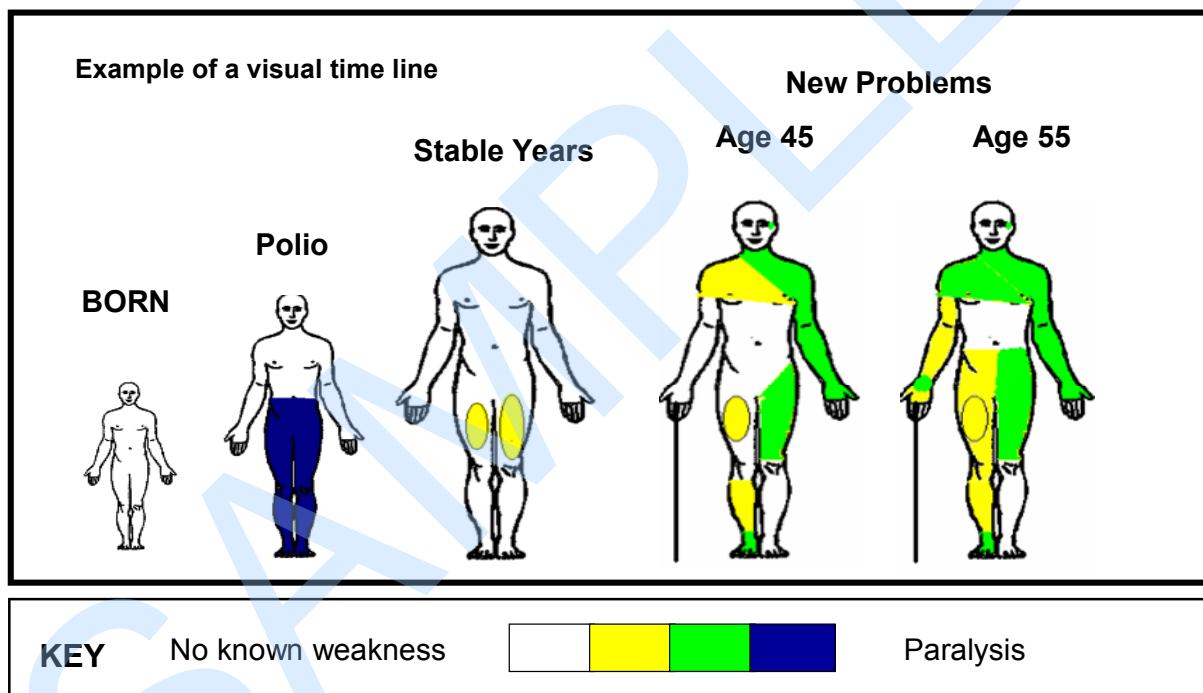


# EXAMPLES OF RESPONSES

N.B. Answers are examples and do not all relate to one person.

## 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 - May 2007

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A copy of this sample document can be found at  
[www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife-sample.pdf](http://www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife-sample.pdf)  
or [www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf](http://www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf) for blank form.

# 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. 1951..... Age 4

1.2 Year of maximal recovery 1963.....

1.3 Year first noticed new symptoms 1988.. .....

1.4 Number of years since max recovery 25.....yrs

1.5 Was there some particular event that brought this change to your attention YES NO

If yes, please describe.

Slipped and fell and this time never able to recover to previous level of ability.

.....

.....

.....

.....

.....

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?

No longer able to do the job to the required level. Retrained in another skill and later due to further functional decline had to medically retire.

1.11 Have you had to retire early? **YES** NO

If yes, how many years early? **12**..... 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	
	<b>Age at each stage</b>		<b>4</b>	<b>16—41</b>	<b>45</b>	<b>55</b>
1.21.1	Iron Lung					
1.21.2	Chest Respiratory (Cuirass®)					
1.21.3	Rocking Bed		X			
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					X
1.21.8	Other vent.....					
1.21.9	Tracheotomy					
1.21.10	Crutches		X			X
1.21.11	Cane				X	
1.21.12	Full Leg Brace					X RT
1.21.13	Lower Leg Brace			#	X LT	X LT
1.21.14	Knee Brace					
1.21.15	Spinal brace or corset		X			
1.21.16	Neck brace or collar					X

1.21	AIDS AND EQUIPMENT - cont.	TICK ITEMS THAT APPLY					
		Before	Polio	Stable Yrs	New Problems		
	<b>Age at each stage</b>		<b>4</b>	<b>16 TO 41</b>	<b>45</b>	<b>55</b>	
1.21.17	Wheelchair Manual		X		X		
1.21.18	Wheelchair Electric					X	
1.21.19	Electric Scooter				X		
1.21.20	Car - hoist, ramp, lift etc.				X		
1.21.21	Car control modifications						
1.21.22	Surgical Shoes						
1.21.23	Flat shoes only		X		X	X	
1.21.24	Personal assistance Full Time		X mum				
1.21.25	Personal assistance Part Time						
1.21.26	Assistance Dog						
1.21.27	Stair lift/glide					X	
1.21.28	Through floor wheelchair lift						
1.21.29	Ramps inside or out				X	X	
1.21.30	Bath Lift/Hoist					X	
1.21.31	Toilet Raiser/raised				X	X	
1.21.32	Hoist in Bedroom						
1.21.33	Handrails in bathroom/toilet				X	X	
1.21.34	Handrails elsewhere						
1.21.35	Raised lounge furniture				X	X	
1.21.36	Raised Bed				X		
1.21.37	Electric Bed					X	
1.21.38	Electric Riser Chair					X	
1.21.39	Widened Doors					X	
1.21.40	Modified Kitchen				X		
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>PUSHCHAIR</b> .....		X				

<b>2</b>	<b>NEW SYMPTOMS</b>	<b>Y/No</b>	<b>Short comment</b>
2.1	New unexpected Physical Fatigue	<b>Y</b>	Since fall
2.2	New unexpected Mental Fatigue	<b>Y</b>	When tired
2.3	Not being able to concentrate for as long	<b>Y</b>	When tired
2.4	Losing track of subject when talking	<b>Y</b>	Later in day
2.5	Losing word but knowing its meaning	<b>Y</b>	Increasingly
2.6	Loss of ability to do actions of daily living	<b>Y</b>	Since fall
2.7	New weakness in known polio affected limb	<b>Y</b>	First time KAFO
2.8	New weakness in limb not known polio affected	<b>Y</b>	First time AFO
2.9	New weakness in Trunk	<b>Y</b>	Scoliosis now
2.10	New weakness in Head/Neck/Face	<b>Y</b>	Now neck brace
2.11	New Pain in polio affected limb	<b>Y</b>	Before brace
2.12	New pain in limb not known polio affected	<b>Y</b>	Left arm worse
2.13	New pain in Trunk	<b>Y</b>	Have to sit often
2.14	New pain in Head/Neck	<b>Y</b>	Neck brace helps
2.15	Noticed muscles jumping/twitching	<b>Y</b>	Mainly in legs
2.16	Burning pains in lower legs or arms	<b>Y</b>	If don't get legs up
2.17	New Hearing Problems	<b>N</b>	
2.18	Swallowing - not able to swallow each time	<b>Y</b>	For 15 years now
2.19	Not clearing all food with each swallow	<b>Y</b>	Repeat swallow
2.20	Choking on Solid foods.	<b>Y</b>	Oaty stuff, Yogurt
2.21	Choking on Liquids	<b>N</b>	
2.22	Easy regurgitation of food/liquid	<b>N</b>	
2.23	Do you have acid reflux?	<b>N</b>	
2.24	Voice - has your voice deepened	<b>N</b>	
2.25	Do you lose power as you talk	<b>Y</b>	Used to lecture
2.26	Become hoarse after talking for some time	<b>Y</b>	After about hour
2.27	Vision—blurred vision for more than seconds	<b>N</b>	
2.28	Blurred vision not corrected by glasses	<b>N</b>	
2.29	Moving from bright light to dark difficult	<b>Y</b>	Wait till eyes adjust
2.30	Moving from darkness to bright light difficult	<b>N</b>	



<b>2</b>	<b>NEW SYMPTOMS continued</b>	<b>Y/No</b>	<b>Short comment</b>
2.31	Breathing - run out of breath whilst talking	<b>Y</b>	Can't sing now
2.32	Shortness of breath whilst sitting	<b>N</b>	
2.33	Shortness of breath on modest exertion	<b>Y</b>	Most activities
2.34	Shortness of breath whilst lying down	<b>N</b>	
2.35	Hold breath to do short physical action	<b>Y</b>	When using arms
2.36	Use Day time ventilation	<b>N</b>	
2.37	Sleep - Turn over in sleep easily	<b>N</b>	
2.38	Wake up to turn in bed	<b>Y</b>	Now have grab-rail
2.39	Mainly sleep in one position	<b>Y</b>	On weak side
2.40	Wake at night gasping for breath	<b>N</b>	
2.41	Wake with headache or still feel tired	<b>Y</b>	If wake on back
2.42	Use Night time ventilation	<b>N</b>	
2.43	Men - lost ability to have an erection	<b>N/A</b>	
2.44	Women - lost sensitivity to vaginal stimulation	<b>N</b>	
2.45	Lost the ability to have a sexual climax	<b>N</b>	
2.46	Have a stoma	<b>N</b>	
2.47	Occasionally lose control of bowels	<b>N</b>	
2.48	Take longer for food to go through your gut	<b>Y</b>	Improved diet
2.49	Wear incontinence aid 24 hours	<b>N</b>	
2.50	Wear incontinence aid during night only	<b>N</b>	
2.51	Can you tell if your bladder is full?	<b>Y</b>	
2.52	Lose control of urine with/without realizing it	<b>N</b>	
2.53	Problems with cold intolerance	<b>Y</b>	Wear more layers
2.54	Problems with heat intolerance	<b>Y</b>	Installed fan
2.55	Has your skin become drier?	<b>N</b>	
2.56	Noticed your hands/feet stopped sweating?	<b>N</b>	
2.57	Symptoms disbelieved by health professionals	<b>Y</b>	Tests say Fine
2.58	Symptoms disbelieved by family members	<b>Y</b>	Because of 2.57
2.59	Been diagnosed OK but continue to deteriorate	<b>Y</b>	Since fall, 19 yrs

<b>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'</b>			
		<b>At Best Recovery</b>	<b>How I do it now.</b>
3.1	Roll over in bed	Normal	Have to wake up and use aids to do this now
3.2	Get in/out of bed	Normal	Higher bed, sit up sideways
3.3	Use toilet	Normal	High Rise seat fitted
3.4	Use bath	My way	Used chair and rail—not enough strength now
3.5	Use shower	Normal	Have to sit on stool
3.6	Wash Hair	Normal	In shower, seated with short arm lever action
3.7	Get dressed clothes	Normal	No longer do standing
3.8	Get dressed—braces etc	N/A	
3.9	Dining Chair—up and down	My way	Pushed up with hands—now need riser
3.10	Couch—up and down	My way	Sat forward and used arms, now can't get do
3.11	Saloon car—in and out	My way	Had to change to higher vehicle
3.12	Floor—up and down	My way	All fours, hands back to feet. Now can't do
3.13	Stairs—up	Normal	Use rail, stop halfway, one stair at a time
3.14	Stairs—down	Normal	One stair at a time
3.15	Stairs carrying items	Normal	Cannot do at all
3.16	Kitchen—beating action	Normal	Can only do slowly
3.17	K—peeling veg	Normal	Causes pain, and do very slowly
3.18	K—cutting items	Normal	Can't do safely
3.19	K—lifting saucepans	Normal	Lighter saucepans, now slide—can't lift
3.20	K—stand or sit to work	Normal	Have to sit
3.21	K—take hot item out of oven	Normal	Now have table level oven
3.22	K—carry two full plates	Normal	Use push trolley
3.23	Housework—dusting	Normal	Now employ cleaner
3.24	H—vacuuming	Normal	All house to half a room. Now employ cleaner
3.25	H—moving furniture	Normal	No longer possible
3.26	Decorating	Normal	No longer possible
3.27	Gardening	Normal	Can't cut grass or dig over borders
3.28	Workshop—sawing wood	Normal	No longer possible
3.29	W - car maintenance	Normal	No longer possible
3.30	W - household maintenance	Normal	No longer possible
3.31	Hobby or Craft .....	Normal	Given up—can't do well enough anymore
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>	<b>Do you have any allergies or intolerances to food?</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 had the following illnesses.**

.....  
.....

**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.**

1. Walking - I was paralysed waist down and wore a full and half leg brace. At 16 I threw away my braces and walked with a cane until I was 47. I had to wear specially made shoes as one leg is shorter. I could walk about 3 miles. After 30 years it was a huge step emotionally to go back to a brace. I use a cane all the time now and the distance I can walk has reduced year by year. This meant getting an electric scooter and hoist for my truck. Pain, more arm weakness and shoulder surgery and inability to hold my arms out on scooter controls meant changing to an electric wheelchair. I am only 56.

2. ....  
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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.

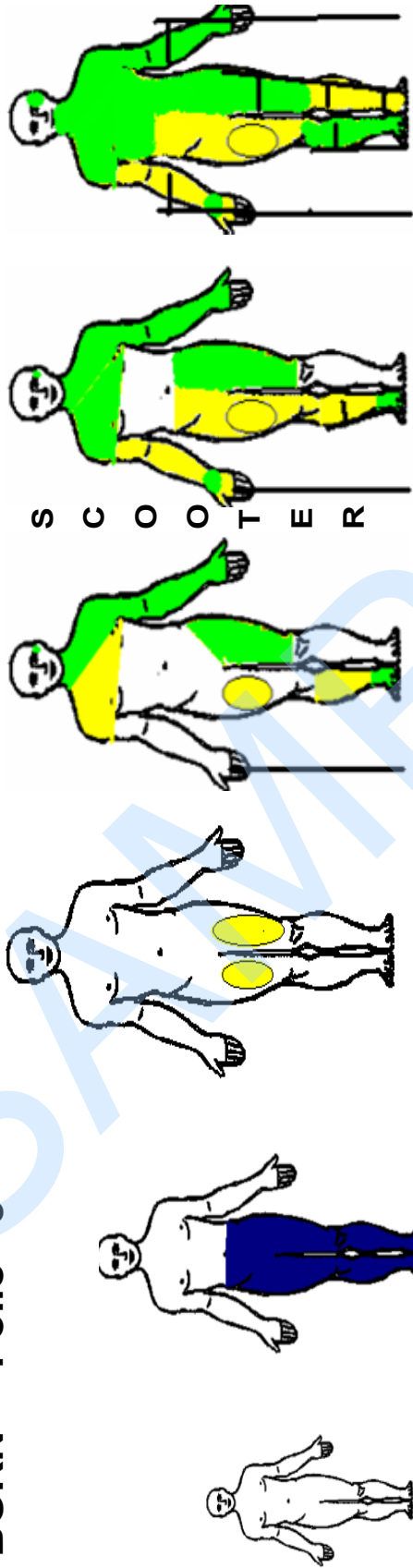
DATE .....	Before	Polio	Stable Years	New Problems		
Your age at each stage	0 - .....	Age .....	..... To .....	Age.....	Age.....	Age....
	Score	Score	Score	Score	Score	Score
Vision issues				1	1	
Hearing issues					1	
Swallowing issues				1	1	
Breathing issues					1	
Neck				1	1	
Chest				1	1	
Upper Back				1	1	
Right Arm - Shoulder					1	
Rt Arm - Upper Arm					1	
Rt Arm - Lower Arm					1	
Rt Arm - Wrist and Hand				1	2	
Lt Arm - Shoulder				1	2	
Lt Arm - Upper Arm				1	2	
Lt Arm - Lower Arm				1	2	
Lt Arm - Wrist and Hand				1	2	
Abdomen		4		1	2	
Lower back		4	1	1	1	
Rt Leg - Upper		4	1	1	1	
Rt Leg - Lower		4		2	2	
Rt Leg - Foot		4		2	3	
Lt Leg - Upper		4	1	2	2	
Lt Leg - Lower		4			1	
Lt Leg - Foot		4			1	
Other .....						

# POLIO TIME LINE – as at May 28<sup>th</sup> 2007

**BORN**      **Polio - 5**

**Stable Yrs 16 to 41**

**New Problems age 48 and 53 and 60**



**S  
C  
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R**

No known weakness	Waist down paralytic polio no known upper body weakness	Some leg weakness, unable to run or rise from squat, legs collapse if bend knees more than 3 inches. Policewoman, Lifeguard, Swimming Teacher, Very fit.	After fall in 88 new arm, neck and eye movement weakness. More leg weakness, right foot dropped, needed cane. Medically retired at 45. Report swallowing issues.	Arm weakness increased. Right wrist weakness, legs increased weakness. Daily functional ability reduced. AFO Now using electric scooter. Automatic car	Electric rise chair. High bed. Arm crutches, KAFO. Move to single story imminent. Minivan with hoist. Have resp. issues.
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No known weakness



Paralysis



## Revision History.

1.01 July 2007.

Original Published.

1.02 December 2007.

Link to original blank form added to front page.

All pages watermarked with text 'SAMPLE'.

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