



POST POLIO MATTERS

What You Need to Know About My Condition

Date: _____

I have **Post Polio Syndrome**, the symptoms of which vary from person to person. This document contains key information about how Post Polio Syndrome affects me and will help you to understand my needs.

Please be aware that I also have _____

Full Name _____ **I like to be called** _____

Address _____

Telephone _____ **Mobile** _____

Next of kin name _____

Next of kin telephone _____ **Mobile** _____

In case of emergency contact _____

GP name _____

GP surgery telephone _____

I AM ALLERGIC TO _____

BLOOD GROUP _____

CURRENT TEST RESULTS (if known) _____

SPECIAL NOTES _____

POST POLIO SYNDROME (PPS) is the accepted name for the constellation of symptoms including NEW weakness, muscle fatigue and/or "central" fatigue, pain, breathing and/or swallowing difficulties, a variety of sleep disorders, fasciculations, gastrointestinal problems. These symptoms can occur both in previously affected muscles and those thought not to have been affected at onset. There are no definitive tests. Diagnosis is by exclusion of other conditions. **N.B. Care must be taken when prescribing any drug or anaesthetic that has sedative or muscle relaxant properties.**

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Lincolnshire Post-Polio Network Registered Charity No 1064177 (known as Polio Survivors Network)

PO Box 954 Lincoln LN5 5ER UK 07480 110334 info@poliosurvivorsnetwork.org.uk

Ability and Mobility

My ability is (delete as appropriate) *somewhat/not* affected by my condition.

My mobility (delete as appropriate) *is/is not* affected by my condition.

I was previously paralysed in my _____

I now have paralysis which affects my _____

I have muscle weakness which affects my _____

I wear (tick all that apply) orthopaedic shoes Ankle Foot Orthosis (AFO) Knee Ankle Foot Orthosis (KAFO)

I use a (tick all that apply) walking stick crutches walker manual wheelchair electric wheelchair mobility scooter

I can walk unaided at home holding onto furniture outside with an aid only ever with an aid

I may have my own methods or equipment at home so I may need help if I am not at home.

- I (delete as appropriate) *do not need help/have my method/require help* getting in and out of bed.
- I (delete as appropriate) *do not need help/have my method/require help* to turn over whilst in bed.
- I (delete as appropriate) *do not need help/have my method/require help* getting in and out of chairs.
- I (delete as appropriate) *do not need help/have my method/require help* getting to and from the bathroom.

Further information on mobility or the methods I use _____

Communication

My condition (delete as appropriate) *does/does not* affect my intellect.

I have (delete as appropriate) *no/some/considerable* difficulty hearing.

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I have (delete as appropriate) *no/some/considerable difficulty* understanding.

I have (delete as appropriate) *no/some/considerable difficulty* speaking when fatigued.

I have (delete as appropriate) *no/some/considerable difficulty* keeping track of conversations when fatigued.

Further information on my communication needs _____

Personal Care

I can take care of (delete as appropriate) *all/some/none* of my personal needs.

I (delete as appropriate) *need/do not need* help to take a bath or shower.

I (delete as appropriate) *need/do not need* help to dress or undress.

Further information on my needs with personal care _____

Eating and Drinking

I eat and drink (delete as appropriate) *independently/with aids/only with someone helping me*.

Further information on my needs when eating or drinking _____

I have these dietary needs/food allergies _____

Respiratory

I have (delete as appropriate) *no respiratory needs/a tracheotomy/to use ventilation equipment*.

Further information on my respiratory needs including any settings to note _____

My respiratory consultant is _____

Medication

| Name of medication | Dosage | Frequency/time of day taken |
|--------------------|--------|-----------------------------|
| | | |
| | | |
| | | |
| | | |
| | | |

As a polio survivor with post-polio syndrome care MUST BE TAKEN with anaesthetics and any medication with sedative or muscle relaxant side effects. Due to weakened muscles I need far lower doses.

Equipment that is essential during my stay: _____

Useful contacts (e.g. neurologist, specialist nurse, social worker)

| Name | Role | Telephone |
|------|------|-----------|
| | | |
| | | |
| | | |
| | | |

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Other important information (e.g. symptoms which may arise which require urgent attention, and what you should do in these circumstances)

As a polio survivor with post polio syndrome care MUST BE TAKEN with anaesthetics and any medication with sedative or muscle relaxant side effects. Due to weakened muscles I need far lower doses.

**Thank you for helping to make my stay
as comfortable as possible.**

The Neurological Alliance, London, Registered charity 1039034, www.neural.org.uk