

Polio Survivors Network

what we have what we are what we do

[www.poliosurvivorsnetwork.org.uk]

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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.

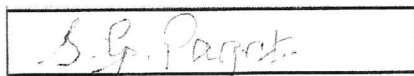
As mentioned in the last Issue of Post Polio Matters, I am writing now to invite you to complete the attached questionnaire. It should be fairly easy to complete and you should be able to complete it as a Polio Survivor or as a carer on behalf of someone who is a Polio Survivor.

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.

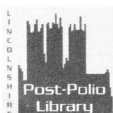
Best wishes



Sandra Paget
Chairperson

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Trustees: Sandra Paget (Chairperson), James Pullin (Vice-Chairman), Glenna Tomlin (Secretary)
Hilary Boone (Treasurer), Ian Hobday (Trustee), Barbara Taverner (Trustee)

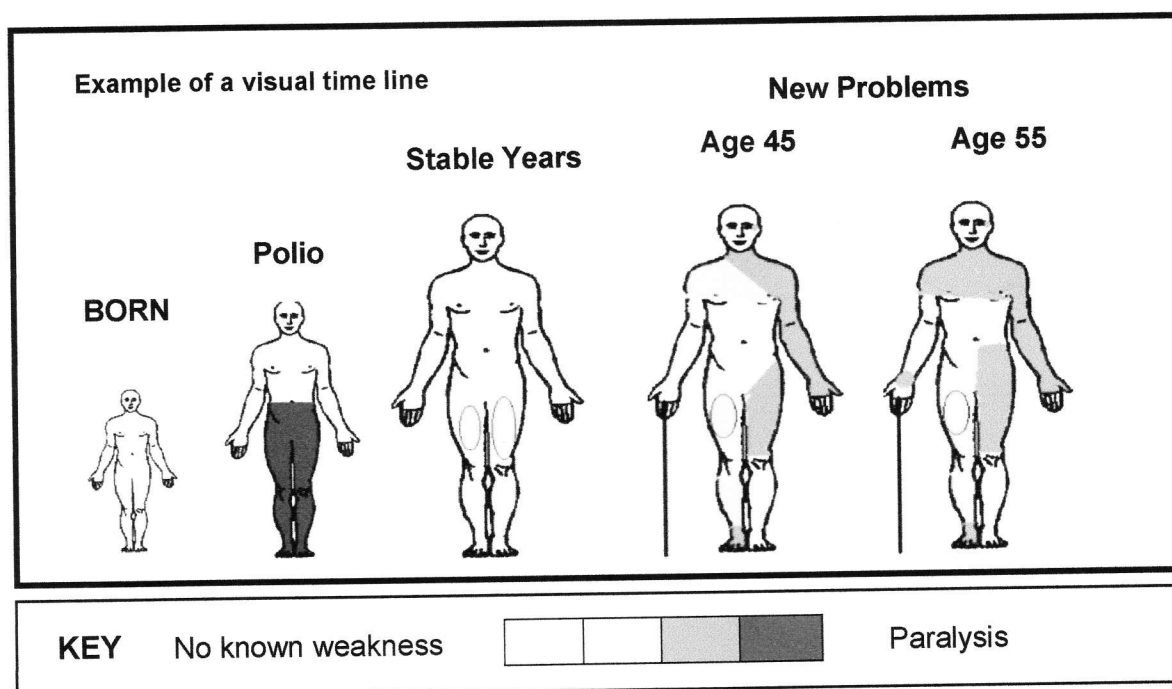


Home of the Lincolnshire Post Polio Library
Supporting Post Polio Health International's WE'RE STILL HERE! Campaign
Member of the Neurological Alliance



MY POLIO LIFE

**A Patient Questionnaire
providing base line information
and comparison charts
on the Life of a Polio Survivor**



**This Questionnaire is to help you
provide pertinent information for your health professionals
and could also be used to collect and collate statistics
on the issues being experienced in your county/state/country.**

Created by the Lincolnshire Post-Polio Network
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A copy of this document can be found at
www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf
or a completed example at www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife-sample.pdf

MY POLIO LIFE

A Patient Questionnaire

providing base line information and comparison charts on the Life of a Polio Survivor

Contents of the Form.

Page 3	This Questionnaire was developed because...
4	Base questions
	1 - Polio and your lifestyle.
6	1.21 - Aids and Equipment Chart.
8	2 - New Symptoms
10	3 - Actions of Daily Living Chart.
11	4 - Major Diagnoses
	5 - Operations related to polio
	6 - Operations not related to polio.
	7 - Accidents or Injuries.
12	8 - Allergies or intolerances to food
	9 - Allergies or intolerances to prescription medication
	10 - Chemical or other intolerances
	11 - Prescriptions currently taken
13	12 - A précis of your Polio Life
14	13 - The five actions of daily living that show the most change.
15	14 - Comparison of the four stages of your Polio Life.
16	15 - My Polio Life Line.

How to use this Questionnaire

- This form can only provide a brief overview. We recommend buying a notebook and using the numbers on this form write out your answers in full. Précis this information for the space allowed. When you are happy with your answers complete the form.
- You need to paint a picture in the health professional's mind that matches yours as to how you have and are living your polio life. It is essential that you are honest and tell it like it really is. **Answering "Yes" you can do an action without qualifying the way you do it can give a health professional the wrong information.**
- We have allowed three columns for New Problems so that you can add information for other dates, either earlier or later on.
- Extract pertinent information from your form/notebook for each appointment to make one page of notes and offer a copy for your medical file.
- Colour in the back page in a similar fashion to the picture on the front page. Remember that colours will not show on black and white photocopying, further notation may be needed on the photocopy.
- A couple of photographs showing you at your best ability in sport/hobby/ education/employment will speak a thousand words.

This questionnaire was developed because....

Damage and Recovery from Polio was varied with no set pattern, a nightmare for health professionals. Some Polio Survivors have lived their lives in wheelchairs and/or calipers, others have walked well but with obvious upper body weakness, and others recovered so well that they have no or little obvious visual polio residuals.

After years of stable functioning some Polio Survivors are experiencing the start of new and unexpected symptoms of fatigue, pain, weakness and functional decline. Terms used are Post Polio Syndrome [PPS], Post Polio Sequelae, Late Effects of Polio [LEOP], Post-Polio Muscular Atrophy [PPMA]. A variety of terms and definitions. The most commonly used term is Post Polio Syndrome [PPS] which refers to the start of new symptoms after years of stable functioning for which there is no other explanation. This can be gradual, or following a traumatic episode, leading to decline in functional ability. Despite some medical articles to the contrary this **is** occurring, and at an earlier age than can be accounted for by the normal aging process.

Not everyone experiences this stage or all of the problems outlined in this form. Currently there are no diagnostic tests. The diagnosis is made from history taking, physical examination and tests to eliminate other causes.

This Questionnaire was developed because of the huge number of polio survivors reporting that some of their symptoms are not being corroborated yet they are continuing to decline. Research into this found that some current methods of assessment are not testing the **endurance of muscles**. This includes:- Manual Muscle Testing to lesser repeats or sustaining level. Observation of an action that does not go to the point where you state your symptoms start. This is resulting in over-grading of actual physical ability and in many cases due to this lack of corroboration of reported symptoms has led to:-

- incorrect and/or inappropriate diagnosis, advice, and treatment.
- state benefits and aids and equipment being withheld.
- employers, other health professionals and family assuming 'it's all in your mind'
- Increased stress, frustration, anxiety and depression.

Appointment time can be limited so you must make the best use of that time. For instance if the appointment is ten minutes you have to present your problem, be questioned and examined in that time. Reams of paper cannot be read in this time. Typing up a few short notes will help and we recommend that you politely offer a copy for your records. The key to accurate assessment of your functional ability is to present to your health professional that your new symptoms have forced you to change the way you do an action. This questionnaire and its charts will quickly show this change and point health professionals to where further assessment is necessary.

Demonstration of the actions has been shown to be extremely helpful in showing which muscles are being used and how.

It is essential that accurate assessment rules out other causes for your symptoms. Health professionals need to be made aware that new problems **are** being seen in areas not thought to have been previously affected. This was first medically recorded in 1875.

Name [leave blank if preferred]

Town Country

Date today

Male/Female Race

Date of Birth Age Now

Original Diagnosis

Date of Diagnosis Age

Town Country

Highest Educational Level

Do you have medical records from your polio years? YES NO

Do you have/can you get copies of your current medical records? YES NO

Do you still live within 50 miles of where you caught polio? YES NO

Have you had to move to a more accessible property or make some major additions/alterations to your current home? YES NO

If Yes, at what age did you move/have alterations done?

1. Have you maintained maximal recovery level? YES NO

1.1 Year of polio and age. 19 Age

1.2 Year of maximal recovery 19

1.3 Year first noticed new symptoms 19..... 200.....

1.4 Number of years since max recoveryyrs

1.5 Was there some particular event that brought this change to your attention YES NO
If yes, please describe.

.....
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.....

- 1.6 Were you in employment at this time? YES NO
- 1.7 If yes, state job

 .
- 1.8 List other types of jobs you had prior to this.

- 1.9 Have you had to change nature of job? YES NO
- 1.10 If yes, why?

- 1.11 Have you had to retire early? YES NO
 If yes, how many years early? yrs
- 1.12 Did you expect this to happen? YES NO
- 1.13 If still working, do you expect to continue to normal retirement age? N/A YES NO
- 1.14 How many years? yrs
- 1.15 Please circle at start of new physical problems
 Single / Married / Partner / Divorced / Widowed
- 1.16 If a relationship has ended do you think your new problems were a factor? YES NO
- 1.17 Do you have a good relationship with your sibling/s? YES NO
- 1.18 If not do you think your polio was a factor? YES NO
- 1.19 Your current accommodation status. Please circle:
 I live
 Alone
 With a disabled partner
 With an elderly partner
 With an able bodied partner
 With other family members
 In warden assisted accommodation
 In residential accommodation
 In a nursing home.

1.20 Have your new problems had any impact on the following?

Please circle 1 is severe, 2 moderate 3 some 4 none 5 not applicable

		Sev	Mod	Some	None	N/A
1.20.1	Your personal life	1	2	3	4	5
1.20.2	As the breadwinner	1	2	3	4	5
1.20.3	As the home keeper	1	2	3	4	5
1.20.4	Your partner's life	1	2	3	4	5
1.20.5	Your family life	1	2	3	4	5
1.20.6	Your sibling's lives	1	2	3	4	5
1.20.7	Your children's lives	1	2	3	4	5
1.20.8	Your social life	1	2	3	4	5
1.20.9	Your sporting ability	1	2	3	4	5
1.20.10	Your hobby/craft ability	1	2	3	4	5
1.20.11	Your retirement plans	1	2	3	4	5

1.21	AIDS AND EQUIPMENT	TICK ITEMS THAT APPLY					
		Before	Polio	Stable Yrs	New Problems		
	Age at each stage						
1.21.1	Iron Lung						
1.21.2	Chest Respiratory (Cuirass®)						
1.21.3	Rocking Bed						
1.21.4	Mini-lung (portable respirator)						
1.21.5	Frog Breathing						
1.21.6	CPAP						
1.21.7	Bi-level with/without backup rate						
1.21.8	Other vent.....						
1.21.9	Tracheotomy						
1.21.10	Crutches						
1.21.11	Cane						
1.21.12	Full Leg Brace						
1.21.13	Lower Leg Brace						
1.21.14	Knee Brace						
1.21.15	Spinal brace or corset						
1.21.16	Neck brace or collar						

1.21	AIDS AND EQUIPMENT - cont.	TICK ITEMS THAT APPLY					
		Before	Polio	Stable Yrs	New Problems		
	Age at each stage						
1.21.17	Wheelchair Manual						
1.21.18	Wheelchair Electric						
1.21.19	Electric Scooter						
1.21.20	Car - hoist, ramp, lift etc.						
1.21.21	Car control modifications						
1.21.22	Surgical Shoes						
1.21.23	Flat shoes only						
1.21.24	Personal assistance Full Time						
1.21.25	Personal assistance Part Time						
1.21.26	Assistance Dog						
1.21.27	Stair lift/glide						
1.21.28	Through floor wheelchair lift						
1.21.29	Ramps inside or out						
1.21.30	Bath Lift/Hoist						
1.21.31	Toilet Raiser/raised						
1.21.32	Hoist in Bedroom						
1.21.33	Handrails in bathroom/toilet						
1.21.34	Handrails elsewhere						
1.21.35	Raised lounge furniture						
1.21.36	Raised Bed						
1.21.37	Electric Bed						
1.21.38	Electric Riser Chair						
1.21.39	Widened Doors						
1.21.40	Modified Kitchen						
1.21.41	Eating utensil modifications						
1.21.42	Telephone Modifications						
1.21.43	Voice activated system						
1.21.44	Modified Workplace						
1.21.45	Other						

2	NEW SYMPTOMS	Y/No	Short comment
2.1	New unexpected Physical Fatigue		
2.2	New unexpected Mental Fatigue		
2.3	Not being able to concentrate for as long		
2.4	Losing track of subject when talking		
2.5	Losing word but knowing its meaning		
2.6	Loss of ability to do actions of daily living		
2.7	New weakness in known polio affected limb		
2.8	New weakness in limb not known polio affected		
2.9	New weakness in Trunk		
2.10	New weakness in Head/Neck/Face		
2.11	New Pain in polio affected limb		
2.12	New pain in limb not known polio affected		
2.13	New pain in Trunk		
2.14	New pain in Head/Neck		
2.15	Noticed muscles jumping/twitching		
2.16	Burning pains in lower legs or arms		
2.17	New Hearing Problems		
2.18	Swallowing - not able to swallow each time		
2.19	Not clearing all food with each swallow		
2.20	Choking on Solid foods.		
2.21	Choking on Liquids		
2.22	Easy regurgitation of food/liquid		
2.23	Do you have acid reflux?		
2.24	Voice - has your voice deepened		
2.25	Do you lose power as you talk		
2.26	Become hoarse after talking for some time		
2.27	Vision—blurred vision for more than seconds		
2.28	Blurred vision not corrected by glasses		
2.29	Moving from bright light to dark difficult		
2.30	Moving from darkness to bright light difficult		

3 ACTIONS OF DAILY LIVING - This chart is to briefly show if you have had to change the way you do actions. At best recovery state 'Normal' or 'My' method or 'Not Able'			
		At Best Recovery	How I do it now.
3.1	Roll over in bed		
3.2	Get in/out of bed		
3.3	Use toilet		
3.4	Use bath		
3.5	Use shower		
3.6	Wash Hair		
3.7	Get dressed clothes		
3.8	Get dressed—braces etc		
3.9	Dining Chair—up and down		
3.10	Couch—up and down		
3.11	Saloon car—in and out		
3.12	Floor—up and down		
3.13	Stairs—up		
3.14	Stairs—down		
3.15	Stairs carrying items		
3.16	Kitchen—beating action		
3.17	K—peeling veg		
3.18	K—cutting items		
3.19	K—lifting saucepans		
3.20	K—stand or sit to work		
3.21	K—take hot item out of oven		
3.22	K—carry two full plates		
3.23	Housework—dusting		
3.24	H—vacuuming		
3.25	H—moving furniture		
3.26	Decorating		
3.27	Gardening		
3.28	Workshop—sawing wood		
3.29	W - car maintenance		
3.30	W - household maintenance		
3.31	Hobby or Craft		
3.32	Other		

4	MAJOR DIAGNOSES	YEAR
4.1		
4.2		
4.3		
4.4		
4.5		
4.6		
4.7		
4.8		
5	OPERATIONS RELATED TO POLIO	
5.1		
5.2		
5.3		
5.4		
5.5		
5.6		
5.7		
5.8		
6	OPERATIONS NOT RELATED TO POLIO	
6.1		
6.2		
6.3		
6.4		
6.5		
6.6		
6.7		
6.8		
7	ACCIDENTS OR INJURIES	
7.1		
7.2		
7.3		
7.4		
7.5		

Allergies and Intolerances. Prescriptions currently taken.

8	Do you have any allergies or intolerances to food?
8.1	
8.2	
8.3	
8.4	
8.5	
9	Do you have any allergies or intolerances to prescription medicine/s?
9.1	
9.2	
9.3	
9.4	
9.5	
9.6	
9.7	
10	Do you have any chemical or other intolerances?
10.1	
10.2	
10.3	
10.4	

11	Prescription	Dose	X a day	Taking for	For long?
11.1					
11.2					
11.3					
11.4					
11.5					
11.6					
11.7					
11.8					
11.9					
11.10					
11.11					
11.12					

12. A précis of my Polio Life.

12.1 Prior to my getting polio I had the following illnesses.

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12.2 Polio to best recovery. [Briefly describe your polio life to best recovery]

I was diagnosed with in 19..... at age

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12.3 Stable years [Briefly give facts about your education, your jobs [includes housewife and bringing up children, etc] and your sporting and hobby levels.

I achieved best recovery at age

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12.4 New symptoms/problems. [Briefly describe how your life has changed]

I started to notice a gradual decline in Or new problems in
following

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Were you expecting this change in your life at this age? YES NO

13. The 5 actions of daily living that show the most change in my life.

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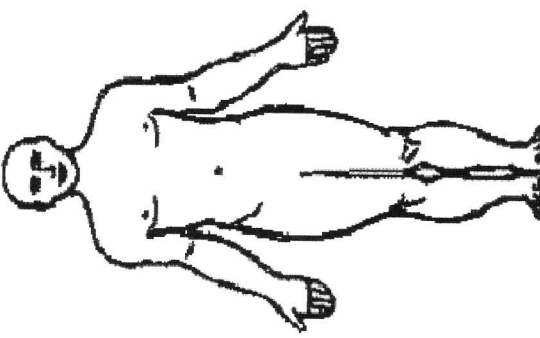
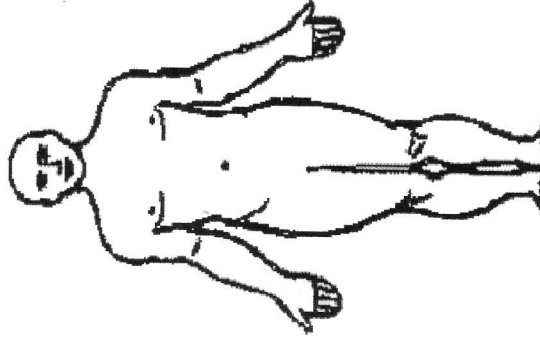
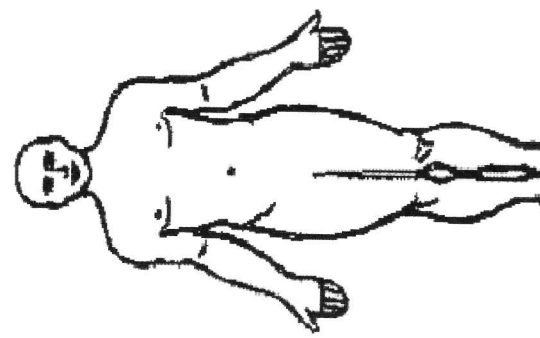
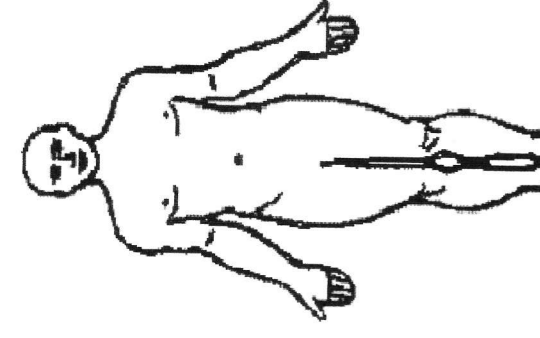
4.
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5.
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14. Comparison of the stages of your Polio Life.

- 1 - Mild Weakness or mild loss of ability
- 2 - Moderate Weakness or moderate loss of ability,
- 3 - Severe Weakness or severe loss of ability.
- 4 - Paralysis or unable to use.

DATE	Before	Polio	Stable Years	New Problems		
Your age at each stage	0 -	Age To	Age.....	Age.....	Age.....
	Score	Score	Score	Score	Score	Score
Vision issues						
Hearing issues						
Swallowing issues						
Breathing issues						
Neck						
Chest						
Upper Back						
Right Arm - Shoulder						
Rt Arm - Upper Arm						
Rt Arm - Lower Arm						
Rt Arm - Wrist and Hand						
Lt Arm - Shoulder						
Lt Arm - Upper Arm						
Lt Arm - Lower Arm						
Lt Arm - Wrist and Hand						
Abdomen						
Lower back						
Rt Leg - Upper						
Rt Leg - Lower						
Rt Leg - Foot						
Lt Leg - Upper						
Lt Leg - Lower						
Lt Leg - Foot						
Other						

Pre Polio	Polio at Age	Best Recovery	Date now	KEY
				

Revision History.

1.01 July 2007.

Original Published.

1.02 December 2007.

Link to completed example (sample) form added to front page.

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