

HOW TO MANAGE MY SYMPTOMS & MEDICINES

PARKINSON'S PASSPORT

On time, **every** time with
Parkinson's medicines



Australian
College of
Nursing

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Australian
College of
Nursing



Parkinson's
Australia



NPS
MEDICINEWISE

How to use your Parkinson's Passport

- ▶ Use the *Parkinson's Passport* to record details about your Parkinson's symptoms and medicines. Keep it up to date.
- ▶ Show it to all your health professionals (e.g. GP, pharmacists, specialists and nurses).
- ▶ Review the booklet regularly with your GP, and at least once a year, or as required, with your neurologist.
- ▶ Keep copies of the *Checklist for managing my Parkinson's symptoms* in the back of your passport to give to your nurse if you go into hospital or an aged-care facility. This will help you to get the care you need.
- ▶ Show your *I have Parkinson's* card to the hospital emergency department triage nurse, so they know you need your Parkinson's medicines on time.

Need more copies?

The *Parkinson's Passport*, *Medicines List* for people with Parkinson's and *Checklist for managing my Parkinson's symptoms* are available in editable PDF format for download and print from **nps.org.au/parkinsons-passport** and **parkinsons.org.au**.

Copies can be ordered from Parkinson's Australia by phoning **1800 644 189**.

We want to hear from you

Please send your feedback about the *Parkinson's Passport* to **info@nps.org.au**.

Contact details

My name

.....

Phone

.....

Neurologist

.....

Phone

.....

GP

.....

Phone

.....

Parkinson's nurse

.....

Phone

.....

Next of kin

.....

Phone

.....

Symptom management checklist

Parkinson's disease causes difficulties in moving, and other motor and non-motor symptoms, due to low levels of the brain chemical dopamine.

Symptoms may include slowness, tremor, depression, anxiety, sleep problems and pain. Symptoms vary from person to person, fluctuate throughout the day and change over time.

I have ticked the symptoms that apply to me

Help me have my medicines on time

Yes

The timing of my medicines is very important for managing my Parkinson's symptoms. An hour late may mean I am extremely slow, sitting rigid and in pain for that hour. This could make my symptoms harder to manage. Please see my *Medicines List* for my individualised dose and timing instructions.

I can manage my own medicines

Yes

Please let me manage and take my Parkinson's medicines myself. This may make it easier for me to take them on time.

Please be patient and listen carefully

Yes

I need time to speak and my voice may be soft. My face may not express my emotions: even if I don't smile, I do appreciate your help.

Help me get moving if I freeze

Yes

Humming a marching tune, counting or helping me imagine I'm going up stairs can get me moving again. You can also help me get out of bed by giving simple step-by-step instructions. Please do not rush me — it could make me anxious and actually slow me down.

Use my 'on' times for activities

Yes

In my 'on' times, the Parkinson's medicines are working and I am best able to move. In my 'off' times, symptoms such as tremor, slowness, stiffness, speech, balance, fatigue, anxiety and depression are at their worst.

Timing activities, such as showering and meals, during 'on' times will make things easier and I will need less help.

Help with my swallowing difficulties

Yes

I may eat my meals slowly if I have trouble swallowing. Please don't assume I have finished a meal if I have paused, and I may need my meal reheated at times.

Refer me to a speech pathologist if I show signs of swallowing difficulties, such as coughing or choking on food or drinks. If I can't swallow, I may need my medicines reviewed so I can take them through a nasogastric tube or use patches.

Prevent falls

Yes

Sometimes I lose my balance, and I could fall. Referring me to a physiotherapist can help for both balance and walking problems. I may be dizzy if I get up too quickly, which can also lead to falls. Checking my blood pressure when lying and standing, and giving fluids (if appropriate) may help.

Help me to turn in bed**Yes**

I have trouble turning in bed, even though I may be mobile during the day. Please look for pressure areas and help me in and out of bed for toileting. A bed pole and referring me to a physiotherapist may also help.

Please manage my pain**Yes**

Analgesics may not help if I have pain from muscle rigidity or dystonia. If I get pain in an 'off' time or because my medicines were late, Parkinson's medicines will often relieve it. If I get pain even when I have my Parkinson's medicines on time, I may need them reviewed. Referring me to a physiotherapist may also help.

I also have the following:

Tremor

Dyskinesias (involuntary movements)

Constipation

Sleep disturbances

Memory problems

Slowness in thinking

Concentration problems

Impulse control disorders

Anxiety

Depression

Hallucinations or psychosis

**One minute I can
be walking around
normally and the
next I can't move —
it can be confusing
for hospital staff.**

John, man with Parkinson's

Medicines that must be avoided

This is only a small selection — many other medicines can also worsen Parkinson's symptoms or interact with Parkinson's medicines. **Check the contraindications on the prescribing information carefully before starting any new medicine.**

Antinausea medicines to avoid

- ▶ metoclopramide (e.g. Maxolon)
- ▶ prochlorperazine (e.g. Stemetil)

The above medicines are a common cause of serious adverse effects in people with Parkinson's. Domperidone (Motilium) is usually recommended if an oral medicine is appropriate, and ondansetron (e.g. Zofran) IV if an oral medicine is not appropriate (ondansetron is contraindicated in patients on apomorphine).

Antipsychotic medicines to avoid

- ▶ chlorpromazine (e.g. Largactil)
- ▶ haloperidol (e.g. Serenace)
- ▶ olanzapine (e.g. Zyprexa)
- ▶ risperidone (e.g. Risperdal)

Some antidepressants

Check the contraindications on the prescribing information carefully before starting any new antidepressant medicine.

Some blood pressure lowering medicines

Check the contraindications on the prescribing information carefully before starting any new blood pressure medicine.

Nurses prescribe
Maxolon* and
Stemetil** all the
time — but I had
no idea they
were a problem
in Parkinson's.

Karen, Emergency Department nurse

*metoclopramide

**prochlorperazine

Parkinson's disease medicines

Medicines for Parkinson's disease provide symptomatic relief. No medicine has yet been shown to slow progression of the disease.

Medicine regimens are individual

Doses, preparations, frequency and timing need to be individualised according to symptoms, and to minimise side effects.

Parkinson's medicines come in various doses and preparations (e.g. controlled release, immediate release, subcutaneous infusion).

Give Parkinson's medicines on time

Even 15 minutes late can make symptoms significantly worse.

Let the person with Parkinson's self-medicate if possible

This may give the best chance of medicines being taken on time (providing there is no significant cognitive impairment).

Don't stop or reduce the dose without consulting a neurologist or geriatrician

Abrupt withdrawal or reduction in dose of Parkinson's medicines may cause serious symptoms, such as worsening tremor, rigidity and bradykinesia. Abrupt withdrawal may also trigger neuroleptic malignant syndrome, resulting in acute worsening of Parkinson's symptoms, high fever, reduced level of consciousness and autonomic dysfunction.

Avoid interactions with meals

Food, particularly protein, can interfere with absorption of levodopa. It is best if levodopa medicines are given consistently 30 to 60 minutes before meals.

Chart Parkinson's medicines before surgery

Make sure Parkinson's medicines are charted before surgery, or contact the anaesthetist for further instructions.

Review medicines if pain persists

Many people with Parkinson's have pain, either from muscle rigidity or dystonias (sustained cramps). Pain due to dystonia is not usually helped by analgesics, but is helped by Parkinson's medicines. If dystonia persists, slow-release levodopa or agonists in combination may be needed, especially during 'off' periods such as during the night.

Manage nausea

Some people may need to take Parkinson's medicines with juice or jelly to reduce nausea. If nausea persists, domperidone (Motilium) is usually recommended if an oral medicine is appropriate, and ondansetron (e.g. Zofran) IV if an oral medicine is not appropriate (ondansetron is contraindicated in patients on apomorphine).

Avoid metoclopramide (e.g. Maxolon) and prochlorperazine (e.g. Stemetil) as they can worsen Parkinson's symptoms.

Treatments for advanced disease

People whose Parkinson's symptoms are not well controlled may require one of the following advanced treatments:

- ▶ levodopa/carbidopa (Duodopa) intestinal gel — medicine is directly infused into the duodenum or upper jejunum by an electronic pump
- ▶ apomorphine (Apomine) — administered by injection or infusion subcutaneously by an electronic pump
- ▶ deep brain stimulation — a surgically implanted device electrically stimulates the brain.

It's not uncommon for someone with Parkinson's to go into hospital 'for a few days' and end up having to stay for 3 weeks because their medicines were mucked around.

Graham, man with Parkinson's

Parkinson's disease glossary

Akinesia

Inability to start movement.

Bradykinesia

Slowness of movement.

Dyskinesias

Involuntary movement (e.g. twisting), which can affect any part of the body. This often occurs if Parkinson's medicine levels are high.

Dystonias

Painful fixed cramping postures, usually of the limbs. They are most common when Parkinson's medicine levels are low (e.g. night or early morning).

Impulse control disorder (ICD)

Involves changes in behaviour such as problem gambling, overspending, overeating and hypersexuality (preoccupation with sexual feelings). It can be provoked by some Parkinson's medicines.

'On' and 'off' states

Fluctuations in symptoms that can occur after a few years of treatment, when the effects of Parkinson's medicines wear off between doses. In the 'on' state, the medicines are working and movement is easier. Mood can also be best in 'on' times. In the 'off' state, symptoms such as tremor, slowness, stiffness, speech, balance, anxiety or depression are at their worst.

Parkinson's disease

A progressive brain disorder that causes problems controlling body movement. Dopamine is a chemical in the brain that helps control smooth movement. In Parkinson's, not enough dopamine is produced, causing symptoms such as slowness, tremor and muscle rigidity.

Punding

Prolonged, repetitive behaviour with little useful purpose, that impacts on other areas of lifestyle. For example, repeatedly dismantling equipment, constant internet use and arranging and rearranging objects. It is often associated with high dopamine intake.

Tremor

A rhythmical to-and-fro movement, often affecting the fingers, hands or legs, and sometimes the jaw, chin or head. Tremor usually occurs when Parkinson's medicine levels are low. It may be increased by emotional strain or excitement.

For more information

The information in this booklet is a guide only and is not comprehensive.

Health professionals

Health professionals can find further information on the Parkinson's Australia website, at **www.parkinsons.org.au**, or from your pharmacist or the Drug Information Service in your area.

An online learning module about Parkinson's disease for health professionals is available at **www.rrmeo.com/parkaus**.

People with Parkinson's

Call Parkinson's Australia on **1800 644 189** for more information about Parkinson's disease, or visit **www.parkinsons.org.au**.

Consumer medicine information (CMI) leaflets for individual medicines are available on the NPS MedicineWise website, at **www.nps.org.au/medicines**, and from pharmacies.

I always carry
around a couple
of days' supply of
my medicines,
just in case.

Peter, man with Parkinson's

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Contributors in the development phase included:

- ▶ Marilia Pereira,
Shoalhaven Neurological Nurse Educator,
Nowra Community Health Centre, NSW
- ▶ Professor Lynn Chenoweth,
Professor of Aged and Extended Care Nursing,
UTS, Sydney
- ▶ Dr Paul Clouston,
Neurologist, Specialist Neurology Services,
Westmead, NSW
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Parkinson's Australia: **www.parkinsons.org.au**

Freecall **1800 644 189**

NPS MedicineWise: **www.nps.org.au**

Call **NPS Medicines Line** on (1300 MEDICINE) 1300 633 424, for medicines information over the phone, from anywhere in Australia for the cost of a local phone call (calls from mobiles may cost more), Monday to Friday, 9am to 5pm AEST.

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Level 7/418A Elizabeth St
Surry Hills NSW 2010
PO Box 1147
Strawberry Hills NSW 2012

 02 8217 8700
 02 9211 7578
 info@nps.org.au
 www.nps.org.au



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