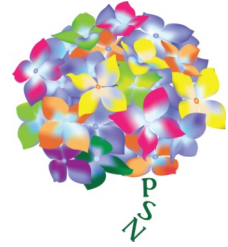


# Polio Survivors Network

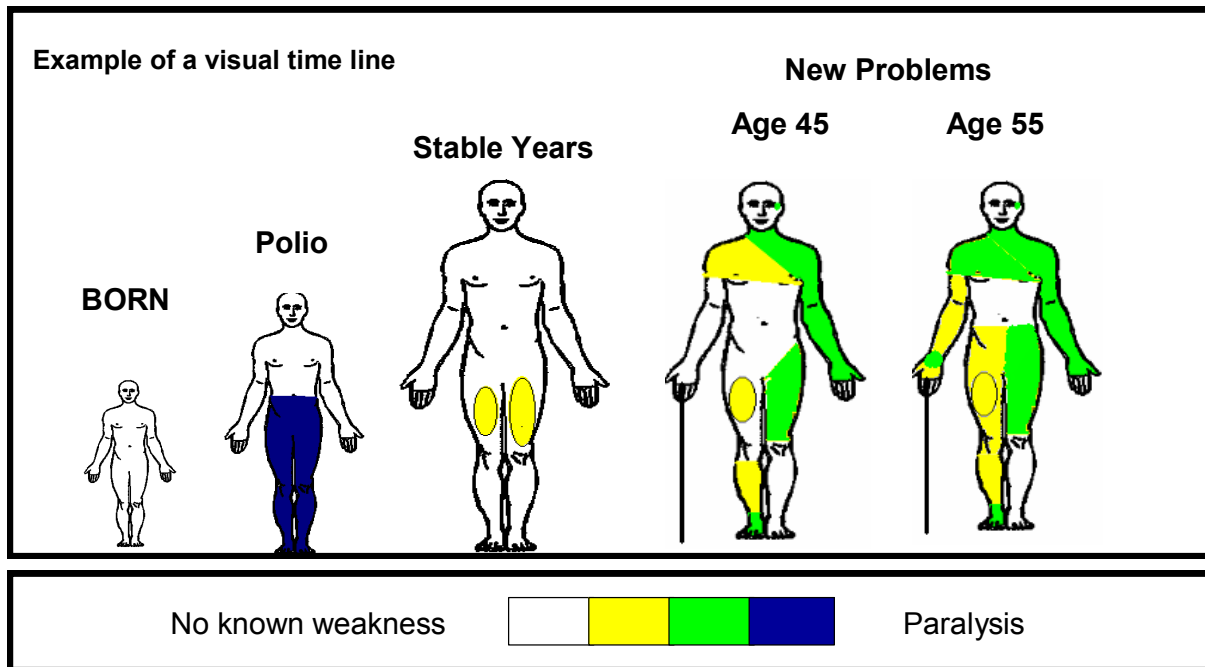
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PRESENT

## 'MY POLIO LIFE'

**A Self Assessment Patient Questionnaire  
to assist you with collating information on  
your Life as a Polio Survivor**



### My Polio Life - A Self Assessment Tool

Created in May 2007 - Updated August 2011

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### How to use this Questionnaire

- This form is for your use, you decided which questions to answer but remember it can only provide a brief overview. We recommend your using a computer or pad of paper and using the numbers on this form write out your answers in full. Then also précis each piece of information for the space allowed. When you are happy with your answers complete the form. Keep the longer version in a file with any other information, e.g. letters or stories relating to your life, medical test results, letters from health professionals, photos, etc.
- 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 chart in a similar way to the front page picture. Remember that colours will not show easily on black and white photocopying, further symbol notation, e.g. dots or hash lines may be needed unless you copy in colour.

## **This questionnaire was developed because....**

Damage and Recovery from Polio was varied with no set pattern, no two polio survivors are the same, we are 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 older 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 by tests 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. All this can result in your actual physical ability being over-graded 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. Demonstrating an action so which muscles you are using to do this, which in many cases are not those expected, can be extremely helpful to health professionals.

It is essential that accurate assessment rules out other causes for your symptoms. Health professionals may need to be made aware that your new problems **are being seen in areas/muscles not thought to have been previously affected**. First medically recorded in 1875! The polio virus changed the way your body works. A symptom/problem could be PPS, something else or both..

**Base Line Questions**

Name ..... Date today .....

Address .....

..... Country .....

Male ..... Female ..... Race .....

Date of Birth ..... Age Now .....

Original Polio 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 addition/alteration to your current home? YES NO

If Yes, at what age did you move/ this happen?

.....

.....

.....

.....

**Main Questions.**

1. Have you maintained maximal recovery level? YES NO

1.1 Year of polio and age. ....

1.2 Year of maximal recovery .....

1.3 Year first noticed new symptoms .....

1.4 Number of years since max recovery .....

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 any than apply:  
 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	
	<b>Age at each stage</b>					
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		
	<b>Age at each stage</b>						
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 .....						

<b>2</b>	<b>NEW SYMPTOMS</b>	<b>Y/N</b>	<b>Short comment</b>
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		



<b>2</b>	<b>NEW SYMPTOMS continued</b>	<b>Y/N</b>	<b>Short comment</b>
2.31	Breathing - run out of breath whilst talking		
2.32	Shortness of breath whilst sitting		
2.33	Shortness of breath on modest exertion		
2.34	Shortness of breath whilst lying down		
2.35	Hold breath to do short physical action		
2.36	Use Day time ventilation		
2.37	Sleep - Turn over in sleep easily		
2.38	Wake up to turn in bed		
2.39	Mainly sleep in one position		
2.40	Wake at night gasping for breath		
2.41	Wake with headache or still feel tired		
2.42	Use Night time ventilation		
2.43	Men - lost ability to have an erection		
2.44	Women - lost sensitivity vaginal stimulation		
2.45	Lost the ability to have a sexual climax		
2.46	Have a stoma		
2.47	Occasionally lose control of bowels		
2.48	Take longer for food to go through your gut		
2.49	Wear incontinence aid 24 hours		
2.50	Wear incontinence aid during night only		
2.51	Can you tell if your bladder is full?		
2.52	Lose control of urine with/without realizing it		
2.53	Problems with cold intolerance		
2.54	Problems with heat intolerance		
2.55	Has your skin become drier?		
2.56	Noticed your hands/feet stopped sweating?		
2.57	Symptoms disbelieved by health professionals		
2.58	Symptoms disbelieved by family members		
2.59	Been diagnosed OK, continue to deteriorate		

3	<b>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'</b>		
		<b>At Best Recovery</b>	<b>How I do it now.</b>
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		

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

<b>Allergies and Intolerances. Prescriptions currently taken.</b>	
<b>8</b>	
8.1	
8.2	
8.3	
8.4	
8.5	
<b>9</b>	<b>Do you have any allergies or intolerances to prescription medicine/s?</b>
9.1	
9.2	
9.3	
9.4	
9.5	
9.6	
9.7	
<b>10</b>	<b>Do you have any chemical or other intolerances?</b>
10.1	
10.2	
10.3	
10.4	

<b>11</b>	<b>Prescription</b>	<b>Dose</b>	<b>X a day</b>	<b>Taking for</b>	<b>For .... long?</b>
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 .....**  
.....  
.....  
.....

**12.2 Polio to best recovery. [Briefly describe your polio life to best recovery]**  
.....  
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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.**  
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**12.4 New symptoms/problems. [Briefly describe how your life has changed]**  
.....  
.....  
.....  
.....  
.....  
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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.**

- 1. ....  
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- 2. ....  
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- 3. ....  
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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						
	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
