

**healthwatch**  
Somerset



# **REPORT ON HEALTHWATCH SOMERSET CONSULTATION WITH MEMBERS OF BRITISH POLIO FELLOWSHIP IN SOMERSET.**

November 2016

## **Introduction;**

The British Polio Fellowship has been developing support for its members in the SW and part of this is a new group in Taunton started. They have been keen to express their views on how the NHS deals with their condition of the late effects of Polio and Post Polio Syndrome (PPS). After being introduced to Healthwatch Somerset, it was regarded that a very good way to document the care they receive from the NHS in relation to their condition, at both primary and hospital level, was to work with Healthwatch Somerset on this. There is concern that PPS is not well understood by the NHS and that a consultation project on this may provide the documentary evidence needed to raise the issue with health commissioners via Healthwatch Somerset. The Group and British Polio Fellowship have been very grateful for the grant to allow this collaborative consultation to take place.

## **Project activities:**

The agreed activities in this project were:

1. A questionnaire to be sent by post to all British Polio Fellowship members in Somerset county which asked about the experience members have of their primary and secondary health care and social care in relation to their late effects of Polio and Post Polio Syndrome.
2. Focus groups to held in July 2016 which enabled discussion between members - allowing for more in-depth analysis of the support and care they receive for their health and care needs. It also enabled members to share their experiences of how they manage their own condition thus improving support for each other.
3. Communication to individual members to find out more about their situation with PPS.
4. Meeting individuals (selected)
5. Working with Healthwatch to help the Information book for Health Professionals is distributed to primary care centres in an appropriate way.
6. Lastly an important part of the project has been the analysis and evaluation of the activities mentioned above. This is being carried out by the Fellowship's SW Development Officer

## **Response to the activities;**

1. Questionnaires.

75 questionnaires were sent out to member's households. Often the partner of the person affected by Polio is also a member of the Fellowship but obviously did not complete the questionnaire for themselves. 22 questionnaires were returned. This is a 29% response.

2. Focus groups: 3 held in Washford (TA23 0NY), Coxley (BA5 1QZ) and Taunton (TA1 3DH): in total 19 attended – there were good and lively discussions.
3. Met members again in meeting in Taunton.
4. Met members again in meeting in Taunton.
5. Part of on-going action plan.
6. Analysis and report completed and sent to Healthwatch Somerset.

## **Analysis of methodology:**

The response to the questionnaire was not as good as I had hoped, as the questionnaires went out to members who have experience of polio and would benefit from responding.

Those questionnaires returned provided a lot of information about their health and social care provision. The most uncompleted aspect of the questionnaire was the Social Care section as few experience receiving social care.

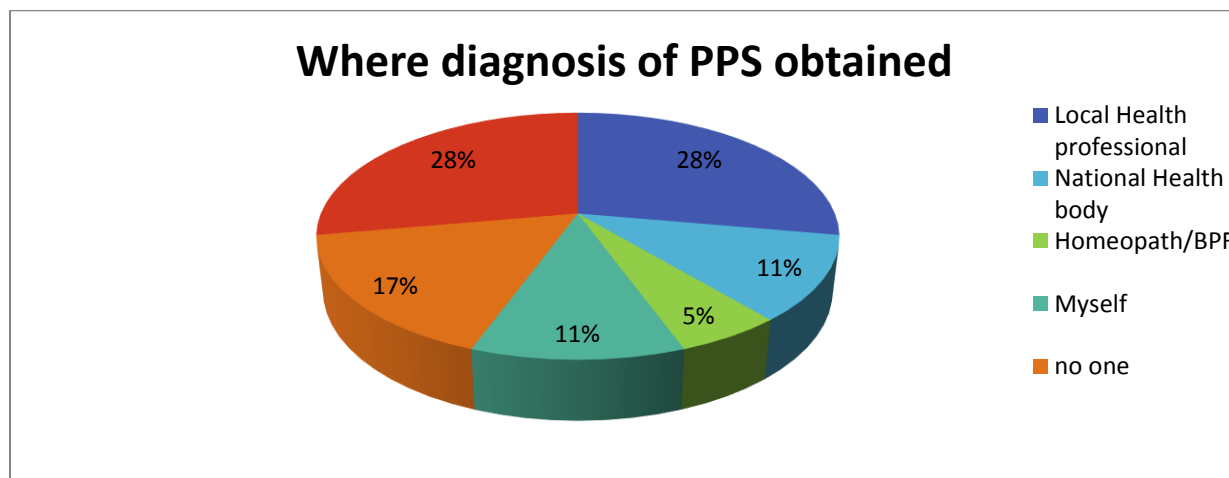
The Focus groups went well with copious comments noted down for collation and analysis. They were cordial and informative sessions for members as well as excellent evidence gathering.

### **Results;**

Please see the Appendixes for full details of the questionnaire answers and Focus group discussions.

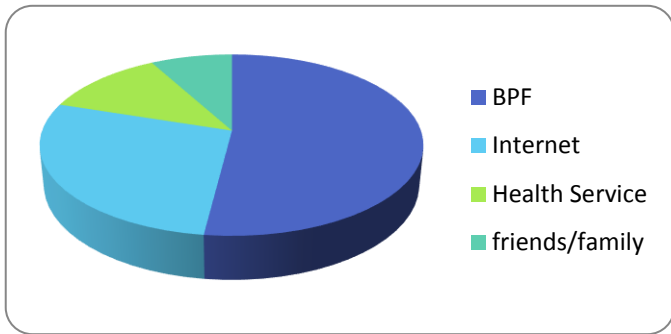
### **First – how members have got their PPS diagnosis:**

This prompted a wide range of answers, with common responses being that they have not been officially diagnosed although they have the symptoms, with others self-diagnosing from their own research. A couple of hospital Consultants got mentioned as well as the Lane Fox Unit in London, but only one mentioned GPs as the route to diagnosis.



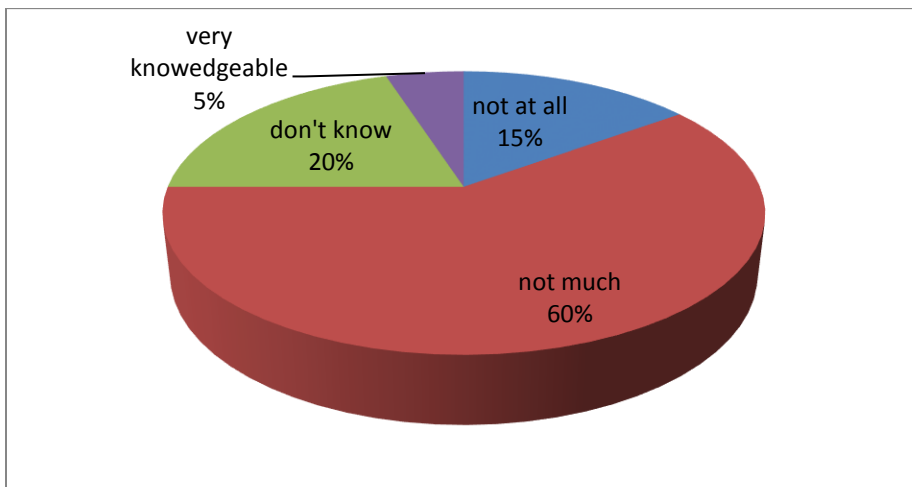
Following on from this many comments were about the length of time it has taken to get a diagnosis of PPS, due to issue of GP dealing with one health issue at a time so not linking it with PPS, lack of GPs understanding of the symptoms thus making it difficult for them to diagnose, the fact that a patient having a history of Polio not being foremost in the mind of the GP when looking at the health problems the patients presents. A few members felt that when they offered information on PPS to their GPs they were given a frosty reception rather than GPs working with the patient's own understanding.

**We then asked members where they got their information on PPS from;**



From this chart it is clear that the British Polio Fellowship has a major role in helping members understand about PPS with NHS not being the main source.

**When asking members ‘how knowledgeable did they feel health and social care are about PPS’** the overwhelming response was not at all or not much. This is rather disappointing and something that should be flagged up to NHS authorities.



**At the Focus groups we started with primary health care** – how did people feel about their GPs and their knowledge and understanding of Polio and Post Polio Syndrome.

A couple of now retired GPs were mentioned as being very helpful and the Ernham Lodge Practice was singled out as helpful. General comments were that ‘good’ primary care were those practices that are open and willing to learn about PPS in order to support their patients. There were also negative comments about primary health care. ‘Eyes glazing over when PPS mentioned’ was one response. Also lack of interest and not using the information provided to them by patients, with the lack of acknowledgement that patients can be the ‘expert’ in their illness.

**We wanted to know how these difficulties with Doctors not knowing about PPS, affected members – how they deal with it.**

Members felt that the lack of knowledge of GPs led them to learn as much as possible themselves, to then self-medicate or give the information to their GPs in the hope that they might read it and understand better. Some respondents also said they avoid going to their GP or have changed practice to get better support.

These issues have led those affected to be depressed, anxious or stressed due to not really knowing what is causing their problems. Affirmative diagnosis relieves this and allows those

affected to accept their condition and learn how best to live with it. Not knowing what causes something also stops the understanding of what measures to take to alleviate the symptoms.

During their consultations with GPs, 65% of respondents felt that PPS was not in the mind of the GP when discussing problems, i.e. they do not consider if PPS might be a cause of the particular issue. Some members have asked the question 'could this problem be to do with my PPS?' to insure the GP can consider the option, with mixed responses (GP dismissive, acknowledges it).

On a positive note there is some acknowledgement of good GPs (at Yeovil, Chard & Glastonbury).

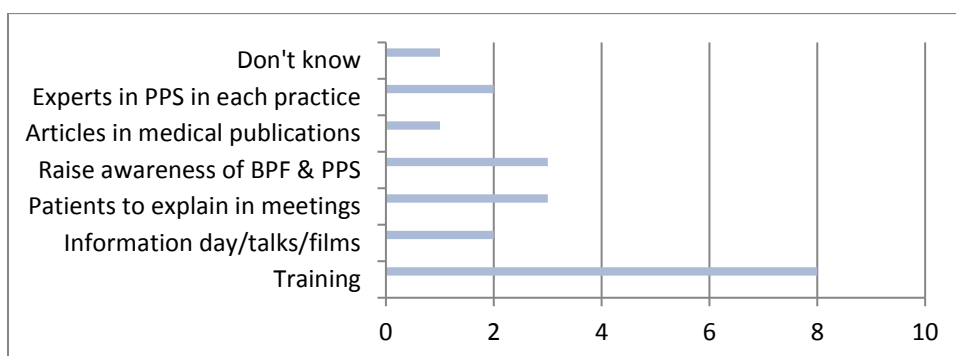
There is a general issue around being able to get timely appointments to see a particular GP and this is of special relevance to those affected by Polio because if only one GP in the practice has experience of the effects of Polio it is important that those affected can access them, but often for urgent appointments people have to see whoever is available thus adding to the potential to misdiagnosis and treatment.

### **The questionnaire asked about holistic care.**

Those responding said that holistic care was not something they had experienced. GPs address the problem presented to them and do not look at the patient's medical history to identify links between issues. So a treatment for particular problem may exacerbate another.

### **We asked Members how this lack of knowledge of PPS among health Professionals could be addressed:**

The largest response was that there is a need for training in Polio and PPS to understand the symptoms and treatment – including knowing who/where to refer patients to and to consider alternative therapies as part of the treatment/management package.



### **We then asked about Orthotics.**

This raised a number of concerns. Issues identified were problems getting timely appointments with the added stress of longer journey to get to appointments as some local services have been closed down. Ill-fitting callipers have made some people give up on using them, and the need to get a referral from their GP every time they needed maintenance causing delays. There was one positive comment that most recent appointment with Orthotist was helpful, with holistic and empathetic approach. There are some people with on-going issues.

Suggestions to how to improve orthotic service are as individual as the patients – see Appendix A

### **General Comments:**

There is a feeling that if GPs don't have an understanding of PPS or its management, they are unable to treat people affected accurately.

Some members manage their PPS with little intervention from the NHS or their GPs as they have been living positively with issues caused by their Polio for many years and are self-reliant. Difficulties occur if new health issue arises which may or may not be related to their history and symptoms of Polio but PPS is not considered as part of the analysis of the new health problems by GPs.

British Polio Fellowship members in Somerset seem a generally self-reliant group who know PPS cannot be cured but want to know the best ways to manage it.

There needs to be an acknowledgement that the most assertive individuals make waves. This project gave the opportunity for all members in the area to participate which has broadened the scope and results of the project.

There was also a few who acknowledged that people are more inclined to listen to the patients and their views now and that can help raise understanding of the illness.

Swimming in a Hydro pool (necessary due to cold intolerance – one symptom of PPS) would be very beneficial but is too expensive to access on a regular basis.

### **The effect on mental health and feelings of isolation and loneliness:**

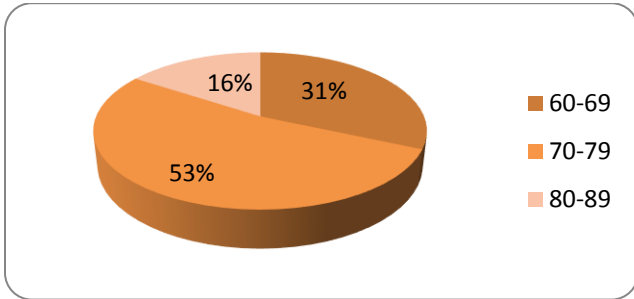
Isolation and loneliness are faced by people affected by Polio. Half of those completing the questionnaire mentioned issues of isolation, depression, emotional drain, frustration, anger, depression and demoralisation. Comments such as 'shut myself away from the world' are concerning.

People named a variety of causes;

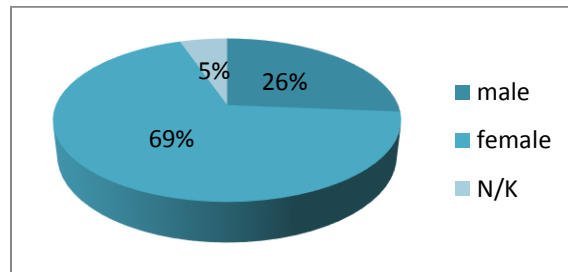
- Lack of understanding by Health professionals of this illness.
- Feeling that Health professionals do not care as PPS is not one of the key illnesses the NHS focuses on.
- The Dismissive attitude of health professionals to PPS
- The Symptoms being a nightmare – caused by some lack of understanding of the illness and how to live with it.
- Having a rare illness - feeling alone and isolated.
- Emotionally drained from having to be strong to cope.
- Limited mobility requires reliance on public transport that is not easily used (bus stops too far for walking), taxis are expensive and community transport unreliable and give degrading feelings for having to use it.
- Orthotics taking so long to provide new/repared essential equipment causes periods of inactivity and isolation. Also having many visits to get equipment 'right' costs patients lots of time and money that could be used on socialising thus improving mental health.
- Wheelchair users are put off buses by potential embarrassment of the chance of having to ask another passenger to move buggy or luggage.
- Too tired to go out.

## Demographics and disability information;

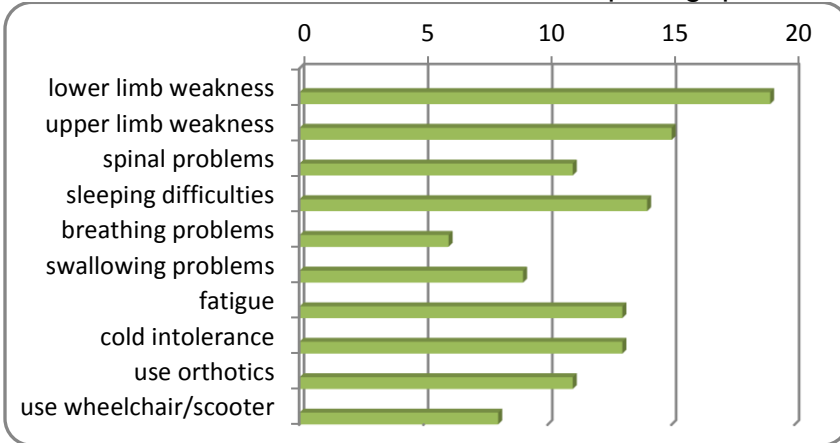
Age: in percentages:



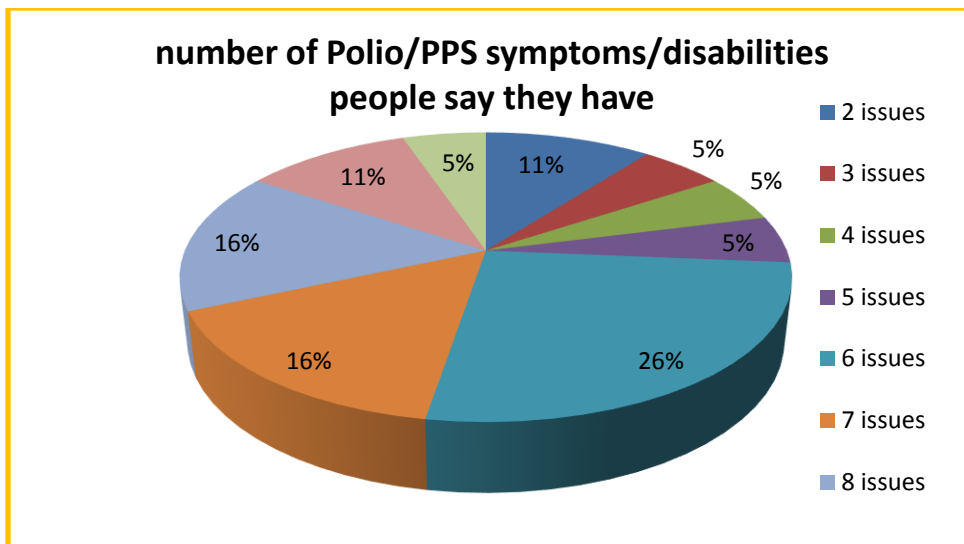
Gender: percentages:



Disabilities and health issues of those completing questionnaire:



Number of Polio/PPS Symptoms/disabilities individuals say they have:



### Conclusions:

- The majority of responses indicate the lack of GPs understanding of PPS symptoms and treatment available to support patients and some reluctance by GPs to learn more.
- The members' response to this is to find out about PPS themselves and then try to gain GPs confidence and understanding to help them gain knowledge and support the patient better or just look after themselves with minimal primary care input.
- Regional specialists with understanding of PPS are few, so many people attend Lane Fox PPS Clinic at St Thomas' Hospital in London for diagnosis, and management of the illness.
- British Polio Fellowship has a major role to play in helping members (and potentially non-members) gain understanding of their health situation and living with it better. Support groups such as the Taunton group are helpful in this area.
- 63% of members who responded to the project are under 75, 31% of members who responded were in 60's, so their disabilities and Symptoms of PPS, although some can be related to old age, are affecting them even before and during the early years of retirement.
- There is evidence of mental stress, depression, feeling of isolation and anxiety caused by the lack of proper and timely diagnosis and lack of willingness of GPs to accept the patient as more knowledgeable than themselves about PPS.
- The orthotic service seems to need improvement.

### Actions in response to the findings:

Healthwatch Somerset will support.

- Work to improve GPs understanding of PPS symptoms and management and reducing reluctance to refer to specialists. This could be done by:
  - Communicating direct to GPs of members and providing information
  - Using new resource specifically designed for GPs and produced by British Polio Fellowship's Expert Panel. Working with Healthwatch in the future to assist getting this information book to all GPs.
  - Offer GP training in PPS. This has already been offered in some areas but not taken up.
- Work to improve specialist knowledge of PPS in the region.



- Engage with the Orthotic service to look for ways to improve service and deal with individual issues raised by this consultation.
- Raise awareness of the BPF Somerset support groups (Taunton, Yeovil and Minehead) so as to increase its support to individual members in the county and the support offered for benefit advice and claims by the BPF.
- Aim to raise the issue of isolation and loneliness caused by the limitations of the illness:
  - Finding ways to communicate to members to improve people's understanding of their illness so they can cope more positively with it. BPF SW Development Officer is looking into developing a telephone befriending scheme as one way to try to address this.
  - Consider transport issues when planning meetings.
  - BPF SW Development Officer to look into ways of assisting individuals with their 'nagging' issues.
- Suggest that information displays be provided in Somerset's Hospitals to raise awareness of the illness. This has been done at other hospitals in the south west.

Lastly we asked for general comments: here are some;

**Local health & Social care  
are essentially reactive. No  
experience of health  
initiatives for PPS sufferers**

Living with  
PPS is a  
nightmare

**Most  
consultants,  
nurses ,  
physio's are  
kind but their  
lack of**

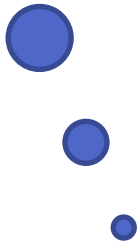
**POLIO IS LOW  
PRIORITY WITHIN  
MEDICAL  
PROFESSION**

**Living with PPS is like having venereal disease**

**Very pleased  
and grateful for  
the help I've  
received**

**Please treat  
orthotics  
patients as  
intelligent**

**Have not yet met anyone who appears  
to acknowledge PPS.**



# PPS can be very isolating.

## Appendix A

### Responses to Healthwatch Somerset questionnaire

#### Who diagnosed you as having PPS?

- Not yet diagnosed x 5
- Dr Will Hanon, Royal Devon & Exeter Hospital
- No one x 2
- Lane Fox Unit, St Thomas', London x 2
- Self diagnosed x 2
- Dr Cosh
- Do not have PPS x 4
- Can't remember
- Dr Atherton –Bristol Royal Infirmary
- Acknowledged by GP but not formally diagnosed
- Suggested by Homeopath who directed me to BPF
- Dr Stone Respiratory Consultant and another Dr doing neurological tests

#### Problems getting a diagnosis of PPS?

- Long winded, GP not happy I had researched my condition and asked for referral to PPS specialist. Still considers my symptoms due to stress.
- Took 7 years and lots of investigations. PPS confirmed as nothing else fitted.
- Lack of knowledge on my part & with Health professionals, reluctance of many academics to accept existence of PPS, time delays in getting appointments
- Drs treat one symptom at a time, so difficult to discuss lots of different symptoms at one time. Rarely see same GP more than once so no continuity.
- Best 'diagnosis' is that I have some sort of neuropathy
- Drs never seem to think polio could be the cause of symptoms.
- Do not know who to ask
- No diagnosis from GPs – only respiratory crisis that nearly killed me got a final decision.
- Tried once to get diagnosis but not tried again even though symptoms worse.
- Historical medical notes often missing so original diagnosis and problems not flagged up.
- No problem at St Thomas' Hospital, London
- None as I am being seen by Drs at Lane Fox Unit, St Thomas' Hospital, London
- Self-diagnosis via internet mainly.
- Taken a very long time
- Not sought official diagnosis as I do not think it makes any difference to my treatment from health professionals. I self-manage my illness.

#### Where have you got most of your knowledge of PPS from?

- BPF Bulletin 2
- BPF & internet x 5
- British Polio Fellowship x 6
- Head Physio at Burnham Hospital

- Internet x 3
- Family member who researched for me
- Medical practitioners
- St Thomas' hospital
- Friend with polio

**How knowledgeable do you consider health & social care services are about PPS?**

- Not at all x 2
- Almost none existent
- Little knowledge or awareness x 2
- Don't know x 3
- Not very x 4
- Not too good!
- Very knowledgeable
- Very poor – assume every illness I have is PPS so don't get appropriate treatment.
- Not good – it's up to me to try and explain.
- I know more about polio than GPs do.
- Patchy with health
- Social care – our problems not seen as priority – bottom of list or support.
- Social care - did not help with ramps round the house or purchase of wheelchair.
- GP and Respiratory consultant very knowledgeable

**When you visit your GP how does the GP include PPS as part of the discussion round diagnosis and treatment of a problem?**

- Not at all x 2
- No – in fact he seems to avoid it.
- My GP is fine (Dr Nicholl – Preston Grove practice, Yeovil)
- No
- Not spoken of unless I mention it - then rather dismissive.
- Excellent attention (Dr who covers Nursing Home in Chard)
- They haven't
- Never
- He is aware of my condition and the resulting problems (Dr Down, Tawstock, Chard)
- No – but maybe my fault?
- 2 Drs in practice are fairly knowledgeable but several younger ones are not.
- She doesn't
- Never discuss Polio with GPs as I am under care of Lane Fox Unit, London.
- He does now – Dr Corfield is excellent (Glastonbury)
- He doesn't until I mention it
- He acknowledges it
- Often

**If there is a specific GP in your practice who has an understanding of PPS, how easy is it for you to make appointments with him/her?**

- No specific GP to go to in practice x 3
- No one I know of x 4

- Fortunate to have been with same GP for many years – but still problems getting appointments
- Don't know x 4
- Not impossible – but long wait
- Been told one Dr in practice has some knowledge but I have never seen him – you see whoever is available
- Not always easy
- Assume GP has knowledge
- Physiotherapist attached to practice although no specialist knowledge was understanding and sympathetic.
- Always, if possible see the GP with PPS knowledge

**Regarding Hospital care please describe your experiences at different institutions you have attended.**

- Lane Fox – St Thomas' London
  - Internal admin laborious but otherwise fine
- Honiton Hospital – Physiotherapy Department has no knowledge of PPS
- Frenchay Hospital, Bristol (now closed) - long waits & journey. One consultant had knowledge of Polio from working in Hong Kong.
- Clevedon Hospital – very nice but came away with no more help
- Yeovil District Hospital –
  - Orthotist first person to have any idea of PPS. With minor operations for non PPs related illness – no one considered polio specific difficulties with anaesthesia or physio/exercise recovery regimes.
  - OK
- R D & E, Exeter – Consultant admitted not knowing much about polio or PPS. Carpal tunnel syndrome, fibre neuropathy and mild disc protrusion identified but none considered to be relevant to possible PPS.
- Frome Community Hospital – hip & leg pains – given exercise – polio not mentioned
- Musgrove Park Hospital –
  - consultant (for bowel) had no knowledge or training in polio
  - Not good for orthopaedics
  - Not listened to when on ward about not being able to transfer from wheelchair to toilet without calliper. So I was dropped by nurse. On many visits always made to feel uncomfortable – staff don't understand that without calliper I cannot weight bear.
  - For Decompression of spine – wonderful surgeon and good nurses & physio.
  - For pain in hip & leg – took long time to sort and I doubted if they were really interested in finding a solution.
  - Respiratory unit have good knowledge of PPS. New staff always open to receive info on PPS.
- Bristol Royal Infirmary – V good.

**'What experience have you had of holistic care from local health and social care services in Somerset'?**

- None x 13
- My impression is that due to budgetary constraints only the very worst cases get support from Social Care

- good
- not good generally
- I am always asking why a holistic approach is not taken – the general answer is that we'll sort out 'a', 'b', or 'c' without considering how that may impact 'd', 'e', or 'f'.

**What do you think could be done to improve the Medical Profession's understanding of the effects of living with Polio and PPS?**

- Having one GP, nurse & physiotherapist from each practice with understanding of PPS x2
- PPS awareness to be part of medical training x 3
- Articles in medical publications
- Part of on-going professional training
- Just don't know.
- For medical staff not to dismiss the effects on polio on current problems
- Orthotists should have good knowledge of PPS
- Medical professionals need to have basic awareness – as much as they have for Parkinson's – initiative for this to come from NHS or BPF?
- Training days by BPF
- Information days for Health professionals led by professionals – possibly using patients to explain what living with PPS is like.
- Take notice of PPS
- Needs to be much more awareness, training and consultation
- Let Polio victims explain in a forum
- Giving talks and films
- Giving patients time to explain
- Make medical profession aware of the BPF Website
- Education the best way

**If you need orthotics services, what is your recent experience of the service provided to yourself?**

- Have to fight tooth & nail to see anyone, at last appointment had to show the girl how to make my splints.
- Not brilliant. Local unit closed down – now have yearly appointments at Taunton – do not bother anymore
- Have seen gradual decline in service – longer waits and poor quality BUT most recent appointment – pleasantly surprised by knowledge, empathy and skill of current orthotist. His holistic approach to find best solution is encouraging.
- Had private orthotic made but gave up as body did not want to adjust to it.
- Frequently need new boots
- Gave up on the orthotics, either too painful because of ill-fitting or I just could not cope with what provided.
- Never any follow up from appointments. No action taken regarding problem.
- Dreadful – have to travel to Taunton (Minehead resident). Seen 5 different orthotists in past year. Needed new calliper and shoes – after 8 visits still not fitting properly. Shoes 2 sizes too big. Made to feel I'm a nuisance and fussy.
- Very good at St Thomas', London, very helpful, responsive and efficient.

- Not as good as it used to be.
- Only get given 1 pair of shoes - very ugly.
- No contact with orthotist regarding calliper repairs. You take it in to Minehead hospital and can give only written instructions on problem.
- One leg 2" shorter than other so I have to buy shoes for hospital to raise up – harder and harder to find soles suitable for this process
- I have to 'fit' into what they provide. They do not seem able to cater for individual disabilities

**What do you think could be done to improve orthotics services for people with PPS?**

- Advice on where to get shoes suitable for orthotic adaptations.
- Orthotist need to be fully aware of PPS mechanisms.
- Providing modern callipers of carbon fibre, titanium & electronics now available rather than continuing using older style steel framed ones which need manual strength to put on and use.
- Orthotist to understand we cannot go back to 'normal' but looking for best solution
- Easier access
- More accessibility and better follow up
- Let the patient meet the person making the shoes or calliper – not go through a 3<sup>rd</sup> party.
- Be allowed to go to private providers with agreed budget from NHS (like direct payments)
- \*\*\*\*\* listen when customer talks to you. Treat orthotics patients as intelligent, busy people who need help NOW – not 6 months down the line.

**Reflecting on living with PPS, please use this space to add anything else that you would like to share about your experiences both positive and negative, of local health and social care services.**

- Various GPs I've used have had no understanding of PPS and not willing to learn. How can a GP treat a patient without knowing what they are treating? Eventually moved GP practice again and found one with GP with knowledge (DR McClintock of Blackdown practice). He was excellent – treated me as an intelligent person with a right to understand my treatment and ailments. He is now retired.
- As most health professionals don't know about Polio and PPS they don't know how to offer you any help. Now just relying on BPF magazine to keep me going. PPS can be very isolating.
- Local health and social care are essentially reactive. No experience of any health initiatives for PPS sufferers in my area. We don't shout the loudest nor are in a social group favoured by politics or popular culture.
- Very pleased and grateful for all the care I've received
- Living with PPS is a nightmare – constant pain – if someone does not understand PPS they think you are faking.
- At the symptoms gradually manifest I am sure support will be appreciated.
- People more inclined to listen than in the past but they are not aware of all the problems and don't know where to look for answers or information.
- Living with PPS is like having a venereal disease – you can't talk about it, there's no cure, you can't talk about your difficulties without sounding like a whiner. The emotional

drain of having to be strong to be able to cope never gets discussed. Wouldn't it be lovely if anyone had time to listen?

- Lucky to have good respiratory Consultant.

## **Appendix B**

### **FOCUS GROUPS ANSWERS – JULY 16**

#### **1. Focus on GPs first:**

##### **Good ones – why good**

- Dr Jordon – Neurological Unit in Bath – now retired
- Dr Clintock – Blackdown Practice – now retired
- Ernham Lodge Practice
- Those that try to find out as much they can
- Those who are open and willing to learn

##### **Not so good ones – why not**

- Those not heard of PPS – but honest that he knows nothing
- Anything information given to GPs is just filed
- Eyes glaze over when one mentions PPS
- Not interested
- Have little knowledge of PPS
- Assume we don't know what we are talking about, think we are idiots
- Not acknowledging symptoms of PPS when they should be
- Harley House - Assume everything is to do with Polio but don't do anything to address the problems – not interested in finding solutions.
- Don't refer us to specialists

#### **2. How have you coped with GPs that don't seem to help you much? What's your strategy?**

- Learn as much as possible - flatter GPs
- Be willing to learn
- Giving info to GPs – but does not always help
- Stop going to them!
- Find out ourselves about PPS
- Self-medicate
- Try not to go and see them
- Change practice – difficult if live in rural area as often little choice.
- Educating them

#### **3. How do problems with GPs affect you?**

- Depression due to not having symptoms explained
- Not knowing what causes problems leads to stress
- Been referred to talking therapy due to anxiety
- Feeling of isolation due to NHS ignorance of PPS and lack of interest and research into it.



**4. What have you done to help GPs understand Polio or Post Polio Syndrome?**

- Given them information and tried to talk to them

**5. Where have GPs referred you for specialist help?**

- No one except orthotists
- Nerve Specialist at Wellington
- Sleep Unit and cardiology
- Physiotherapy
- Consultant sent me for hydrotherapy

**6. What are the specialists like?**

**Good ones or bad?**

- Poor follow up on appointments
- Good – Tricia Acton at Musgrove (Mr Heals department)
- Good – Dr Stone
- Dr Thorpe – not so good
- Dr Stone – Respiratory Consultant at Musgrave Hospital

**7. Thoughts on Physiotherapists?**

- Physiotherapists exercises makes it worse
- Went private to a Physio who had good knowledge of PPS
- Physio at Minehead – not worth going to!
- Some don't know about PPS and don't want to know
- Can't disentangle what told to do from other things affecting the person
- One is good and understands
- They need to know about PPS as this may affect what they recommend

**8. What about Orthotics?**

- Some give helpful advice
- Hit and miss
- Old treatment leads to isolation
- No joined up thinking
- Replacements for hand splints nor able to be made without patient's support
- Problem with having to go back to GPs for referral for repairs and maintenance
- Problem with being given shoes 2 sizes too big after 9 months wait.

**9. Moving on to care in the home – practical help.**

- Partners are unpaid carers
- Carers allowance not available as it's means tested – this is unfair
- Partners do much more than they should

**10. Thoughts on Occupational Therapists? E.g. equipment in the home.**

- Got a webbed sling – this is helpful - also up & down loo seat and walking frame
- Find OTs judgmental and difficult when sorting out alterations.

**11. We don't just need to complain but to have suggestions about how things can improve – what are your ideas on this?**

- Need a miracle!
- Educate GPs but how?
- CPD training
- Need list of local boots shops to get shoes that can be adapted
- BPF having stalls to raise awareness

**12. Any experiences we have not yet covered – areas of concern you would like mention**

- CPAP machines not the right size for women.
- System does not allow for best practice
- Hate being dependent on my husband
- I shut myself away from the world – don't want to go out
- Stay in when too tired to do anything – people only see me when I am on a good day
- Feel lonely due mobility problems – can't afford to use taxis and buses not good. Medical appointments can take one's entire transport budget not allowing for social activities.
- Reduction in Mobility Allowances when being moved from DLA to PIP is counterproductive in the long term as it leads to isolation and loneliness which can detrimentally affect one's health.

**Musgrove Hospital: Issues:**

- Go for physio and hydro but departments far from car parks so get tired out before the sessions.
- Disabled bays too far away as well
- Buggy service inadequate
- Can't see if disabled bays near hospital are free due to trees obscuring them
- Fewer park & ride buses now
- Yeovil and Bridgewater buses do not go direct to hospital.
- Bus services – problem with space for wheelchairs being used for buggies or luggage

**General problems:**

- No ramps on many shops so prevented from entry
- Cafes – chairs too close together.
- Issue with blue Badges – was refused as arm weakness seemed not relevant.

## Tell us your story...

Healthwatch Somerset want to hear from you about your experiences so that we can tell services your needs to create the best local services.



Text us - text somerset followed by your message to: 07860 021 603



Email us: [info@healthwatchsomerset.co.uk](mailto:info@healthwatchsomerset.co.uk)



Call us: 01823 751 403



Write to us at: Healthwatch Somerset,  
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Edington, Bridgwater, TA7 9LF

Or visit our website to see more at: [www.healthwatchsomerset.co.uk](http://www.healthwatchsomerset.co.uk)