# How to use 'My Polio Life & Preparing for an Appointment'

After years of stability, some Polio Survivors are facing symptoms such as fatigue, pain, weakness, and functional decline, collectively known as Post Polio Syndrome (PPS). PPS onset can be gradual or triggered by a traumatic episode, resulting in a decline in functional ability earlier than expected in normal aging. Diagnosis relies on history, physical examination, and exclusion of other causes, as there are no specific diagnostic tests available.

PPS symptoms differ among individuals, ranging from those who have spent their lives in wheelchairs or callipers, to those with upper body weakness despite walking well, and even those who show little to no visible polio residuals. This document compiles crucial information about how PPS impacts *you*, aiding healthcare professionals to understand *your* specific needs.

**Tip:** Taking along a photo showing you at the peak of your physical ability can speak a thousand words.

Accurate assessment of your functional ability relies on honestly conveying how new symptoms have altered your actions. Specify changes in the way you perform tasks because simply stating you can do something can mislead health professionals. This tool helps illustrate the changes, directing professionals to areas requiring further assessment.

**Tip:** Demonstrating how you perform actions can be helpful to show which muscles you are using and how.

To help demonstrate deterioration colour the chart detailing muscle weakness Pre Polio, Polio at Age X, during Best Recovery and Date now to indicate the areas affected and how badly. We hope you find the example below useful.

Pre Polio	Polio at Age	Best Recovery	Date now 91/91/2924
No known weakness	Waist down paralytic polio	Some leg weakness, unable to run & squat.	Arm weakness, right wrist weakness, legs
	No known upper body weakness Knee collapses when bent more than 3 inches.  Lifeguard, very fit	increased  weakness, AFO, automatic car, electric scooter	
No known	weakness		Paralysis

Wishing you all the best with your appointment(s).

## My Polio Life & Preparing for an Appointment

After years of stable functioning polio survivors can experience unexpected symptoms. Damage and recovery from polio varies with no set pattern and as no two polio survivors are the same, we can be a nightmare for health professionals!



### My Polio Life in Brief

Prior to having polio my life/health was
My life/health after having polio until I was most recovered was
My life during the stable years (e.g. health, education, job, children, hobbies, etc)
The five actions of daily living (e.g. washing, walking, cooking, sleeping, using stairs, etc) that show the most change/deterioration in my life since maximum recovery from polio. Listed from most change to least:
1)
2)
3)
4)
5)

Pre Polio	Polio at Age	Best Recovery	Date now

No known weakness

Paralysis

## **My Symptoms**

(Tick all the ones relevant to you)

General	Speech	Sleep
☐ Physical fatigue	☐ Deepened voice	☐ Unable to roll over in bed
☐ Mental fatigue	☐ Losing power when talking	easily —
Poor concentration	Hoarse after talking for some	☐ Waking up to turn over in bed
Loss of ability to do actions of	time	☐ Mainly sleeping in one
daily living	Eating/Drinking	position
Symptoms not believed by health professional	☐ Swallowing - not able to	☐ Wake up gasping for breath
☐ Symptoms not believed by	swallow each time	lacksquare Wake up with headache or
family member	☐ Not clearing all food with each swallow	still feeling tired
No diagnosis but continue to	Choking on solid foods	Sexual
deteriorate	☐ Choking on liquids	Lost ability to have an
Weakness	Regurgitation of food/liquid	erection
☐ Weakness in polio affected	☐ Acid reflux	Lost sensitivity to vaginal
limb		stimulation
Weakness in non-polio	Breathing —	Lost ability to have a sexual climax
affected limb	Running out of breath whilst	Cililiax
☐ Weakness in trunk	talking	Bowels/Urination
☐ Weakness in head/neck/face	☐ Shortness of breath when sitting	Have a stoma
Pain	☐ Shortness of breath on	☐ Occasional loss of bowel control
Pain in polio affected limb	modest exertion	☐ Take longer for food to go
Pain in non-polio affected limb	Shortness of breath when lying down	through gut
Pain in trunk	Holding breath to do short	☐ Wear incontinence aid 24
☐ Pain in head/neck/face	physical action	hours a day
☐ Twitching/jumping muscles	☐ Use ventilator during day	Wear incontinence aid during
☐ Burning pains in lower	☐ Using ventilator at night	night only  Can't tell if bladder is full
legs/arms		Loss of urinary control
	Vision	without realising
Memory	☐ Blurred vision for more than seconds	
Losing track of subject when	_	Temperature/Skin
talking	☐ Blurred vision (not corrected by glasses)	Cold intolerance
Losing word but knowing its meaning	Difficulty when moving from	Heat intolerance
	bright light to dark	Hands/feet don't sweat
Hearing	☐ Difficulty when moving from	☐ Dry skin
☐ Hearing problems	dark to bright light	

#### **During your appointment**

Think about what your most troubling symptoms are, how are these effecting your life, what is most important to you about how you live or want to live your life.

It is ok to ask questions. Write a list of the questions you have in the space below e.g. How many polio survivors have you treated? I used to be able to do 'X' this way but since 'YY' I have had to modify the way I do it, what has changed to cause this? Is a referral to a specialist physiotherapist or occupational therapist with experience in managing neurological conditions possible to help me learn about pacing recommended for assessment and training in energy management techniques? What are my options and the possible benefits and risks? What help do I need to make a decision?

Practice what you want to say and what help you are hoping as an outcome for each point/question.

Take someone along who is aware of your situation and history, they can take notes for you too.

Be honest even if it is hard to hear yourself say the words - you have to be specific and tell it like it really is.

If there is not enough time to discuss everything ask for a further appointment.

My questions/concerns/queries:				