

What you Need to Know About My Condition

I am a Polio Survivor: Age _____ Year _____ in _____

And now have Post-Polio Syndrome diagnosed in [_____]

Post-Polio Syndrome or PPS is the accepted name for the constellation of NEW symptoms. These symptoms can occur both in previously known affected muscles and those thought not to have been affected at onset. They vary from person to person and can fluctuate from one time to another. Symptoms including NEW weakness, muscle fatigue and/or 'central' fatigue, pain, breathing [inc hypoventilation], swallowing difficulties, a variety of sleep disorders, fasciculations, gastrointestinal problems.

There are no definitive tests. Diagnosis is by exclusion of other conditions.

This document contains key information and how Polio and Post-Polio Syndrome affects me personally, and will help you to understand my particular needs.

Also been diagnosed with _____

ALLERGIES and IMPORTANT FACTS -

N.B. Ventilator User _____ Settings are:- _____

- I could be a **CO2 retainer** and if given Oxygen this needs regular testing.
- Care prescribing any **Drug or Anaesthetic that has sedative or muscle relaxant properties** must be taken due to my weakened muscles.
- **Single Action Manual Muscle Testing could over grade** my reported endurance of muscle action, ability to perform a pattern of movement

FULL NAME

I like to be called:-

ADDRESS

Post Code:-

TELEPHONE NUMBER

NEXT OF KIN / [ICE] In Case of Emergency:-

Tel No:-

Name

Address

Relationship

IMPORTANT CONTACTS

Details	Name	Tel No:-
Support Worker		
GP Surgery / Name		
Specialist Nurse		

MEDICATION.

n.b. It is essential that my medications are on time

I would like to self medicate if possible

Yes		No	
Yes		No	

Medication Name	Dosage	Time	For

Special Comments:-

EATING AND DRINKING.	I eat and drink independently. Yes / No
Drinking: I use	
Eating: I use	
Food Allergies/Intolerances:	
My Dietary Needs:-	

MOBILITY and ABILITY

My Mobility is not is somewhat affected is considerably affected

I use the following aids and equipment. [cross out items not used]

Cane	Ankle Foot Orthosis Rt / Lt	Manual Wheelchair	Drive Manual Car
Crutches	Calliper Rt / Lt	Electric Scooter	Drive Automatic Car
Rollator	Special shoes	Electric Wheelchair	Wheelchair Car Lift
Push Trolley			Wheelchair Car Hoist

My Ability is not is somewhat affected is considerably affected

I have muscle weakness in the following areas of my body.

Head		RIGHT Shoulder		LEFT Shoulder	
Neck muscles		Upper Arm		Upper Arm	
Swallowing		Lower Arm		Lower Arm	
Eating		Wrist		Wrist	
Chest muscles		Hands / fingers		Hands / fingers	
Breathing		Hip		Hip	
Trunk muscles		Upper Leg		Upper Leg	
Bladder issues		Knee		Knee	
Bowel issues		Lower Leg		Lower Leg	
		Ankle		Ankle	
		Foot		Foot	

	unaided	Use aid - state which	Need assistance
I can stand			
I can transfer			
Moving up to 2 yards			
Moving 2 to 10 yards			
Moving 10 to 25 yards			
Moving 25 yards plus			
In and out of chair			
In and out of bed			
PERSONAL CARE			
I can use the toilet			
I can wash face, hands			
I can clean teeth, do hair			
I can shave			
I can bathe or shower			
Dress and Undress			

COMMUNICATION

	No Difficulty	Some Difficulty	Considerable difficulty
Intellect, recalling facts			
Need family support.			
Hearing			
Hearing Aids detail			
Use Sign Language			
Sight			
Sight Aids detail			
Use cane/have dog			
Speaking			
Speech Aids detail			
How you can help me when talking to me or when I am trying to tell you something.			

BEFORE I AM DISCHARGED FROM HOSPITAL YOU NEED TO PLAN

MORE INFORMATION

Overall UK PatientPlus article for health professionals on Post Polio Syndrome.
www.patient.co.uk/doctor/Post-Polio-Syndrome.htm

Lincolnshire Post Polio Library 100+ full text medical articles. [A PSN service]
[Linked from www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

European Federation of Neurological Societies - Post Polio Syndrome
www.efns.org/fileadmin/user_upload/guidline_papers/EFNS_guideline_2011_Post-polio_syndrome.pdf

PolioToday.org - The Salk Institute
 Videos of 3 Breathing & Sleep Symposia 2009/2010/2011, Expert Opinions & more
www.poliotoday.org

Polio Survivors Network - P.O. Box 954, Lincoln, LN5 5ER - Tel:- 01522 888601
 Email:- info@poliosurvivorsnetwork.org.uk
 Website:- www.poliosurvivorsnetwork.org.uk

This leaflet is based on one developed by the Neurological Alliance* with the help of its member charities. Particular thanks are due to the Motor Neurone Disease Association, the Sarah Matheson Trust, The Tuberous Sclerosis Association and the Walton Centre. Polio Survivors Network are members of the Neurological Alliance and have adapted this form for the benefit of polio survivors and their specialised needs.

*Neurological Alliance, Dana Centre, 165 Queen's Gate, London SW7 5HE
www.neural.org.uk admin@neural.org.uk 020 7584 6457