

Polio Survivors Network

A service user led support network
for Polio Survivors
experiencing Post Polio Syndrome

Members' Survey



October 2011

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About the Polio Survivors Network

The Polio Survivors Network (PSN) was originally known as the Lincolnshire Post Polio Network (LPPN) and founded by Hilary Boone, who, in 1995 discovered she had developed Post Polio Syndrome (PPS). Although, a Polio Survivor she had, at that time, no knowledge of Post Polio Syndrome or symptoms. Hilary researched and educated herself about this condition, met with the Leicestershire Post-Polio Network and started a similar network, the Lincolnshire Post-Polio Network in 1996.

By November 2009 LPPN had more members living outside Lincolnshire, including overseas members and a decision was made to change the name to Polio Survivors Network.

PSN is a Service User controlled charity providing support and information about PPS to Polio Survivors, their families, health and social care professionals and researchers. PSN has no paid workers and does not receive any government grants. All work is done and paid for by members' subscriptions, members' donations and funds raised via application to various funding bodies. In the last financial year we were grateful to receive financial support from The Helen Jean Cope Charity, Cadbury, and Wickes and sales of Val Scriveners cards.

The current Trustees, Hilary Boone, Glenna Tomlin and Gillian Bryan are mindful of the goodwill, good work and support of previous Trustees. We would like to take this opportunity to gratefully acknowledge the work of the lead author of this report, Sandra Paget. We would also like to recognise the continuing support of our Members, some of whom have been with us from the beginning.

Hilary Boone

Glenna Tomlin

Gillian Bryan

**Polio Survivors Network.
October 2011**

Polio Survivors Network

A charity registered with the Charity Commissioners of England and Wales - Reg. 1064177

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Introduction

Poliomyelitis (Polio) is caused by an enterovirus that attacks the central nervous system and mainly affects children under 5 years of age but older children and adults are also susceptible¹.

Until the development of an effective vaccine, in the 1950s, epidemics were common, particularly in the 1940s and 1950s. Although significant numbers made a full recovery, others were left with life-long damage to their physical functioning. Polio epidemics in most countries are now eradicated, although epidemics are still occurring in some developing countries².

Post Polio Syndrome (PPS) is a neuro-muscular disorder that develops in Polio Survivors between 10 - 40 years after the original infection. As yet, there is no bio-marker for PPS and diagnosis is made by excluding other conditions. Symptoms include fatigue, new muscle weakness, muscle fatigue and pain, swallowing problems, respiratory problems and sleep problems.^{3,4}

In November 2010 the Trustees, at the time, Hilary Boone, Sandra Paget, James Pullin and Glenna Tomlin, decided to undertake a survey of the Polio Survivors Network's membership to assist their understanding of members' concerns and to help represent these concerns as part of PSN's awareness raising and education activities.

We are not professional health researchers and realise there are probably many mistakes in the construction of the questionnaire but we all consider we have expertise arising from our life experiences.

It is only the epidemics that have gone away in the UK but those who survived and their families are still here.

Method

156 questionnaires with a covering letter (see Appendix 1) and a return envelope were sent by post to members of the Polio Survivors Network living in the United Kingdom. The questionnaire was constructed by the Trustees who are **not** professional researchers. The questions were worded so that carers/others could respond on behalf of recipients. For the Questionnaire see Appendix 2. The survey was conducted between November 2010 and January 2011 and the data was counted by hand.

Results

Of the 156 questionnaires sent out 70 (44%) were returned. Not all questions were answered. The age-range of all those responding is 51 - 87 with an average age of 69.

Males responding = 28 with an age range 53 - 87 and an average age of 74. Females responding (including two carers aged 70) = 42 with an age range 51 - 67 and an average age of 67.

The majority of respondents were over 65 with ages falling between 60 - 80 with more females (22) falling between 60-70.

Most of the respondents caught polio between the ages 0 - 5 years (42 of 68 responding, (61%). 50 of the 63 (79%) responding to Q3 (type of polio) reported they had had paralytic polio and that they had received a diagnosis of PPS

The main symptoms of PPS reported were, fatigue, muscle pain, weakness in muscles, breathlessness, falls, loss of concentration and swallowing problems.

54 people reported they had discussed their symptoms with their GP with 18 reporting their GP had a good understanding of PPS. 4 male respondents reported "don't know".

37 people reported which type of clinician diagnosed their PPS with 26 people reporting that a neurologist diagnosed PPS.

Most people did not receive a full health assessment at diagnosis. 8 people were unsure whether they had received such assessment.

Medical Support (Q 13 - 21)

Most of those responding reported never seeing a Consultant Neurologist, physiotherapist or Speech therapist.

Table 1

| Clinicians | 12 months | | 6 Months | | Other | | Never See | |
|-----------------------------|-----------|-----|----------|-----|-------|-----|-----------|-----|
| | (M) | (F) | (M) | (F) | (M) | (F) | (M) | (F) |
| Consultant Neurologist | 4 | 9 | 2 | 3 | 3 | 2 | 9 | 30 |
| Physiotherapist | 2 | 2 | 1 | 3 | 4 | 5 | 6 | 3 |
| Speech and Language | | 1 | | | | 1 | 12 | 22 |
| Psychologist or Counselling | | | | | | | 12 | |

About half of those responding thought the professionals listed in Table 1 had a good understanding of PPS. 10 people had asked to be seen by the professionals listed above and 8 were seen. 6 reported dissatisfaction with the outcome.

Most people were not and had not been in an iron lung and the longest time reported was 2 years.

22 people reported having respiratory/breathing problems. No treatments were reported. 9 people reported using ventilators, 3 Bi-level, 4 CPAP. 4 people reported night time use only and 3 people reported day time use. 1 person reported using all the time.

5 people reported they were dissatisfied with regard to their ventilation needs.

Table 2

| Clinicians | 12 months | | 6 Months | | Other | | Never See | |
|------------------------|-----------|-----|----------|-----|-------|-----|-----------|-----|
| | (M) | (F) | (M) | (F) | (M) | (F) | (M) | (F) |
| Respiratory Consultant | 2 | 5 | 2 | 3 | 1 | 1 | 15 | 10 |
| Respiratory Nurse | 1 | 2 | 1 | 2 | | | 18 | 12 |
| Respiratory Team | | 2 | 1 | | | | 18 | 12 |

Information Provision (Q 22 - 29)

58 people responded and 17 said they had received information about PPS at diagnosis. 4 people were unsure whether they had been given information. 33 people said they would have liked more information.

19 people reported receiving information verbally and 7 received information in writing. 3 were unsure .

Most respondents were not referred to a website or a patient organisation/support group.

Question 28 asked about other sources of information and the main sources given were Polio Survivors Network, British Polio Fellowship, Internet and the Lane Fox Unit. 1 person reported that they had asked for information in a particular format and received it.

Respite Care and Neuro Rehabilitation (Q 30 - 35)

65 people responded with 4 people reporting having received respite care. 52 people reported they did not need respite care. 2 people reported that they did not think respite care improved quality of life.

2 people reported receiving neuro-rehabilitation and were satisfied with the outcome.

Mobility (Q 36 - 45)

About half of those responding to Q.36 (wheelchair use) reported using a wheelchair and the majority of people using local wheelchair services reported the service was easy to contact, repairs done to a good standard and thought staff understood their needs. 14 people reported using an electrical wheelchair and 18 a manual wheelchair. 3 people reported they needed a wheelchair but had been refused by the NHS. 18 people bought their own wheelchair and 20 people said they used an electric scooter.

68 people responded to Q41 (public transport) with 38 people reporting that they could not use public transport.

60 people responded to Q43 (orthotics and aids) with 48 people reporting having to use these aids. The majority of people reported using local orthotics services and thought their service was easy to contact, repairs done to a good standard and staff understood their needs.

Although the majority of people using local wheelchair and orthotics services reported satisfaction with these services people also reported poor experiences of these services. (More detailed questionnaire responses for Q36 - 45, Appendix 2)

Employment (Q 46)

58 people responded with 47 people reporting not currently working. 34 people reported having to stop working or reducing their working hours due to PPS.

Equipment (Q48 - 53)

64 people responded with 25 respondents reporting having received an assessment of their needs. 20 people reported the assessment had been carried out by Community Occupational Therapy. 15 people reported that they thought the person doing the assessment understood their needs. Very few people responded to Q52 (waiting time) but of those who did a range between 1 week and 1 month was reported. 15 people reported their needs were met.

Other Medical Conditions (Q54)

68 people responded with 49 people reporting other conditions, including diabetes, asthma, cardiac problems, Myalgic Encephalomyelitis, cancer and others.

Complementary Therapies (Q55)

61 people responded with 24 people reporting they used complementary therapies such as massage, acupuncture and chiropractic.

See Appendix 2 for detailed responses to the questionnaire

Discussion

Incidence and Prevalence

Information about incidence and prevalence of PPS in the UK is weak. The Department of Health in the UK, through the Policy Research Programme commissioned a review of six rare neurological conditions, including PPS (Review of the Epidemiology of Service Use of Long Term Neurological Conditions (RESULT)) which suggests an incidence of 0.03 - 0.18 and prevalence of 0.71 - 0.77.⁵

The Health Protection Agency (HPA) has published notifications of polio in England and Wales between 1912 - 2007⁶. Information given by NHS Choices is that PPS affects approximately 20% - 66% of people who have had polio with symptoms developing between 10 and 40 years after the initial illness. Symptoms can take an average of 30 years to develop.

In a paper published online in July 2010 it was suggested that 15% - 85% of Polio Survivors may go on to develop PPS³.

For the purposes of their report the Scottish Medicines and Scientific Advisory Committee (SMASAC) Working Group Post Polio Syndrome/Late Effects of Polio gave an estimated prevalence of between 1,000 - 6,000 cases of PPS for Scotland⁷.

Whilst we do not know how many of those who survived polio are still alive it is possible that a considerable number of people could require treatment, management and support for 30-40 years or more in the United Kingdom. A similar observation also made by Lauro Halstead in his review of PPS in the USA⁸.

Recommendation

Improved recording of PPS is diagnosis and use of the new Read Codes for PPS.

Greater understanding of the epidemiology and service use of Polio Survivors.

Medical Support

It is of concern that many of the respondents did not think their General Practitioner and other health professionals had a good understanding of PPS and that most respondents reported never seeing a neurologist, a physiotherapist, a speech and language therapist or counsellor. In particular, respondents reported being told by their GP that ... "PPS did not exist" ... or that their symptoms were due to "ageing".

Whilst there is amongst some clinicians discussions about aspects of PPS, the evidence now strongly supports that PPS does exist with some evidence for treatment, management and support. Indeed, the existence of PPS now acknowledged by the fact that the World Health Organisation has given PPS an ICD Code and in the UK the NHS has now given PPS a Read Code for each of the two major systems used for Primary Care records.

At the time this survey was carried out respiratory/breathing problems were reported by 22 respondents. However, no-one reported receiving treatment or therapy for these problems, although respondents did report using ventilators with 5 respondents reporting dissatisfaction with the support they receive for their ventilation needs. Sleep problems were also reported which can

be related to respiratory/breathing problems. Our (wider) membership, when members have been referred, report poor service from respiratory and sleep services around the country.

We have tried to find standard guidance for respiratory/ventilation services for post polio syndrome and/or neuromuscular disease in the UK. There seems to be only NICE guidance specifically for non-invasive ventilation use in Motor Neurone Disease⁸ which suggests recommendations for the identification and management of respiratory problems early on. This guidance also gives information about obtaining and using equipment and other information about testing and monitoring etc.

Both Farbu and Gonzalez indicate that respiratory insufficiency is a risk for people with PPS and should be considered. Diagnosis of PPS is arrived at by eliminating other causes for symptoms. The Map of Medicine⁹ indicates that a definite diagnosis includes new muscle weakness and we assume this to mean new weakness in any muscle and thereby muscles involved in breathing. Respiratory problems can cause fatigue and sleep problems as well as lead to chest infections and can be life-threatening.

The European Federation of Neurological Societies (EFNS)¹⁰ recommends early monitoring for respiratory problems and also noted that PPS patients in the UK were mainly taken care of by GPs.

It is also noted by Gonzalez that PPS can co-exist with other conditions. Of the 68 people who responded to Q 54 (Other Medical Conditions) 49 people reported having other medical conditions, such as asthma, diabetes, cardiac conditions and cancer. We are concerned that recommendations for prevention and management of chronic conditions such as diabetes, heart health and depression may be difficult for Polio Survivors to achieve. For example, recommendations for a healthy lifestyle include exercising for 30 minutes, 5 times a week and to reduce weight. Both can be difficult to achieve in the context of PPS. Although it is noted in the literature that exercise programmes tailored to the individual are beneficial in the context of PPS.

The questionnaire gave recipients the option to provide anecdotes to the questions or about their life experiences and these are presented at Appendix 3.

Recommendations

Greater awareness raising and education for GPs. about PPS and its impact on daily life.

Research into prevention of PPS.

A review of the respiratory tests and monitoring of respiratory functioning for people with PPS.

A review of the provision and commissioning of respiratory services, including non-invasive ventilation support, in the UK for all those with neurological conditions who require these services.

A review of sleep tests and provision and commissioning of sleep services for people with PPS.

A review of the provision and commissioning of physiotherapy/physical activity, speech and language, counselling services for people with PPS.

Improved understanding of the management of other conditions in the context of PPS.

Conclusions

There is a growing perception by Polio Survivors that they are an underserved, forgotten and misunderstood patient group whose needs are not well understood. (See Appendix 3 - anecdote of typical experiences reported by our members).

The intention of this report is to bring to the attention of clinicians and health researchers the experiences of our members with PPS and to raise awareness of possible areas of research which we feel are needed.

We no longer live in fear of polio epidemics but they are part of our social history. The experiences of those who survived, many of whom were young children at the time of these epidemics, and their families live on in their memories, sometimes with enduring emotional scars. We would like to see the social history of polio epidemics researched and documented.

Thank you for reading this report.

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Gillian Bryan

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October 2011

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European Polio Conference, Copenhagen, Denmark.

Post Polio Syndrome - a challenge of today

August 31st to September 2nd, 2011

European Polio Union [EPU] & the Danish Society of Polio and Accident Victims [PTU]
Presentations online at

www.informed-scientist.org/congress/european-conference-on-post-polio-syndrome

Conference Papers in Supplement 49 of the Journal of Rehabilitation

www.medicaljournals.se/jrm/content/?volume=43&issue=49

Polio Survivors Network

Appendix 1

what we have what we are what we do

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Dear Member,

November 22nd 2010

Members' Survey

Our Polio Survivors' Network (PSN) began its life some fifteen years ago as a local network in Lincolnshire and known to most of our members as Lincolnshire Post Polio Network (LPPN). Our original aims were to raise awareness of Post Polio Syndrome (PPS) and support Polio Survivors experiencing the effects of PPS. During these fifteen years our membership has grown and now includes people living in all parts of the UK and the USA. Our aims remain the same and are still valid.

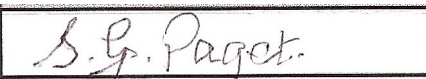
As we are now developing a more national profile it will be helpful for the Trustees to have a better understanding of the make-up of PSN's current membership, e.g. age range, how many men and women, how long it took to get a diagnosis, whether you had to give up working due to PPS etc. This type of information will help us represent your concerns more effectively, enable us to better raise awareness and help us when applying for funds.

As mentioned in the last Issue of Post Polio Matters, I am writing now to invite you to complete the attached questionnaire. It should be fairly easy to complete and you should be able to complete it as a Polio Survivor or as a carer on behalf of someone who is a Polio Survivor. **Please do not put your name on the questionnaire.** If you have any difficulty please get in touch and I will be happy to help. My contact details are below. If you are a group contact and need extra copies for your members, or both polio survivor and carer would like to complete one please email info@poliosurvivorsnetwork.org.uk or ring me.

Your help in completing this questionnaire will help our network and I hope as many of you as possible will do so and return to us in the envelope provided as soon as you can but at the latest **3rd January, 2011**. I am sorry that we have not been able to provide a stamp on the return envelope. The Survey will be written-up and sent to members and relevant health care professionals.

Together we can raise our concerns but to do so we need you to let us know what these are. Thank you for your help and I look forward to hearing from you.

Best wishes



Sandra Paget, Chairperson

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Trustees: Sandra Paget (Chairperson), James Pullin (Vice-Chairman),
Glenna Tomlin (Secretary), Hilary Boone (Treasurer),
Home of the Lincolnshire Post Polio Library
Supporting Post Polio Health International's WE'RE STILL HERE! Campaign
Member of the Neurological Alliance



Detailed responses to questions

Question 1. Do you live alone or with a partner/spouse, friend.

| | Alone | Partner/spouse | Family/friends | Care Home |
|--------|-------|----------------|----------------|-----------|
| Male | 6 | 22 | | |
| Female | 9 | 24 | 5 | 3 |

Question 2. Age when you or the person you care for had Polio.

| | Age | 0 - 5 | 6 - 10 | 11 - 15 | 16 - 20 | Over 21 |
|--------|-----|-------|--------|---------|---------|---------|
| Male | | 14 | 5 | 3 | 2 | 4 |
| Female | | 28 | 5 | 3 | 2 | 2 |
| Total | | 42 | 10 | 6 | 4 | 6 |

Question 3. What type of polio did you or the person you care for have?

| | paralytic | non-paralytic |
|--------|-----------|---------------|
| Male | 20 | 7 |
| Female | 30 | 6 |
| Total | 50 | 13 |

Question 4. Have you or the person you care for received a diagnosis of post polio syndrome?

| | Yes | No |
|--------|-----|----|
| Male | 19 | 8 |
| Female | 31 | 11 |

Question 5. What were the first symptoms you or the person you care for reported?

Most respondents reported typical symptoms, such as, fatigue, muscle weakness, pain etc.

Question 6. Did you discuss these symptoms with your GP?

| | Yes | No |
|--------|-----|----|
| Male | 22 | 4 |
| Female | 32 | 8 |

Question 7. Do you think your GP has a good understanding of Post Polio Syndrome?

| | Yes | No | Don't Know |
|--------|-----|----|------------|
| Male | 7 | 16 | 4 |
| Female | 11 | 22 | |

Question 8. How long did it take from first symptoms to diagnosis?

Replies ranged from months to years and is difficult to report. One respondent reported 9 years to a diagnosis of PPS.

Question 9. Who gave you the diagnosis?

| | G.P. | Neurologist | Respiratory Consultant | Other* |
|--------|-------------|--------------------|-------------------------------|---------------|
| Male | 3 | 8 | 1 | 3 |
| Female | 4 | 18 | 3 | 3 |

[* Included Rehabilitation Consultant]

Question 10. When you or the person you care for was first diagnosed was a full assessment of health needs done?

| | Yes | No | Not sure |
|--------|------------|-----------|-----------------|
| Male | 5 | 11 | 3 |
| Female | 9 | 17 | 5 |

Question 11. If yes who did the assessment?

Two people reported a Consultant carried out the assessment.

Question 12. What happened?

Insufficient responders

Medical Support**Question 13. Do you or the person you care for see any or all of the following on a regular basis, for example, once a year?**

| Clinicians | 12 months | | 6 Months | | Other | | Never See | |
|-----------------------------|------------------|------------|-----------------|------------|--------------|------------|------------------|------------|
| | (M) | (F) | (M) | (F) | (M) | (F) | (M) | (F) |
| Consultant Neurologist | 4 | 9 | 2 | 3 | 3 | 2 | 9 | 30 |
| Physiotherapist | 2 | 2 | 1 | 3 | 4 | 5 | 6 | 3 |
| Speech and Language | | 1 | | | | 1 | 12 | 22 |
| Psychologist or Counselling | | | | | | | 12 | |
| | | | | | | | | |

Question 14. Do you think any of the professionals above have a good understanding of Post Polio Syndrome?

| | Yes | No | Not sure |
|--------|------------|-----------|-----------------|
| Male | 9 | 8 | 6 |
| Female | 15 | 13 | 8 |

Question 15. If you or the person you care for has answered No to any of the above, have you asked to be seen by any of the above for your symptoms?

| | Yes | No |
|--------|------------|-----------|
| Male | 6 | 6 |
| Female | 4 | 20 |

Question 16. Were you seen?

| | Yes | No |
|--------|------------|-----------|
| Male | 5 | 1 |
| Female | 3 | |

If **No** what reason was given?

If **Yes** were you or the person you care for satisfied with the outcome?

| | Yes | No |
|--------|------------|-----------|
| Male | 2 | 4 |
| Female | 2 | 2 |

If **No**, why not? No responses

Question 17. Were you or the person you care for in an iron lung?

| | Yes | No | Don't know |
|--------|------------|-----------|-------------------|
| Male | 3 | 21 | 1 |
| Female | 7 | 32 | |

If **yes** how long for?

Insufficient responses but, 2 years; 2 months and 3 months were reported.

Question 18. Do you or the person you care for have respiratory/breathing problems now?

| | Yes | No |
|--------|------------|-----------|
| Male | 10 | 13 |
| Female | 12 | 30 |

If **yes** how long for?

Few people responded. Of those who did a range of 4 years - 20 years

What treatment/therapy do you receive?

None reported

Question 19. Do you or the person you care for use a ventilator?

| | Yes | No |
|--------|------------|-----------|
| Male | 3 | 15 |
| Female | 6 | 35 |

If **yes**

| | night time only | day time only | all the time |
|--------|------------------------|----------------------|---------------------|
| Male | 2 | | |
| Female | 2 | 3 | 1 |

| Type of ventilator | Bi-level | CPAP | Other |
|---------------------------|-----------------|-------------|--------------|
| Male | 1 | 2 | |
| Female | 2 | 2 | 1 |

Question 20. How often do you see any of the following:

| Clinicians | 12 months | | 6 Months | | Other | | Never See | |
|------------------------|------------------|------------|-----------------|------------|--------------|------------|------------------|------------|
| | (M) | (F) | (M) | (F) | (M) | (F) | (M) | (F) |
| Respiratory Consultant | 2 | 5 | 2 | 3 | 1 | 1 | 15 | 10 |
| Respiratory Nurse | 1 | 2 | 1 | 2 | | | 18 | 12 |
| Respiratory Team | | 2 | 1 | | | | 18 | 12 |

Question 21. Are you satisfied with the support you receive with regard to your ventilation needs?

| | Yes | No |
|--------|------------|-----------|
| Male | 4 | 1 |
| Female | 8 | 4 |

If **no** what are your reasons?

No responses

Information provision

Question 22. When you or the person you care for was first diagnosed were you given any information about Post Polio Syndrome?

| | Yes | No | Not sure |
|--------|------------|-----------|-----------------|
| Male | 5 | 16 | 2 |
| Female | 12 | 21 | 2 |

If **yes** who gave you the information?

| | Doctor | Nurse | Other |
|--------|---------------|--------------|--------------|
| Male | 4 | | |
| Female | 10 | | |

Question 23. Would you have liked more information at diagnosis

| | Yes | No | Later |
|--------|------------|-----------|--------------|
| Male | 13 | 3 | 2 |
| Female | 20 | 10 | 2 |

If **later**, how much later?

Insufficient responses

Question 24. How was the information given?

| | Verbally | In writing | Not sure |
|--------|-----------------|-------------------|-----------------|
| Male | 7 | 1 | 1 |
| Female | 12 | 6 | 2 |

Question 25. Did you ask for some information but not given any?

| | Yes | No | Not sure |
|--------|------------|-----------|-----------------|
| Male | 3 | 10 | 4 |
| Female | 7 | 19 | 1 |

Question 26. Were you referred to a website?

| | Yes | No | Not sure |
|--------|------------|-----------|-----------------|
| Male | 2 | 13 | 1 |
| Female | 4 | 24 | |

If **yes** which website - No websites given.

Question 27. Were you referred to a patient organisation/support group?

| | Yes | No | Not sure |
|--------|------------|-----------|-----------------|
| Male | 18 | 1 | |
| Female | 4 | 27 | |

If **yes** which - British Polio Fellowship

Question 28. What other sources of information are available to you ?

Those responding gave a mixture of other sources with many giving more than one.
The most often reported were:

Polio Survivors Network (LPPN), British Polio Fellowship, Internet, Lane Fox Unit

(Question 29. overleaf)

Question 29. If you need information in a particular format, e.g. large print, Braille, CD, have you asked for information to meet your requirements?

| | Yes | No |
|------------------|------------|-----------|
| Male | 1 | 5 |
| Female | | |
| Was it provided? | Yes | No |
| Male | 1 | |
| Female | | |

If **No** what was the reason given?

There were no responses

Respite care and Neuro-rehabilitation

Question 30. Have you or the person you care for received respite care?

| | Yes | No |
|--------|------------|-----------|
| Male | 2 | 23 |
| Female | 2 | 38 |

Question 31. Do you or the person you care for need respite care?

| | Yes | No |
|--------|------------|-----------|
| Male | | 21 |
| Female | 1 | 31 |

Question 32. If you or the person you care for receives respite care, do you think it helps to improve the quality of your life?

| | Yes | No |
|--------|------------|-----------|
| Male | 1 | 2 |
| Female | 2 | |

Question 33. Have you or the person you care for received neuro-rehabilitation?

| | Yes | No |
|--------|------------|-----------|
| Male | | 21 |
| Female | 2 | 27 |

If **yes**, was it in-patient rehabilitation community rehabilitation

No responses

No responses

What happened?

Question 34. Were you satisfied with the outcome?

| | Yes | No |
|--------|------------|-----------|
| Male | 1 | |
| Female | 2 | |

Question 35. Do you think the staff understood your needs?

Yes. No Not sure

Responses were unclear

Mobility

Question 36. Do you or the person you care for use a wheelchair ?

| | Yes | No |
|---------------|-----------------------|---------------------|
| Male | 9 | 17 |
| Female | 25 | 15 |
| If yes | electric chair | manual chair |
| Male | 4 | 5 |
| Female | 10 | 13 |

Is it provided through the local Wheelchair Service

| | Yes | | No | |
|--|------------|------------|------------|------------|
| | (M) | (F) | (M) | (F) |
| Provided by local wheelchair Service | 2 | 16 | 7 | 7 |
| Is the service easy to contact | 3 | 16 | | 1 |
| Are repairs done to a good standard | 3 | 12 | | 2 |
| Do you think the staff understand your needs | 2 | 12 | | 4 |
| | | | | |

If **Not** provided by your local wheelchair service who provides it?

Other providers.

Question 37. What other experiences, good or bad, of your Wheelchair Service do you have?

much too slow : local wheelchair service is poor : the greed of some of the companies : poor experience of local wheelchair service. They did provide a manual transit wheelchair eventually : had to wait-four-and-a-half years for NHS one : excellent : I find them too indifferent to my needs : too long to get things done.

None except prices for wheelchairs and any other disabled equipment is very extortionate : they were very lousy and I had to wait 6 months to see them. I could not wait that long so I purchased my own and the one I bought indoors.

(name omitted) Mobility Service maintain wheelchairs. They are inefficient and unreliable. Many of the staff treat you like a stupid idiot, incapable of conveying/ understanding anything. Maintenance appts last about 10 minutes.

I choose to have vouchers and go to a specialist dealer, so don't have much experience of w/services.

When electric chair first required very long waiting list (several years) - so purchased my own. Later chair for upstairs provided.

Could respond sooner when chair needs repair - 3 days was usual. Bring my own in from the car otherwise unable to manage.

When I had a car an excellent Co. fixed it so it could go on the roof of car. Wish I still had it.

Lack of funds inhibits provision of top-rate wheelchair. For my own comfort I now spend longer in my bed.

Got manual chair - footplates only heel would fit. 3 weeks later came with board to clip onto both footplates gave 2 inches more - could not get out of chair as could not reach down to remove it.

Repairs to manual chairs are prompt but need to be done frequently because of poor quality metal.

Question 38. Do you or the person you care for need either an electric or manual wheelchair but been refused by the NHS

| | Yes | No | |
|--------|--|-----------|--------------|
| Male | | 18 | |
| Female | 3 | 27 | |
| | If yes , what reason was given? | | No responses |

Question 39. Did you buy your own?

| | Yes | No |
|--------|------------|-----------|
| Male | 8 | 2 |
| Female | 10 | |

Question 40. Do you use a scooter

| | Yes | No |
|--------|------------|-----------|
| Male | 8 | 2 |
| Female | 12 | 7 |

Seven (M) purchased their own

Question 41. Can you use public transport

| | Yes | No |
|--------|------------|-----------|
| Male | 18 | 9 |
| Female | 12 | 29 |

If **No** what are your difficulties

Typical response: not all vehicles suitable for wheelchair so don't try.

Question 42. Do you have a "disability friendly" taxi service in your area

| | Yes | No | Don't know |
|--------|------------|-----------|-------------------|
| Male | 16 | 4 | |
| Female | 27 | 4 | 4 |

Question 43. Do you use orthotics/calipers/walking aides, hand/arm aides etc?

| | Yes | No |
|--------|------------|-----------|
| Male | 20 | 5 |
| Female | 28 | 7 |

If **yes** what do you use?

Elbow crutches, built up boots : sticks, splints, raised shoe : walking frame, toilet seat, bath lift, shoes : orthotics, callipers, walking aide : Kafo left leg, Afo rt leg : raised shoe, walking stick : calliper and sometimes a walking stick : occasional walking stick : callipers until PPS set in and my back was weak so I was more comfortable in wheelchair : calliper and walking stick : sticks : calliper on left leg with specially adapted shoe : calliper and two sticks : stick : walker : walking stick : 1 full length calliper and walking stick : stick, crutches, foot raisers, wraparound foot orthosis in cold weather : orthotic insoles (private and NHS) walking stick when needed : I am in a wheelchair but also wear a calliper : callipers and crutches at all times : two elbow crutches : 2 callipers and crutches : callipers (UTX) on both legs : SAFO ankle supports and 2 crutches : callipers - on right leg below knee : long length calliper (KAFO), elbow crutches when walking a few steps indoors : I used callipers until I was 14. Then a whole variety of things in my shoes until operations began now I use orthotics only.

If **Yes**:

| | Yes | | No | |
|--|-----|-----|-----|-----|
| | (M) | (F) | (M) | (F) |
| Provided by local orthotics Service | 11 | 20 | 7 | 9 |
| Is the service easy to contact | 9 | 18 | | 2 |
| Are repairs done to a good standard | 7 | 14 | 1 | 5 |
| Do you think the staff understand your needs | 9 | 13 | 1 | 6 |
| | | | | |

Question 44. What other experiences, good or bad, of your Orthotics Service do you have?

nothing but excellent : very bad : just good : had some shoes made to accommodate the SAFOs and stressed that I needed lightweight and flexible soles. They were unusable : everything takes forever - callipers 3 months to refurbish : time taken for repairs : took two years to make right calliper : too long in between fittings and too long for repairs : I started to wear a calliper again in 1991 the chap was excellent. Ten years later it was a nightmare the bloke did not have a clue.
gave up on orthotics, 3 unusable drop foot appliances, referred to 'new man' , tried his best but no appliances could fit into my shoes. My choice to sort it out myself.

Question 45. Do you or the person you care for need a particular type of orthotic but been refused?

| | Yes | No |
|--------|-----|----|
| Male | 2 | 15 |
| Female | 2 | 29 |

If **yes**, what reason was given and what do you need?

No responses

Question 46. Did you buy your own?

| | Yes | No |
|--------|------------|-----------|
| Male | 7 | 6 |
| Female | 11 | |

Employment

Question 47. Are you currently working?

| | Yes | No |
|--------|------------|-----------|
| Male | 6 | 12 |
| Female | 5 | 35 |

Have you had to stop working or reduce your working hours due to Post Polio Syndrome or because you care for someone with Post Polio Syndrome?

| | Yes | No |
|--------|------------|-----------|
| Male | 12 | 12 |
| Female | 22 | 15 |

Equipment

Question 48. Do you or the person you care for need any equipment at home?

| | Yes | No |
|--------|------------|-----------|
| Male | 6 | 20 |
| Female | 27 | 11 |

If **yes**, what do you need No responses

Question 49. Have you received an assessment of what equipment you need?

| | Yes | No |
|--------|------------|-----------|
| Male | 6 | 16 |
| Female | 19 | 14 |

If **yes**, who did the assessment?

| | Adult Social Care | Community Occupational Therapy | G.P. |
|--------|--------------------------|---------------------------------------|-------------|
| Male | 1 | 4 | 1 |
| Female | 1 | 16 | |

Question 50. Where did the assessment take place ?

| | Home | Hospital |
|------|-------------|-----------------|
| Male | 4 | 1 |

Please describe what happened:

no responses

Question 51. Do you think the person doing the assessment understood your needs?

| | Yes | No |
|--------|------------|-----------|
| Male | 4 | 1 |
| Female | 11 | 5 |

Question 52. How long after the assessment did you wait for the equipment to arrive?

| | Weeks | Months | Years |
|--------|--------------|---------------|--------------|
| Male | 1 | 1 | |
| Female | 5 | 2 | |

Question 53. Did you get what you needed?

| | Yes | No |
|--------|------------|-----------|
| Male | 4 | |
| Female | 11 | 2 |

If **No**, what reason was given?

Insufficient response

Other medical conditions

Question 54. Have you been diagnosed with any other medical condition, e.g., diabetes, asthmas, cardiovascular, etc.

| | Yes | No |
|--------|------------|-----------|
| Male | 17 | 9 |
| Female | 32 | 10 |

If **yes**, what is the condition? A range of conditions were reported and included, asthma, diabetes, ME/CFS cardiovascular, blood pressure and cancer.

Complementary Therapies

Question 55. Do you use a complementary therapy?

| | Yes | No |
|--------|------------|-----------|
| Male | 2 | 20 |
| Female | 22 | 19 |

If **yes** what do you use?

A range of therapies, including acupuncture, massage, and chiropractic

ANECDOTAL EVIDENCE (Optional)

This page is for additional information to any of your answers. If you wish to do so just put the number of the question and write whatever you think would be useful for us to know. This page (adding more if you wish) can also be used for any other issues you think we should know about.

Male aged 78

- Question 39/40. I am fortunate in having no financial problems. My retirement pension income is over £■■■,000 p.a. Also my wife still works and has a high income. I can therefore afford to purchase any equipment I need.
- Question 41/42 I have a disabled badge and use my car to get around.
- Question 7 My original G.P. (1995/1996) had no knowledge of PPS. However, in 1997 he retired and I had a new G.P. who is very knowledgeable about PPS.

Male aged 80

In common with many others with PPS (bulbar type in my case) was not diagnosed early even by a PPS expert (■■■). The primary site of polio (throat, larynx) started causing mayhem by allowing secretions into my lungs during sleep. Because I was not consciously aware of this deterioration, I do not have PPS, years of pointless consultations and investigations followed - the most difficult thing of all was not to be believed.

The 'star' was a cons. neurologist who said something was wrong but he did not what it was, and a cons. physician with an interest in chronic fatigue who listened and put two and two together. It was a very long haul up to that point.

The main conclusion was doctors see too few people with PPS to establish a bank of knowledge so whenever possible self help is preferable.

Male aged 74

This "survivor's" experience probably won't help at all!

While I seem to have many PPS signs

- Exhaustion
- Joint Pain and Weakness
- Muscle Atrophy
- Bulbar Symptoms (mild but definite)
- Sleep Problems

I still lead an almost normal life and am considered 'good for my age'. I have not tried to get a proper assessment as all the symptoms are so mild and I manage. General quality of life though is affected.

Male aged 62

There is plenty of information on the Internet i.e. Canada and the U.S.A. They seem to be some time ahead of us. Dr. Richard Bruno has a website.

Male aged 79

- 1) I was prescribed 'Symbicort' which made my nose bleed four times requiring cauterisations. I have now been diagnosed with an pharyngeal pouch and waiting to see a Specialist Surgeon. My appointment has been cancelled 3 times in 3 months. I have now been given ■■■th December at ■■■ Hospital.

Sorry my handwriting is poor, my hands are weak and very cold.

Male aged 86

There is little experience by professionals of Post Polio Syndrome.

Hospital administration is inefficient and wasted; communications are poor. I have requested tests for PPS, as I appear to be getting weaker as I age, but have not received any evident conclusions from the Consultant. I complained to him about the inefficiency (which he deplored), but I am no further forward - so I've given up! It's a waste of everyone's time and resources.

Male aged 61

Whilst the understood acceptance of PPS is better, the real issues is rehabilitation and the role of managed decline with age, too much emphasis is placed upon either 'self help' i.e. programs such as the old expert patient ideas. Whereas the real issues are to do with ongoing support with physio/massage updating medications. The modus of time used in NHS are, despite what they 'write', not holistic but reductionist, specialist and acute and or time limited care.

So I would like more support on an ongoing patient focused level involving complimentary as much more physio as psychology input.

Male aged 64

I had polio at 9 months old in 1947. Left with left leg thinner and shorter than right. Wore built up shoe for 15 years but not worn now.

No particular symptoms of PPS as yet. Still working full time in manual job.

Carer aged 70 of Male aged 79

- 1) He was prescribed 'Symbicort' which made his nose bleed four times requiring cauterisations. He has now been diagnosed with a pharyngeal pouch and is waiting to see a Specialist Surgeon. His appointment has been cancelled 3 times in 3 months. He has now been given ■■■th December - ■■■ Hospital..
-

Carer aged 70 of Male aged ?

4/5 Johns upper body appeared strong he's party trick was to walk on his hands. It seems that this area of his body had been affected by the disease and this became apparent as he grew older. This was not understood by his doctors.

The doctors did not recognise what the various complaints he went to them about were really manifestations of the same problem. At no time were we given the chance to get help towards any goods etc to improve mobility.

Male aged 77

G. P. Says doesn't know much about PPS with only a handful of people in his practice affected. Just having to live with the problems and learn how to manage the problems.

Male aged 66

43. As a result of polio, also have acute scoliosis. This condition has a severe impact on my quality of life. It effects my walking, sitting and laying down in bed. It also effects my balance and has resulted in a number of falls whilst out of doors. There appears to be no treatment for the condition in adults. I frequently look-up various websites for information but all that seems to be available are reports, papers and more reports and papers. No real progress in any form of treatment has been forthcoming. Believe me, scoliosis is a most devastating, debilitating ailment to have. I only mention this because in my case, it has been brought on by having had polio.

Female aged 54

There are many blanks left because:

- A) I was too young to know. I rely on 2nd hand info from my mother, now aged 91. I'm sure she'd be willing to be questioned.
- B) I lived in ■■ and ■■ for 18 years, where they recognise the joint issues and deal with them. Acupressure and Acupuncture. The Western Doctors shelled out loads of anti-inflammatories which I didn't want to take. I kept them only for emergencies, such as to get me through 'short' treks in ■■!

In 2008 I was diagnosed with a Brain Tumour, and after several falls I was advised to walk with a stick until my muscle power improved. How terribly slow all those 'medical measure' are. The falls caused other issues, such as 'frozen shoulder'. That prevented the leg physiotherapy, so I am now on shoulder therapy. That is progress don't get me wrong, but the polio scars (physical) don't help.

Female aged 68

I have had great difficulty in getting assessment for care from Social Services. No financial help for respite care which is very expensive for respiratory patients.

Now obtained a care assessment, very stressful. Direct payments not offered, had to insist on this. Communication between hospital and GP poor. It used to be very good years ago.

Female aged 72

I think you are all very brave committee members to undertake all this when you don't always feel so good yourselves. Thank you.

Female aged 63

Following information read in the BPF Bulletin, I requested a referral to the ■■ Hospital. My G.P. was able to obtain the funding and I went for an assessment. I was an inpatient for several days and this resulted in the referral to the Orthopaedic Consultant and the Orthotics Department, also the Occupational Health Visitor. They were brilliant and without that referral my life would be more difficult.

My GP has been very supportive. He also referred me to a Gait Consultant (at my request, again from the Bulletin) who was unable to make any suggestions except to advise me to lose weight. I was 9 stone 10 lbs. I lost a stone and it helps. The BPF and LPPN have been my saviours.

Female aged 60

I'm sorry to have taken so long to answer your survey, I must hold my hand up and say I didn't feel well enough to fill it in when I received it and put it to one side then the weather was so bad it stressed me out and then it was Christmas so unfortunately I forgot about it.

The following may not be of interest to you, but although you have yes and no answers some are quite difficult to tick a simple yes or no, for an example.

Question 7. Do you think your GP has a good understanding of PPS?

I have answered yes but it has taken me over 15 years and 8 GP's and 3 Consultants before I found a GP that said he knew about polio.

In the early 1990s my old GP retired, the new GP I saw advised me to take pain killers for my aches and pains he told me give it six months and return if I was no better. This was to continue for a few years (during this time there was a large turnover of GP's at my surgery and it was rare you could see the same GP twice.)

In 1997 I went to see a GP and asked about PPS. I was sent to ■■ to see a Rheumatology Doctor ■■. I received the first letter dated 18th November 1997 for an appointment on the 3rd March 1998, the second letter changed my time from 9.40 to 10.30 and the third letter changed the date to the 17th March and the time to 11.00 a.m. I gritted my teeth and remained patient despite the fact that on the day he made me wait until I was his last patient. I had gone through to the next waiting section and everyone disappeared the shop shut up and I was alone for 20 minutes then the nurse came passed and asked if I had seen the doctor come out of his office I told her I didn't know what he looked like and asked her if I was the last patient to which she replies yes off she went and I am then called in to see him. Dr. ■■ examined me and informed me I didn't have arthritis and he explained the effect Polio has on the nerves with the aid of a drawing. I asked him about PPS and at this point he laughed and with a huge grin on his face he told me polio was painless and that my aches and pains down to ageing. With having my appointments changed so many times and being made to wait until last plus the sneering condescending way he spoke to me he made me feel like a total time waster. Today with hind sight I realise he knows absolutely nothing about polio and I am cross with myself for not challenging him.

As a child with polio you simply did not make a fuss you were expected to maintain a stiff upper lip and so I struggled on for a couple of years. I had started to use a walking stick to help with my balance about 1993 and by the late 90's felt I needed more support with my balance so changed from a walking stick to crutches then went back to see a GP it was now the early 2000s. By this time patient's records had been put onto computer. I saw a lady doctor she asked me why I was walking with crutches I told her I had polio as a child to which she replied it's not on the computer. She sent me to see the Physiotherapist about the pain in my hip but that didn't do any good. It took months to see the physio and I was only allowed so many sessions which was spread over several months. I did the exercises I was given for a few more months but it was not any help by now it had taken me the best part of 10 months so I made an appointment and got to see the same lady doctor. She asked me again why I was walking with crutches I told her I had polio as a child and for the second time she said to me it's not on the computer. I told her she had sent me on a course of physio then she said 'oh yes here it is',. She gave me some pain killers to try.

I then went to see another GP who diagnosed me as being depressed and gave me a prescription for Prozac. I did not take any Prozac as I do not have bats in my belfry.

That doctor left the practice so I saw yet another GP who when I told him my symptoms promptly said he didn't know about polio, however he would make an appointment for me to see a Consultant. This was the turning point as the Consultant diagnosed me with PPS.

I went back to see the GP who sent me to the Consultant but he had also left the practice and I got to see another different GP who to my astonishment did know about polio.

Question 44: Orthotics service.

As a child I was in hospital at ■■ so I asked to be referred to ■■ when I developed a bad pain in my knee. The solution to stop the pain was to go back to wearing a calliper this was in the late 1980's. The chap that measured and fitted my calliper was an older chap who was himself disabled and he was brilliant he got everything spot on first time.

Ten years later I needed a new calliper and went to my local Orthotics Service it was a nightmare. My original calliper was full length but the new one just covered my knee although I had a fitting we were in a small room so I only walked a couple of steps. I didn't realise that this would be the finished calliper I thought it was the bottom half after experiencing the brilliant chap at ■■ I assumed my local Orthotics just had a different way of working. When my new calliper arrived I realised I could only walk in a straight line I could not turn left or right as I could not keep my balance also my knee was no longer rigid and the pain was back. I went back and this time he made me a full length calliper but this was at least one inch too short which made my hip ache. I went back and all I wanted was an inch adding to the top section. He made me another full length calliper which would have been ok but he added an inch to the top section and an inch to the bottom section. I again asked if I could have a calliper that only had the inch added to the top section but not the bottom. He informed me that was not possible if you increased the size of the top section you had to increase the bottom he was adamant about that and would not alter it.

I could not wear the calliper that is too long. I wore the one that was an inch too short but eventually I could no longer stand the pain in the soft tissue on the inside of my hip. I went to ■■ Orthotics (without an appointment I got there first thing in the morning) I asked if I could have a new calliper they said they would refer me to my local Orthotics. I asked where the chap was I had seen before and was told he had retired. I told them it was no good sending me to my local Orthotics as the calliper he had made for me has given me bad hip pain. There was a woman and an Orthotic chap present she said to me rather sniffy it costs £800 for a calliper to which I replied I am more than happy to pay for it and that I know this calliper is giving me the pain in my hip and that will be a small price to pay to stop it. That called her bluff the Orthotics chap made me a new one and much to my relief he got it correct as soon as I put it on and started walking the difference it made to my hip was incredible within a few days the hip pain had disappeared.

Question 52.

I had a shower installed that is accessible from my wheelchair. Actually my Consultant had advised me that it may be cheaper to have it installed myself rather than going through the authorities. The woman that came to see me told me I would probably have to pay half of the cost but it would depend on the other people that lived in the house as their income would be included before a decision was made.

She had listened to what I had to say but the plan she drew up was as if she had not heard a word I said the plan was to suit her idea of my needs and filled me with dread.

Also I was the one wanting the shower what the income or savings of the other people in the house was in my opinion none of mine and certainly none of her business.

I chose to pay myself by taking out a loan. I had the shower installed to suit my needs.

At the same time she had measured me up for a ramp at my front door but I did not want anything more to do with the woman so I paid for the ramp myself.

Female aged 55

Q. 12. I believe that PPS would have remained undiagnosed if it hadn't been for the fact that the Consultant had first hand knowledge and experience of it. I feel very lucky, as the diagnosis answered the 'mystery' that is me and my life.

My polio was mild and surgery corrected the affects (stretched tendon) when I was 8 years old. I thought I was then 'cured'. However, as the Consultant explained I have never been 'cured' and have been 'disabled' all my life! But the PPS would have remained undiagnosed if not for him. Over the past year I have had a lot of contact with the medical profession (severe fracture and cancer) but none have been remotely interested in PPS and what effect that may have upon my outcomes. Good luck with this survey. Thank you.

Female aged 62

Oops! Sorry, didn't see this page until filled the form in!

Having gone through the process of being advised to see a Consultant Neurologist would suggest a more useful and productive way forward would be to ask for referral to a Neuro-Physio. My own experience has been amazing, she knows all about PPS and thorough assessments identified needs I didn't know I had!!

I have recommended this to many Polios and all have benefitted hugely, many not even realising there was/is such a person.

Female aged 61

I think PPS is a rarely understood condition, in part because most health professionals do not cover it in their training and none has ever seen an acute case of polio unless they have worked in part of the third world where polio has not been eradicated. I certainly wasn't prepared for the disbelief, ignorance and misogyny I experienced when I first presented myself with PPS symptoms to various Consultants, etc. I was told I had 'psychological problems' and that the fatigue was a result of 'Mass Hysteria' by Polio Survivors. I found the hostility, general lack of understanding and dismissing attitude of some of these professionals hard to cope with and still don't really know why PPS evokes such responses. Is it because Polio Survivors are considered too assertive? Or because many are women of 'a certain age' and labelled neurotic? Or do they remind medical professionals of past medical failures? Is it just bad or lazy doctoring, or the use of the last-resort diagnosis of the baffled, to blame the patient? Maybe we've got too many problems for the over-worked NHS to cope with, and there isn't enough of the little expertise available to go around and really make a difference. All I know is that most of my problems I have to cope with myself and in a cash-starved UK I can't see much improvement for the future with a rapidly increasing population of older people.

Female aged 68

It is very difficult to get the doctor interested if you are not paralysed, especially if the medical records are lost (■■ Hospital) flood. Where can we get tested?

Female aged 76

My G.P. 'is very supportive' and is always on the end of the phone for me.

I am hypersensitive to most drugs and anything I take has to be started at a very low dose, this he totally understands.

The only medication I take is a 'water tablet'. My severe scoliosis causes breathing problems and I have a back up antibiotics prescription in case of chesty coughs and wheezes.

Female aged 69

Q 13. I have decided not to go back to ■■ to see ■■. It took me two years of insistence and hard fight to get a referral to ■■ so that I would maybe benefit from ■■. I saw ■■ at 6 monthly intervals for 2 years while I waited for this referral, but when I finally saw the physiotherapist (Senior!) and the Senior! Occupational Therapist they decided my problems were due to 'aging' so I thought if they knew more than ■■ then there is no point in seeing him, so I wrote and thanked him for all he had done for me over 2 years.

I did get some help and set of exercises from the Outpatient Physiotherapist ■■ at ■■ hospital and I also had two sessions of weekly hydrotherapy for 8 weeks (last year and the year before) which was of benefit. I did not ask for it this year because of the difficulties of getting there and the effort needed. Half an hours exercise in warm water is very good but once a week for 8 weeks is not really life changing.

Female aged 74

After 2 years in hospital (I was totally paralysed from my neck down) I regained enough movement to walk a little with someone helping me, until 1990s but one arm is totally useless and I have partial use only in the other. (I need help holding a cup, and eating soup has now become a dangerous occupation !!!)

If it wasn't for the loving care my husband gives me I would end up in a care home or probably would not be still alive.

Female aged 62

I have learned to try not to mention my physical problems because nothing is obvious to others and everyone has problems. Nothing can be gained and as I was told a few years ago at a pain clinic, no-one medical is interested in chronic pain sufferers as they cannot be cured so there is no satisfaction for medics. I am fortunate in that I have no breathing problems at present.

16. The neurologist told me he had no training in post polio syndrome. (He was a middle aged man!) He did the nerve tests on me (quite painful and 'nerve wracking' took days to get over the fatigue it caused) They only proved the original damage and carpal tunnel syndrome (sorry for repetition).

Female aged 66

I have osteoarthritis in most joints. My right knee being worst but my surgeon is not sure he can replace the joint as bone from leg was removed to act as spinal support in 1955 so possibility of losing my leg from knee down. As my support ensures no pain in knee we decided to leave the knee intact. My main problem is constant muscle pain mainly across buttocks and up right side of spine so live on diet of pain killers and massaged Ibugel. Also do knee exercises every day and take glucosamine. This has helped the movement in my knee to increase which my surgeon noticed.

Female aged 66

Several years ago I made the choice to keep away from doctors as regards anything to do with polio or PPS. I have educated myself from the internet, and believe I know best what is right for me. I no longer have the doctor who diagnosed me, as I have moved. I don't want to risk visiting others in the medical profession who know less than I do. Its all about self-help! I will probably buy a wheelchair from ■■ in the spring.

I do drive and use blue badge parking spaces. I can walk a short way.

Female aged 81

As I can no longer wear my spectacles because of the ventilator headgear, and I am no longer able to use my computer - and as my arms no longer work very well I cannot write at length either, even if I could see what I was writing.

Writing about the experiences of the last 73 years would require more time and effort than I have at my disposal.

My general physical deterioration, the paucity of help from knowledgeable staff, and the lack of first rate equipment has brought me to my lowest ebb.

Female aged 63

15. Counsellor—requested after learning of help from USA sources. GP Counselling Service provided 10 sessions 50 mins. Excellent, let off steam, learned loads about myself and why I had done many things in past life. GP became more supportive. Saw 4 years later I session due to bad med appt - helped to talk. GP more supportive again.

20 - 21 2005 ■■, see report and letter. See Chiro report. 2006 to 2009 ■■■■■■■■. Testing too minimal & lack of understanding or in fact willingness to accept/understand hypoventilation is affecting rest of life.

43. KAFO - ■■ visited home, then GP and Consultant and had made - plus spare - still awful lack of knowledge & understanding by ■■ Orthotist - best to stay away, small issues gone direct to company.

36. Found could only push manual chair 25 yards. Obtained electric scooter on grant from ■■ but company lied and scooter was not able to be broken down to travel and they never paid supplier so no support when needed repair. Hence seeking new.

44. Orthotic service in ■■ is a joke. Many times orthoses goes back as not right. At meeting with ■■ and head of NHS Department found that up till then no-one had counted how many credit notes. Later told they were appalled how many times equipment not suitable. Steer clear of him.

48 - 52. Requested assistance prior to move –. Had to repeat request again and again - took months. Found out later prior records of disability had been destroyed so being treated as new client. Eventually seen by Community Care Officer - newly started training. Awful - poor knowledge - total lack of understanding. OT visited. I had to fit her cheapest way of working but would not - Community Support Worker and Carer Support Worker for me and for ■■ had knowledge and experience & listened and supported needs and Direct Payments offered.

Female aged 67

9 years ago I fainted while holding a kettle of boiling water, and spent 3 weeks in the burns unit at ■■ Hospital.

While in hospital I met a young woman from ■■ University who was doing a survey with John Hopkins in America in to the effects of Burns on family etc. I explained what happened and that I always thought that having polio as a child I might have something to do with it, but know one would listen, she said she would look in it and found you on the internet.

When you sent me the information I took it to my GP on the next visit, but like most doctors wasn't interested.

All I have ever been given is a batch of the same tests over again which I declined. I usually get the stock answer 'so you had a bit of polio that was years ago'.

Please excuse my writing as Polio affected my right shoulder and arm and I am afraid my writing has got worse over the years.

Female aged 59

20) Reviewed by Resp. Consultant at ■■ Hospital. Sleep Study proved severe restless leg syndrome. Ropinirole prescribed. Excellent results. From getting out of bed 5 - 8 times a night now get a good nights sleep and function better through the day.

■■ is a Tertiary Centre and I feel could be utilised more for patients like myself if GP/Hosp Doc/Neurologists knew of this excellent facility. Also has a thorough Resp. Assessment, i.e. Chest x-ray, lung function tests and numerous blood tests.

13) Referred by Neurologist for further Neurological Tests at ■■ on Assessment Unit testing muscle strength and more blood tests.

Female aged 75

I am waiting for a Neurological assessment, next week, weather permitting. Also I hope to have the Occupational Therapist look to see what she could suggest to help me at home. I am trying to get an Attendance Allowance, also, as my husband does most things now. I have put off deciding on which wheelchair or scooter I can have, until I find out if we can have financial help. I undoubtedly need one soon - by spring perhaps. I have deteriorated much faster this year and have more pain - I find other polio survivors are the most helpful.

Female aged 74

I have been supplied with everything I need. My home has also been adapted for my use. Electric chair and bed bought by me.

**Further information on Post Polio Syndrome can be found:-
On the Polio Survivors Network website**



100+ articles - www.poliosurvivorsnetwork.org.uk/library

Our Newsletters

LincPIN's First Issue - September 1996, Volumes 1 to 6.

Post Polio Matters Volume 7, Issues 1 to 4

www.poliosurvivorsnetwork.org.uk/newsletters

and



PatientPlus article on Post Polio Syndrome for Health Professionals

www.patient.co.uk/doctor/Post-Polio-Syndrome.htm

On the Websites of the following organisations of which we are members:-

European Polio Union

www.europeanpolio.eu

Post-Polio Health International

www.post-polio.org

