lot of laughs during this hard time. I surprised her by Video Calling and luckily, she answered it and then got choked up that she could see me – she is also deaf and to her delight the audio of the WhatsApp Video call was better than a landline call. She is so chuffed and proud and has now taught all her friends how to do it and is a total Video Call convert.

I then had the battle like we all did to get a food delivery, by sheer luck and I don't know how, I have managed to get an Asda food delivery approx. every 14-16 days. Yes, my freezer is stocked up – but sensibly – no, I do not have 100 toilet rolls stashed; I just buy enough shopping for a two-week period.

My neighbours have always been great, and we have always got on and especially helped each other in the last two years that when we

had bad snow. One of the neighbours set up a SOS WhatsApp group at the beginning of March – this has been a total godsend for all of us and a good laugh too. One of these neighbours also lives on her own, we also have an 84yr old neighbour who is vulnerable. Those that can go out shopping, have continually asked if either of them can get anything for me & even had crossed words about who would be going to get my prescriptions for me when I asked if this could be done. Found that a stressful issue for me... I am fiercely independent and will always try to remain this way...as things might change in the future with the lovely HSP progression.

I have to say whilst I don't feel alone, I have great family, friends, neighbours, close work colleagues, never, ever have I felt so lonely in my life. Video calls good but I am missing the interaction with people and I am a touchy feely person and always hug everyone. I do appreciate there are benefits to being on my own -and not having to deal with a partner who is stressed and I can't imagine trying to home school children and try and help them during this time.....it's just highlighted the fact that I am single, I have been for a few years and this is also due to my fear of getting involved with someone and casually mentioning that I have a progressive condition called HSP.

What I have definitely been proud of during this pandemic and no I am not judging anyone at all and I know that every single one of us is different.....I have a long term rare progressive Neurological Degenerative Condition – that has a vast number of types all with an array of weird and wonderful symptoms that also affects each one of us uniquely too and to different degrees. My mum, sister and I all have it and we are all affected so differently...the symptoms are worse as it has gone through the generations and yes, I'm the youngest and unfortunately have the most severe symptoms.

I hope you all understand what I am trying to say next, the country is in the midst of a

pandemic and everyone is struggling to cope with the restrictions it has put on the daily lives, work/school routines, going on holiday, socialising with people....I feel that we as HSP'ers and all those people with health issues/long term conditions were probably just a little bit more resilient to having to go into 'Lockdown' as many of us have already had to make a variety of adjustments along the way with HSP.

I have to say though on the Friday 1st of May – I had a really bad day, luckily a day off work – we had a departmental meeting on the Thursday and during this call were told that whatever Boris was going to announce work wise it would not apply to us. That we would likely be working from home min of 3 to 6 months and more than likely for a year.... that was a harsh reality to check for me – I am just missing being around people. So, I made a cup of tea, sat on my doorstep and messaged our neighbourhood WhatsApp Group to see if anyone fancied 'Tea at 3pm' with me. One of them grabbed her garden chair and sat at the end of my drive....I chatted and sobbed my heart out and then she did too...she lives on her own too and I think she was relieved that she felt comfortable enough to cry in front of me....we then just chatted and ended up sharing some funny stories and had some good laughs.

The small group of neighbours who are in our WhatsApp group and yes, we are mostly all female,

have through this strengthened and developed our friendships more and there is more of a community feel in our street. With VE day celebrations coming up,...bunting and balloons were ordered and we all agreed to do our properties up and then decided to have a social distancing get together out the front of my flat – I have four drives as in a coach house flat – so lots of room for the 11 of us. It was a fantastic day which I feel all of us in the UK needed, we had a tv set up and a BBQ, where we cooked our own food with our own tools. It was a great day, great

community spirit – we all did have a few spirits to drink too....we all agreed that this mini-street party would probably not have happened if not for the Covid Pandemic.

So I am back on a happier vibe, I am still struggling mentally working from home and not getting any space, no garden, I am not going out walking at all – as I personally don't want to risk it...so I am also struggling with my legs more and trying to do a stretch class via YouTube every day. What will be ahead especially for all 'Vulnerables' as the Lockdown eases...I'm not sure, but glad I am not in a more dire situation that a lot of other people are regarding the impact of Covid on their lives.... I have a roof over my head, a job that I am getting fully paid for, great friends, new fun family video calls, fabulous neighbours/support and community feel– and of course the brilliant NHS, who I have always praised and thanked during my HSP Diagnosis and continued HSP journey and the variety of different appointments I have had for all the new different HSP issues along the way.

I hope all of you are well and thank you everyone for the Facebook posts and as always I have to say Della Brookman you are an Angel and a fountain of knowledge and I don't think you realise the support via your posts that you have given all of us – so from me – a HUGE HUGE thank you – fingers crossed I get to see you maybe later this year maybe at the AGM or in Devon....if we can

Karen Woodoff

Regional News

Autumn Meeting at Milford.

We were delighted to greet those that are able to attend both meetings and those that, circumstance determines, can only join us once a year. The door is always open with a warm welcome. We do miss seeing Phil

Burton. His wife, Anne, has sent us the recent news,

‘He is ok but has now lost the use of his hands. We drift from one disaster to another. He has loads of bad days but carries on. He is well looked after but really such a sad situation’

Terry shared the detail, and showed some photos, of the activities experienced during his holiday with the Calvert Trust. His days were certainly full of a wide selection of activities, not necessarily thought to be disabled friendly, but were readily achieved. Some of us were not so sure! The suggestion has been made that if there are enough HSP members interested in this type of holiday, a group week could be organised.

Whilst the Carer’s had time together, we enjoyed our time to socialise and catch up. Not all family members want to join the Carer’s discussions, so they have extra time to circulate. The term ‘Carer’ is ambiguous. For me a ‘carer’ is someone who perhaps shares our lives and takes an interest in what we do and will help us, as and when needed. Fortunately and currently, many of us do not need a ‘Carer’; defined as someone who supports those that cannot survive without support. This then opens discussions as to the type of care needed and available. A few years ago we were lucky when Steph and John Flowers demonstrated the help given by ‘Canine Partners’.

True to his word, Richard brought his orthotic underwear. His explanations were detailed, as to how he was able to have these prototype orthotics and the benefits he has gained through wearing them. Richard thoughtfully brought a spare pair for us to evaluate. Richard also said that since falling can be a frequent occurrence he wears cycling gloves. With the padded areas on the palm, the skin on his hands no longer is sore and broken.

Thanks to Lyn and Barbara, who sold the raffle tickets, the meeting attendees who bought tickets and Roger for distributing the prizes.

Wishing you all a good summer, best wishes

Mike and Jane Bennett

The Midlands

Paul Eccleshall is a member of our Midlands Group. For quite a long time now, Paul had been looking forward to celebrating this very special birthday as he has had quite an eventful year and had begun a very new chapter in his lifetime. He has lived alone for a long time in very difficult circumstances, and had moved into a beautiful new Care Home apartment just last December. He was so looking forward to sharing this very special day with all of his new friends.



Paul Eccleshall celebrating his 70th

Sadly the pandemic put a stop to all of his plans, and he didn’t get to have the party he’d been so looking forward to, but we sent a gift and cards from us all at the Midlands Group which we know he was really pleased to receive, and arrangements will be made for a little celebration at the Care Home just as soon as is possible.

I am sure you will all join us in wishing Paul “A very Happy 70th Birthday!”

June Masding & Penny Cohen

Forthcoming Events

HSP Support Group AGM

Saturday July 4th 10.30am

In the comfort of your own home

Online using the Zoom platform

See Notice of AGM for details

Potato Pants Festival

Saturday 15th August

Could now be held online due to coronavirus pandemic.

Contact Ian Bennett on 01202 849 391

New Members

We welcome the following new members:

Alan Meadows
Peterborough

Aysha Ufuk
Manchester

Julian Stokes
Bristol

Angela Cooke
Leominster

Graeme Owens
South Shields

Louise Donaldson
Oxfordshire

Hugh Stewart
Monmouth

If you are interested in contacting any of the above new members, please contact the membership secretary.

Useful Contacts

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Barbara Jones – Norwich co-ordinator		01603 423 267
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Adam Lawrence's HSP Survey Results

Medication, Activities, Travel Range and Life with HSP

This article presents the results of my seventh on-line HSP survey. This years survey covered medication, activities, travel range and life with HSP, and results are compared with mobility and wellbeing. I repeated some questions from my 2014 survey. 367 respondents completed the survey, predominantly from the USA, UK and Brazil. 150 of these had also completed at least one other survey, of which 22 had completed both the 2014 survey and this 2019 survey. The most notable change from previous years respondents is a large block of responses from Europe, who completed the questions in French, Dutch, Spanish and Italian.

Wellbeing

Respondents completed the Warwick-Edinburgh Mental Well-being scale (WEMWBS) to assess wellbeing which has a score ranging between 14 and 70 with a higher score for those with a better wellbeing. The average score for England and Scotland is 51-52 with most scoring between 41 and 59. The people answering this survey had an average score of 47.4, approximately 5 points below UK norms. The average is still within the “average” definition and similar to those with a self-perceived health status of “poor”.

Although it is a small sample (7), those who do not know if they have HSP have a lower wellbeing score, suggesting diagnosis uncertainties have a negative impact on wellbeing. Those who have SPG4 have an average wellbeing of 47.3, so almost the same as the overall HSP average. Those with SPG7 have a lower wellbeing score of 41.7, more than 5 points below the average. Average wellbeing scores of respondents in different parts of the world are similar, suggesting that any regional differences do not significantly affect wellbeing.

Mobility

Just over half of respondents use walking sticks/poles/crutches/ canes and almost two fifths use wheelchairs/mobility scoters and walking frames/rollators. FES is the mobility aid used by the least number of people, with a take-up of about 5%. There were similar to results from previous years. This table shows these results, including the percentage of respondents. These add to more than 100% as some people use more than one type of mobility aid.

Mobility Aids Used - Summary:	Respondents	Percentage
Using sticks/poles/crutches/canes	186	51%
Using Wheelchair/Mobility Scooter	141	38%
Using Walking Frame/Rollator	77	21%
Using Orthotics/AFO/Insoles	99	27%
Using FES	17	5%

The frequency of using the mobility aids is then used to group people into levels of mobility:

Mobility Aids Used - Overview:	Respondents	Percentage	Mobility Score	Wellbeing
Those without aids	71	19%	0-1	47.9
Those who use mobility aids some of the time	88	24%	2-3	47.0
Those who use sticks most/all of the time	101	28%	4-5	49.0
Those who use frames most/all of the time	39	11%	6-7	45.4
Those who use chairs most/all of the time	68	19%	8-9	46.2

The wellbeing scores do not vary significantly across types of walking aid being used.

People also identified the mobility aids that they used in 2014, which have been scored and put into bands. A low change applies to anyone developing first symptoms or gaining an increase in mobility score of up to 2 across 5 years. A medium change represents an increase in mobility score of around 3-4 across 5 years, and a high change represents an increase of in mobility score of around 5 or more across 5 years.

5 Year Change in Mobility	Respondents	Percentage	Wellbeing
Improvement (score decrease)	3	1%	-
No change	71	28%	49.2
Low (score increase)	88	35%	48.8
Medium (score increase)	51	20%	47.9
High (score increase)	40	16%	45.4

The data shows that the quicker the rate of change of mobility the lower the wellbeing score, although the wellbeing scores are within 3 points of average, suggesting that the effect is not significant.

Medication

In total 320 respondents answered this question. There were 274 people who indicated that they took at least one medication and 46 respondents who indicated that they did not take any medication at all. This indicates that around 85% of people are prescribed at least one form of medication for their HSP, and this proportion is slightly higher than reported in 2014.

Those who do not take medication, either have not started taking medication at all or have stopped taking medicine (either because they do not like the side effects of the medicine or because they are not noticing any benefits of the medicine). The following grid shows the distribution of the number of medicines against mobility.

Mobility Score	No medicine	1 Medicine	2 Medicines	3 Medicines	4 Medicines	5 Medicines	6 Medicines	Total
0-1	16	26	12	0	2	1	1	58
2-3	14	28	19	9	2	5	1	78
4-5	10	35	22	8	8	2	0	85
6-7	4	9	10	5	2	5	1	36
8-9	2	16	19	15	3	6	2	63
Total	46	114	82	37	17	19	5	320
Wellbeing	50.6	48.9	46.8	44.7	44.2	44.8	37.6	

This shows that generally those who do not take medication are the most mobile (lowest mobility score) although there are several whose mobility is not affected who take several medications. For those whose mobility is affected by HSP (higher mobility scores) there is a reasonable spread of the numbers of medication taken across the mobility bands. The most common number of medicines taken is 1 or 2.

The data shows that those who do not take medicine have a significantly better wellbeing and those who take the larger number of medicines have lower wellbeing.

The medicines fall into six general groups, with a number of other medications grouped together in a seventh group. The groups are:

Symptom	Number of medicines	Number of people
Spasticity/spasms	21	327
Pain/nerve pain	33	109
Bladder	12	64
Depression/anxiety	10	17
Bowel	3	8
Sleep/fatigue	2	2
Other	19	23
Total	100	550

The table shows that there are more people taking medicine for spasticity or spasms than in the other groups, whereas there is a higher number of types of medicine used to treat pain or nerve pain.

Spasticity, Spasm and Pain Medication

Almost 60% of the medication being taken is used to treat spasticity and spasms, the key features of HSP. The biggest proportion of this group of medications comprises people taking Baclofen.

Respondents taking medicine for pain form the second largest group of around one fifth of all the medication being taken. The pain medication being taken falls into two main groups, one group is for pain, whereas the other group is for nerve pain, pain from spasms, and other HSP symptoms.

The first group (pain) includes common pain medication, some of which is available over the counter, e.g. paracetamol and ibuprofen, and others are prescription medication like fentanyl and morphine. Further analysis has not been carried out.

The second group includes some medications that are used to treat effects of HSP, and the following table shows a subset of these medications, including those taken by the highest numbers of people and those where there are reports of using it to treat HSP.

The list of medications for spasticity, spasms and pain, where at least five people are taking, are shown in the following table, with descriptions of the medications taken from the UK NHS, drugs.com and other websites.

Medication	Description	People taking medication
Baclofen	Baclofen reduces muscle tone and unwanted muscle contractions. This helps to reduce painful muscle spasm.	178
Botulinum toxin A / Botox / OnabotulinumtoxinA	Botulinum Toxin Type A is used to treat muscle spasms. It stops muscle contractions in the muscle that it is injected into.	26
Gabapentin / Neurontin	Gabapentin is an anti-epileptic medication. It affects chemicals and nerves involved in seizures and some types of pain. It is also used to treat restless legs syndrome.	24
Clonazepam	Clonazepam is used to control seizures or fits due to epilepsy, involuntary muscle spasms, panic disorder and sometimes restless legs syndrome.	23
Tizanidine / Zanaflex	Tizanidine reduces muscle tone, helping to reduce painful muscle spasm. The effects usually lasts for a few hours.	21
Pregabalin / Lyrica	Pregabalin is an anti-epileptic drug. It slows down impulses in the brain that cause seizures. Pregabalin is also used to treat peripheral and central neuropathic pain.	14
Diazepam	Diazepam helps control feelings of anxiety, making people feel less agitated and less tense. It also acts as a sedative and an anticonvulsant. It can help to relieve muscle spasm.	12
Amitriptyline / Elavil	Amitriptyline is used in the management of long term (chronic) pain, especially nerve pain. It can be used for	11

Medication	Description	People taking medication
	improving sleep. Amitriptyline can be used for bedwetting in children	
Dantrolene	Dantrolene is a muscle relaxer that is used to treat muscle spasticity (stiffness and spasms).	9
Duloxetine	Duloxetine is an antidepressant. It's also used to treat nerve pain and can treat stress urinary incontinence in women.	9
Ziclague	Ziclague relaxes the muscles (decreases muscle tone) in a dose-dependent manner.	7
Pramipexole	Pramipexole is used to treat Parkinson's disease and restless legs syndrome. It may be used alone or with levodopa.	7
Cyclobenzaprine / Flexeril	Flexeril is a muscle relaxant. It works by blocking nerve impulses or pain sensations that are sent to your brain.	5
Dalfampridine / Ampyra / Fampridine	Ampyra is used to improve walking in patients with multiple sclerosis (MS). It reduces fatigue.	5

Of these, those with at least 10 people taking are examined in further detail.

Medication	Symptoms	Benefits	Side effects
Baclofen (oral or pump)	Spasticity (123 people) Clonus (22 people) Stiffness (10 people) Other (14 people)	Three quarters get a benefit, mostly medium or low. Half say benefits have not changed over time.	Half get no side effects. Key side effects are: sleepiness, increased fatigue or increased tiredness
Botox	Spasticity (most) Bladder (few) Other (3 people)	Majority get a benefit. Half say benefits are high.	Most get no side effects. Small number say it affects their gait.
Gabapentin	Pain and cramp (most) Spasticity (few)	Majority get a benefit. Half say benefits are medium.	Some get lots, others get none. Most common are sleepiness/fatigue/tiredness
Clonazepam	Spasms (most) Sleep (few)	Majority get a benefit. Third each say benefits are medium or high.	Some get lots, others get none. Most common are sleepiness/fatigue/mood/weakness
Tizanidine	Spasticity and spasms	Majority get a benefit. Most often benefits are medium.	Some get lots, others get none. Most common are sleepiness/fatigue/balance/pain/constipation
Pregabalin	Pain	Majority get a benefit. Third each say benefits are medium or high.	Half get side effects, the most common are effects on focus and fatigue.

Medication	Symptoms	Benefits	Side effects
Diazepam	Spasticity (most) Spasms (few)	All get a benefit, mostly medium or high	Two thirds do not get side effects. Most common are sleepiness/fatigue
Amitriptyline	Pain	Majority get a benefit, half say these are high.	Half get side effects, the most common is fatigue.

Other Medication

An analysis of medication for bladder and depression has not been undertaken.

Respondents taking medicine for other symptoms forms the remainder of medication being taken, totalling 6%. This includes 8 respondents taking medication for bowel issues, 3 respondents take medication to help sleep or reduce fatigue, as 23 others who take a range of medication for a variety of reasons. Several of these are worthy of note:

- Three respondents are taking Noscipine with the aim of stopping the progress of HSP
- Three respondents take Omeprazole to protect their stomach/gut from other drugs they are taking.
- One respondent takes Olanzapine to improve their cognitive function
- One respondent takes Nuedexta to treat the pseudobulbar effect (a less common HSP symptom).
- One respondent takes Liraglutide to help with weight loss to reduce the load on their legs.
- One respondent takes fusidic acid to treat skin problems bought on by HSP.

Medication Review

The table below shows medications being taken by at least five people for spasticity and spasms, and selected medication from other areas. The table reports if the medication is noted as being used to treat HSP by reference to HSP support/research group websites and other similar places. The table also identifies if the medicine has been reported in the literature as being used to treat HSP, by search of the PubMed database. Links are included to references.

Medication	People taking medication	HSP Treatment? (HSP groups)	HSP Treatment? (PubMed)
Baclofen	178	Yes – SPF	Yes, many
Botulinum toxin A / Botox	26	Yes – SPF	Yes, many
Gabapentin	24	Yes – SPF	Trial: 17539946
Clonazepam	23	Yes – SPF	No
Oxybutynin	22	Yes – Gene Review	No
Tizanidine / Zanaflex	21	Yes – SPF	Trial: 7035623

Medication	People taking medication	HSP Treatment? (HSP groups)	HSP Treatment? (PubMed)
Pregabalin	14	Yes - Review	No
Diazepam	12	Yes – SPF	Patient: 2803825
Amitriptyline	11	Yes - SPF	No
Mirabegron	11	Yes – Gene Review	No
Solifenacin	10	Yes – Gene Review	No
Dantrolene	9	Yes - SPF	Review: 20862796
Duloxetine	9	Yes - PLM	No
Ziclague	7	Yes - ASPEH	No
Pramipexole	7	Yes - HSPRF	No
Cyclobenzaprine	5	Yes - Review	No
Dalfampridine / Ampyra	5	Yes - HSPRF	Trial: 25808501

This table shows that there is no consistent source of information for the treatment of HSP symptoms, and to find particular results often requires a lot of hunting around. Several of the more commonly used medications do not have HSP specific trial results published, which may prevent their consideration by medical practitioners who are not so familiar with HSP. There may also be regional variations in availability of or guidelines for prescribing certain medicines, which has not been looked at.

Some of the treatments being tried by individuals are not reported at all, and this shows that some practitioners are being innovative and trying out different medications.

Activities

For people who do not use mobility aids at all (mobility score 0 or 1), regular activities are likely to include walking or running and stretches. Many respondents also do physiotherapy and music. Other activities undertaken regularly include yoga/tai-chi/pilates.

For those who use mobility aids some of the time (mobility score 2 or 3) or use sticks most or all of the time (mobility score 4 or 5), regular activities are likely to include stretches and walking/running. Many respondents also take part in physiotherapy and music. Other activities undertaken regularly include cycling/manual wheelchair and weights.

Where people use walking frames most or all of the time (mobility score 6 or 7), regular activities are likely to include stretches. Many respondents also take part in walking/running and physiotherapy. Other activities undertaken regularly include cycling/manual wheelchair, weights, cardiovascular gym machines and music.

For those who use wheelchairs most or all of the time (mobility score 8 or 9) regular activities are likely to include stretches. Many respondents also take part in cycling/manual wheelchair, physiotherapy and music. Other activities undertaken regularly include walking/running.

People identified the most important activities for exercise to be stretching, walking and aerobic activities. Music and stretches were identified as most important for relaxing. Stretches and physiotherapy were identified as most important for flexibility.

Those who use cardiovascular gym machines on a daily basis have the highest wellbeing. Those who listen/take part in music on a weekly or occasionally basis, and those who garden weekly and get acupuncture occasionally are shown to have higher wellbeing. Weekly cycling/manual wheelchair, occasional yoga/pilates/tai chi and occasional walking/running are shown to have lower wellbeing.

Life-space tracking

Respondents described how far they move about and how often they do this.

- 98% of people with HSP leave the room they sleep in every day. There are 2% of people who leave this room less frequently, but all leave at least weekly.
- 71% of respondents go outside every day, and 25% go outside multiple times per week. There are 3% who do this weekly and 1% who do this less often than monthly or not at all.
- There are 43% of people who go to their local neighbourhood every day, and 33% who go multiple times per week. 19% go weekly or less often, and 5% who do not go at all.
- When travelling beyond the local neighbourhood, 21% do this every day, 26% do this multiple times per week, 45% doing this less often and 8% not doing this at all.
- Travel further afield occurs less frequently, with 11% doing this every day, 14% doing this multiple times per week, 65% going less often and 11% not going at all.

Travel/movement decisions do not appear to depend on mobility. The highest wellbeing is found in those people who travel the furthest every day.

When looking at help needed to move around:

- 93% of people leave their bedroom independently, with 7% needing some assistance to do this.
- 83% of people go outside independently, 17% need assistance and less than 1% not doing this.
- 74% of people go to their local neighbourhood independently, 22% need assistance and 4% do not do this.
- 62% of people go to their local town independently, 34% need assistance and 4% do not do this.
- 52% of people are able to travel further than their local town independently, 42% need assistance and 7% do not do this.

The further a person wishes to travel the more likely it is that they will need to call upon assistance. Patterns suggest that the help sought to move/travel is more than just with transferring between places but is a broader level of assistance covering different aspects of movement. There may also be regional or personal variations in the ease of being able to travel.

Various interesting comments are made about this, with several indicating that they need help using aeroplanes. Many have adapted cars or mobility scooters and can travel independently whereas others rely on another to drive them places. Others note that they need help with transfers, and rely on this to move anywhere, whereas others are children and rely on their parents/carers to help them get around. Some people need help lifting and carrying things rather than getting around, and some indicate that they don't get out as much as they would like because they have caring responsibilities.

Life with HSP

Two thirds of respondents consider themselves to be disabled and one third do not. Although the proportion of people who identify as disabled increases with reduced mobility, there are both people who do not use mobility aids who consider themselves disabled and those who use a

wheelchair all or most of the time who do not consider themselves to be disabled. This indicates that mobility is not the only factor in individuals deciding if they are disabled or not.

One third of people with HSP consider themselves to be lonely and one third consider themselves to be isolated. Both tend to occur more often in those whose mobility is more restricted.

There are many views and opinions around this topic. Some respondents come from a more stable background with supportive family and friends, and getting out and about socially. Others feel more lonely/isolated. These feelings can arise because people are unable or do not want to explain their situation/problems to their close friends/family, or because they don't like the changes that HSP puts on them, including both physical changes and employment changes. Some feel invisible whereas others think they are very visible.

Around half consider themselves to be vulnerable. People identified that they feel vulnerable for two main groups of reasons, one group is around the physical changes of HSP not allowing people to be able to defend themselves or resist attack, the other group is around the consequences of HSP symptoms, including balance problems, incontinence and speed/ease of movement in crowded situations.

Wellbeing Conclusions

Different factors have been shown to have the greatest links with wellbeing. The factors below have been identified as having the strongest links to a wellbeing which is better than average.

- Travel to town or further daily
- Not feeling lonely, not feeling isolated
- Daily use of cardiovascular gym machines
- Weekly or occasional music
- Not feeling vulnerable
- No medication

The factors below have been identified as having the strongest links to a wellbeing which is lower than average.

- Taking multiple medicines for HSP
- Feeling isolated, feeling lonely
- Having SPG7
- Diagnosis uncertain
- Suffered from abuse

Many of these factors are not connected with mobility or are not directly related to HSP. These factors may not form part of routine discussions with medical professionals which frequently focus on mobility, pain, continence and the other direct factors.

It is important to remember that it is possible to take action to improve some of these other factors. It is not necessary to accept, for example, that people are lonely or isolated. Help is available for some factors, and getting such help may result in an improvement in wellbeing.

People should consult with a doctor or other professional to advise on the best approach for any such change they wish to make. Potential areas where changes could be made include:

- Decreasing: loneliness and/or isolation
- Taking part in activities which are enjoyable
- Being able to travel
- Getting help/support/counselling for any abuse
- Treatment/advice/exercises to slow the progression of HSP

Thank You!

I thank all of the respondents in many countries who took time to respond to this survey, without these excellent answers this analysis would not be possible.

Adam Lawrence