

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 ..5.....	Best Recovery	Date now 01/01/2024
No known weakness	Waist down paralytic polio	Some leg weakness, unable to run & squat.	Arm weakness, right wrist weakness, legs increased
	No known upper body weakness	Knee collapses when bent more than 3 inches.	weakness, AFO, automatic car,
		Lifeguard, very fit	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 _____

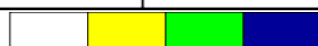
My life during the stable years (e.g. health, education, job, children, hobbies, etc) _____

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

- Physical fatigue
- Mental fatigue
- Poor concentration
- Loss of ability to do actions of daily living
- Symptoms not believed by health professional
- Symptoms not believed by family member
- No diagnosis but continue to deteriorate

Weakness

- Weakness in polio affected limb
- Weakness in non-polio affected limb
- Weakness in trunk
- Weakness in head/neck/face

Pain

- Pain in polio affected limb
- Pain in non-polio affected limb
- Pain in trunk
- Pain in head/neck/face
- Twitching/jumping muscles
- Burning pains in lower legs/arms

Memory

- Losing track of subject when talking
- Losing word but knowing its meaning

Hearing

- Hearing problems

Speech

- Deepened voice
- Losing power when talking
- Hoarse after talking for some time

Eating/Drinking

- Swallowing - not able to swallow each time
- Not clearing all food with each swallow
- Choking on solid foods
- Choking on liquids
- Regurgitation of food/liquid
- Acid reflux

Breathing

- Running out of breath whilst talking
- Shortness of breath when sitting
- Shortness of breath on modest exertion
- Shortness of breath when lying down
- Holding breath to do short physical action
- Use ventilator during day
- Using ventilator at night

Vision

- Blurred vision for more than seconds
- Blurred vision (not corrected by glasses)
- Difficulty when moving from bright light to dark
- Difficulty when moving from dark to bright light

Sleep

- Unable to roll over in bed easily
- Waking up to turn over in bed
- Mainly sleeping in one position
- Wake up gasping for breath
- Wake up with headache or still feeling tired

Sexual

- Lost ability to have an erection
- Lost sensitivity to vaginal stimulation
- Lost ability to have a sexual climax

Bowels/Urination

- Have a stoma
- Occasional loss of bowel control
- Take longer for food to go through gut
- Wear incontinence aid 24 hours a day
- Wear incontinence aid during night only
- Can't tell if bladder is full
- Loss of urinary control without realising

Temperature/Skin

- Cold intolerance
- Heat intolerance
- Hands/feet don't sweat
- Dry skin

