

# PARKINSON'S PASSPORT

## ESSENTIAL MEDICAL INFORMATION



parkinson's  
europe 

## Please provide people with Parkinson's a safe passage when travelling

People with Parkinson's represent 1% of the world's population.

Parkinson's is a neurodegenerative condition that affects a person's ability to speak, coordinate and initiate movements. Our ability to understand you is not affected, but we may need a little longer to respond.

**This 'passport' provides information on the help you can give us when travelling outside the home** – at transport hubs such as airports, as well as hotels and public spaces.

Parkinson's Europe is a not for profit organisation campaigning to help people living with Parkinson's to have access to the highest standards of treatment, support and care.

[parkinsonseurope.org](http://parkinsonseurope.org)

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## Details of this 'passport' holder

Name: \_\_\_\_\_

**Please note the specific Parkinson's related issues below that may affect my journey.**

Please tick relevant boxes:

- My speech and ability to communicate**
- My coordination abilities**
- My mobility**
- I have a Deep Brain Stimulation (DBS) implant** that requires me to keep away from electromagnetic devices. This device is located in my chest or abdomen, with cables that travel up my neck and into the scalp.
- I have an infusion pump to deliver medicine and will be carrying related devices.** The pump is usually carried in a dedicated pouch or attached near my waist. It can be used safely on aeroplanes and will not interfere with the aircraft's instruments, including during take-off and landing.

## Accessibility and support

- We may need more time than usual at check-ins, or receptions. Please allow us extra time.
- Be patient when we are walking, talking and eating – multitasking is not easy.
- Picking things up may be difficult.
- Be aware that Parkinson's affects facial muscles, and smiling can be difficult. We may not be able to respond as you would like us to.
- Do not push or pull us if we find it difficult to move.
- It's easier if we are sitting down when given a drink.
- If you see any of us experiencing difficulties, please don't walk away – ask if we need help.

## Items we may need to carry

- Medication required during a flight or while travelling (pills, tablets or patches).
- Medically necessary devices such as infusion pumps and injectable pens.
- Pre-filled syringes or ampoules.
- Cannulas (short, thin tubes) inserted into the body.

## In a medical emergency

### Do NOT give these medications to people with Parkinson's.

- **Anti-sickness medicines** – such as Metoclopramide, Cyclizine, Prochlorperazine. If an antiemetic is necessary, domperidone should be used.
- **Antipsychotics** – haloperidol should not be used and Quetiapine is the drug of choice. Other atypical antipsychotics (e.g. Risperidone, Olanzapine) may be considered if Quetiapine is not tolerated.
- **Painkillers** – Pethidine and other opioids should not be used at the same time as selegiline and rasagiline.

### During surgery

- If a local anaesthesia is required, adrenalin should be administered with caution.
- **Duodopa pump infusion** treatment may be continued for as long as it's permitted to take fluids and medicines by mouth. It may be switched off during surgery.
- **Apomorphine pump** infusion treatment may be continued before, during and after surgery.

## Avoiding airport and other security and screening/scanning devices

A Deep Brain Stimulation implant can be affected by electrical or magnetic machinery (see list below). I therefore must avoid interaction with electromagnetic systems that may cause me discomfort and affect how the implant operates, and even turn it off by accident.

I should therefore bypass such devices, or pass as far from the device as possible.

- If a body search is required, this needs to be a manual one by security officers.
- A hand-held security wand may be used but this must NOT be placed over my neurostimulator, which is placed in my chest or abdomen.

## Treatment and surgery cont.

- If I have a Deep Brain Stimulation implant, my DBS may be switched off during surgery and only bipolar diathermy treatment may be used.

### I should not have the following treatments or therapies:

- Magnetic Resonance Imaging (MRI) unless specifically approved by my system provider
- Any therapy directed at the site of my implantation, including ultrasound, electrolysis, radiotherapy, electrosurgery and electro-magnetisation
- Radiography that compresses the implantation area(s) (other radiographies are permitted)
- Ultrasound for dental cleaning
- Cardiac defibrillation
- Any medical treatment in which an electrical current is passed through my body from an external source must be used with caution.

## Systems that affect the implant are:

- Airport body scanners.
- Devices such as theft detectors (i.e. those used at entrances and exits of shops, libraries and other public buildings).
- Electrical equipment such as welding machinery.
- Microwave transmitters.
- Power amplifiers.
- Household appliances that contain magnets such as refrigerators, stereo speakers and power tools.

## Emergency contacts

1. Name: \_\_\_\_\_

Relationship to me: \_\_\_\_\_

Telephone (including country code): \_\_\_\_\_  
\_\_\_\_\_

2. Name: \_\_\_\_\_

Relationship to me: \_\_\_\_\_

Telephone (including country code): \_\_\_\_\_  
\_\_\_\_\_

Doctor: \_\_\_\_\_

Practice address: \_\_\_\_\_  
\_\_\_\_\_

Telephone (inc country code): \_\_\_\_\_  
\_\_\_\_\_

Doctor's signature  
or stamp:



Date:     /     /

## Details of devices and implants I may carry or wear

### Deep Brain Stimulation implant information

I had a neurostimulator implant on:     /     /

Device serial number: \_\_\_\_\_

Name of hospital and country: \_\_\_\_\_

### Apomorphine (apomorphine hydrochloride)

administered subcutaneously using an injectable pen OR via a catheter using a small, portable infusion pump system.

My apomorphine dose is as follows:

Timing: \_\_\_\_\_

Injectable pen dosage:     [             ] mg

Infusion dosage:             [             ] mg/hour

### Duodopa intestinal gel and infusion pump

– this medication is administered as a continuous intestinal infusion by a pump.

I received my levodopa/carbidopa pump on:     /     /

Pump serial number: \_\_\_\_\_

- Cassettes should be refrigerated or kept cool (2°C to 8°C) at all times and protected from sunlight.
- Cassettes can be used for up to 16 hours once they reach room temperature.
- My infusion pump should only be handled by someone who is familiar with the device. I may experience difficulties handling my pump and tube connections, which could lead to complications. It may be necessary for a caregiver to assist me.

### Produodopa pump (Foslevodopa/Foscarbidopa)

– this medication is delivered continuously and subcutaneously through a syringe, which is connected to a small pump (usually in its case whilst travelling).

I received my Foslevodopa/Foscarbidopa pump on:     /     /

Pump serial number: \_\_\_\_\_

- Vials should be refrigerated or kept cool (2°C to 8°C) at all times and protected from sunlight.
- Vials can be stored at room temperature (up to a maximum of 30°C) for a single period of up to 28 days. They cannot be returned to the refrigerator once stored at room temperature.
- Vials should not be opened unless for use, as the product is to be used within 24 hours once it is transferred from the vial to the syringe.
- My infusion pump should only be handled by someone who is familiar with the device. I may experience difficulties handling my pump and tube connections, which could lead to complications. It may be necessary for a caregiver to assist me.

## Lecigon intestinal gel and infusion pump

This medication is administered as a continuous intestinal infusion via a portable infusion pump.

I received my Lecigon pump on:    /    /

**Pump serial number:** \_\_\_\_\_

- Cartridges should be refrigerated or kept cool (2°C to 8°C) at all times and protected from sunlight. They can be used for up to 24 hours once out of the refrigerator.
- The pump does not emit radio waves and cannot therefore interfere with on-board electronic instrumentation. There are no contraindications to passing through airport metal detectors with the pump attached. It is advised to NOT pass the pump through an X-ray scanner.
- The pump, PEG or jejunal tube should not be removed without an alternative dopaminergic plan unless clinically necessary for life-saving treatment. If the PEG or tube/catheter must be removed, it should be removed in a controlled setting, date/time/reason should be documented and a neurologist should be informed.

## I am on a clinical trial

I am participating in the following clinical trial:

Protocol ID: \_\_\_\_\_

My patient number is: \_\_\_\_\_

I am being treated with: \_\_\_\_\_

In case of emergency or if further information is required, please contact:

Hospital: \_\_\_\_\_

Study doctor: \_\_\_\_\_

Phone number: \_\_\_\_\_

Study nurse: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Help with administering medication – if required

There may be times when help is required to administer my medication.

It is very important that I receive the correct dose of my medications at the correct times. The table below lists these details. These are:

Name of medication: \_\_\_\_\_

\_\_\_\_\_

Dosage: \_\_\_\_\_

Timing: \_\_\_\_\_

Name of medication: \_\_\_\_\_

\_\_\_\_\_

Dosage: \_\_\_\_\_

Timing: \_\_\_\_\_

## Medication continued

Name of medication: \_\_\_\_\_

\_\_\_\_\_

Dosage: \_\_\_\_\_

Timing: \_\_\_\_\_

Name of medication: \_\_\_\_\_

\_\_\_\_\_

Dosage: \_\_\_\_\_

Timing: \_\_\_\_\_

Name of medication: \_\_\_\_\_

\_\_\_\_\_

Dosage: \_\_\_\_\_

Timing: \_\_\_\_\_