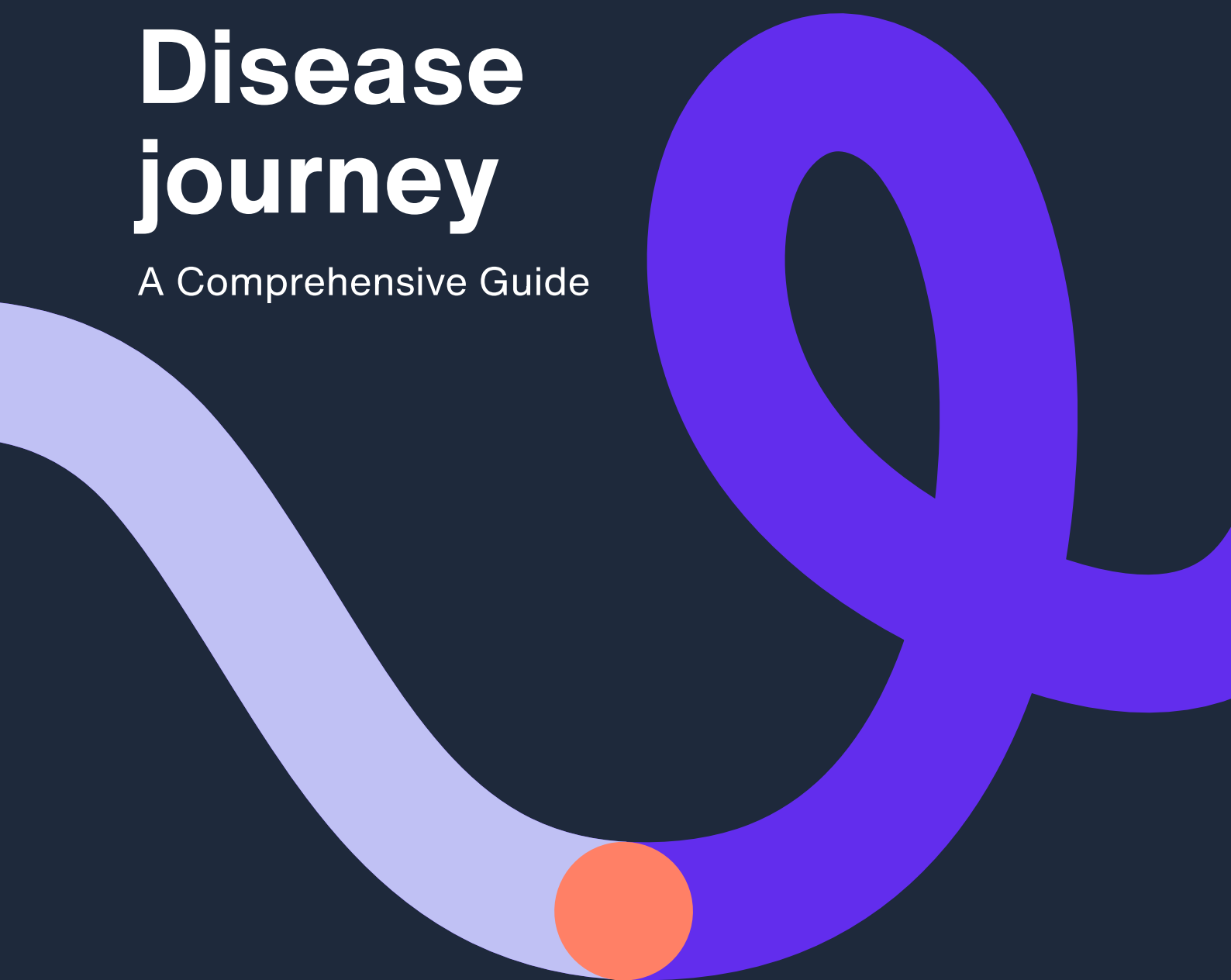




Navigating your Advanced Parkinson's Disease journey

A Comprehensive Guide



Navigating your Advanced Parkinson's Journey

This resource aims to assist you in understanding and recognising the signs of progressing Parkinson's disease to help you and your family prepare and better manage when change happens.

As your experience of Parkinson's changes, different management strategies and options may need to be considered to help you achieve and maintain quality of life.

This provides a summary of key information and considerations relevant to advancing Parkinson's.

Whether you're living with Parkinson's, or you know someone who is, there are a number of resources and support services available.

Parkinson's Australia

www.parkinsons.org.au

or free call 1800 644 189

State-based resources and support groups

NSW: Parkinson's New South Wales - www.parkinsonsnsw.org.au

WA: Parkinson's Western Australia - www.parkinsonswa.org.au

SA, NT & ACT: The Hospital Research Foundation Group

www.fightingparkinsons.org.au

QLD: Parkinson's Queensland - www.parkinsonsqld.org.au

VIC: Fight Parkinson's - www.fightparkinsons.org.au



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Parkinson's disease progression

Parkinson's disease (Parkinson's) is a progressive, neurological disease. Each person with Parkinson's will experience different motor and non-motor symptoms that can impact them such as:

- Tremors
- Stiffness
- Slowness
- Memory issues
- Anxiety
- Pain

Parkinson's disease progresses differently for each person. Some experience mild symptoms for years, while others find their symptoms become bothersome more quickly.

Healthcare professionals around the world broadly categorise Parkinson's progression into five stages. From stage four symptoms become more severe and limiting and most people require help with daily activities. This is sometimes referred to as 'advanced Parkinson's disease.'

Parkinson's disease stages

1

Stage One

Symptoms may be so mild that it can be hard to diagnose the condition, but typically include mild shaking and changes in walking, facial expressions, and posture, usually on one side of the body.

2

Stage Two

Symptoms begin to affect both sides of the body with a worsening tremor, stiffness, and changes in speech, such as a softer voice or slurring.

3

Stage Three

In addition to symptoms experienced in stage two, there is also a loss of balance and slowness of movements. While people can remain fully independent, symptoms begin to slightly hinder activities such as dressing and eating, with an increased incidence of falling.

4

Stage Four

As symptoms become more severe and limiting, most people require help with daily activities at this stage and may need to reconsider living arrangements.

5

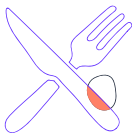
Stage Five

This is the most advanced and debilitating stage where stiffness in the legs makes it very difficult or impossible to walk, and a wheelchair may be required. Constant care may also be needed, and non-motor symptoms such as depression, anxiety, hallucinations and delusions may be experienced more frequently.

Changing or worsening symptoms over time is a characteristic of Parkinson's disease, not a reflection of your past management or treatment success.

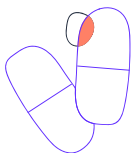
Signs of progressing Parkinson's to look out for

Common signs that may indicate your Parkinson's is changing include:



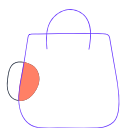
Symptoms affect daily life

Symptoms are increasingly impacting your quality of life – affecting how you move, eat, sleep, think and/or feel.



Unpredictable response to medication

Symptoms become less well-controlled due to a reduced or unpredictable response to medication as disease progresses. For example, your medication may wear off and symptoms return before your next dose.



Reduced independence

You are relying more on others to complete everyday tasks, such as cooking, cleaning, shopping, dressing, and travelling.



Motor and non-motor symptoms of progressing Parkinson's

Non-motor symptoms

Non-motor symptoms may get worse or more unpredictable, including:

- Anxiety and depression
- Apathy
- Constipation
- Dementia and cognitive impairment
- Fatigue / daytime sleepiness
- Sleep problems

Motor symptoms

Movement issues may become more noticeable including:

- Dyskinesia – Involuntary movements in your arms and legs that can interfere with your day-to-day activities. This may also be a side-effect of some medications.
- Bradykinesia: Slowness of movement.
- Tremors
- Stiffness
- Muscle rigidity

These symptoms may appear more when experiencing:

- 'Off time' – Periods between medication doses when you experience symptoms.
- Wearing off – Parkinson's symptoms may return before your next dose of medication.

If you have been experiencing symptom changes, take a look at the checklist at the back of this booklet. Fill this in and take it with you to your next appointment with your healthcare professional.



What to do if you notice your Parkinson's is progressing

If you notice any new or worsening Parkinson's disease symptoms, it is important to let your healthcare team know in case your management plan needs changing to better help you cope.

As your condition evolves, you may also need to seek support from different healthcare professionals. If your GP is your main point of contact, it may be worth seeking a referral to see a neurologist. If you are currently seeing a neurologist, they may refer you to a specialist neurologist, such as a movement disorder neurologist.

They can help to further assess your condition if it's advancing and recommend appropriate treatment options should your condition require additional support.

How to prepare for your Parkinson's appointment

To help you make the most out of your appointment with your healthcare team here are some things to consider.

Ahead of your appointment, prepare by doing the following:



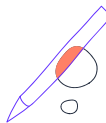
List symptoms

Note any new symptoms or changes in existing symptoms.



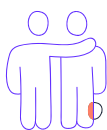
Track medications

Prepare an updated list of all medications, including dosages and any side effects experienced.



Write down any concerns you have

Issues could relate to your condition, treatment, lifestyle impacts, mental health, future planning.



Consider bringing a friend or family member

Taking someone along to your appointment can assist in remembering details of the discussion. This person could also provide a different perspective on some of the symptoms that you may be experiencing and help relay this to your Parkinson's nurse or neurologist.

There are several topics that your healthcare team will be particularly interested in hearing updates from you on.

Take a look at the conversation guide at the back of this booklet. Spend time considering the questions listed to help you decide what information you share with your neurologist.

Managing Parkinson's progression

Medications and treatments



The two main types of treatment for Parkinson's are oral medications and non-oral therapies (also known as device-assisted therapies).

Oral medications can help improve the main symptoms of Parkinson's disease, such as tremors and movement difficulties.

The four types commonly used are:

- Dopamine precursor medications
- Dopamine agonists
- Monoamine oxidase-B (MAO-B) inhibitors
- Catechol-O-methyltransferase (COMT) inhibitors.

Over time, as Parkinson's symptoms progress, it can change the way your body digests and absorbs food and medicine.

Your response to oral medication may fluctuate and changes and additions may need to be made to your medication regimen. For example, you may find that you have to take a combination of tablets to treat your symptoms.

When your symptoms become difficult to control with oral medication despite changes to the dosing frequency and number of tablets you are taking, your neurologist may consider device-assisted therapies.

Your healthcare professional will advise if device-assisted therapies are suitable for you:



Your response to oral treatment is inconsistent



You are experiencing motor fluctuations causing disability or impacting quality of life e.g. severe tremors



You need to take oral tablets more than four times per day to try and stay on top of symptoms.

There are three types of device-assisted therapies:

1 Under the skin pump therapy

A continuous infusion that delivers medicine into the body under the skin (subcutaneously) with the help of a pump.

2 Intestinal gel pump therapy

A continuous infusion that delivers medicine directly into the gut through a surgically inserted tube with the help of a pump.

3 Neurosurgery (brain surgery)

Also known as deep brain stimulation that involves having very fine wires inserted into the brain to conduct electrical impulses to the affected nerve cells.

If speaking to your neurologist about any new treatments, ask questions about the benefits, potential risks, costs, day-to-day management, carer impacts, alternatives, and what might happen if you do nothing.

Individual responses to treatments always vary. The information here is intended only as a guide, and you should always discuss your options with your healthcare team and family.

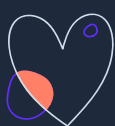
Holistic management



Keep healthy including staying physically and mentally active and focusing on your general health.



Exercise is important to maintain mobility, coordination and quality of life. Speak with your doctor before starting any new physical activity.



Make changes with loved ones by opening up to them about what you support you need.



Be open about your Parkinson's so those around you understand your symptoms and experiences.



Make lifestyle changes such as using aids, removing obstacles in the house or avoiding clothes with buttons to make dressing easier.



Stay connected with friends and family and lean on them for support.

Conversation Guide

By sharing information with your neurologist about your experiences, goals and what's important to you, they will be better equipped to guide you to a treatment plan that fits you and your needs.

How manageable do you feel your Parkinson's symptoms are right now?

Unmanageable **5** ————— **4** ————— **3** ————— **2** ————— **1** Manageable

Thinking about the last six months, have your Parkinson's symptoms changed?

Worsened **5** ————— **4** ————— **3** ————— **2** ————— **1** No Change

What impact are your Parkinson's symptoms having on your quality of life?

Severe Impact **5** ————— **4** ————— **3** ————— **2** ————— **1** No Impact

How are your changing Parkinson's symptoms affecting your life?

- | | |
|--|---|
| <input type="checkbox"/> Relying on others for more support | <input type="checkbox"/> Losing confidence |
| <input type="checkbox"/> Reduced participation in activities | <input type="checkbox"/> Financial strain e.g. unable to work |
| <input type="checkbox"/> Leaving the house less | <input type="checkbox"/> Other _____ |

How many hours of the day do you have dyskinesia (involuntary limb movements)?

How many hours a day are you 'off'?

If you are taking oral medication, how long does each dose last?

Have you experienced any falls? If so, how many falls have you had in the last month?

What things are important to you in the long-term management of your Parkinson's?

- ☐ Physical health e.g. maintain or improve mobility and balance and reduce fall risk
- ☐ Emotional and mental wellbeing e.g. reduce anxiety and depression
- ☐ Daily living activities e.g. maintain independence in personal care tasks such as dressing, cooking, and shopping for as long as possible
- ☐ Social engagement e.g. stay connected with family, friends, and community
- ☐ Participate in social activities
- ☐ Exercises, nutrition and lifestyle e.g. being able to follow a balanced diet and maintain exercise
- ☐ Education e.g. staying informed about the disease, treatment options, and advancements in care
- ☐ Other _____

Assessing Changes

Symptoms Checklist

Recognise changes in symptoms by self-tracking your Parkinson's disease journey.

If you have ticked any of the boxes, **make an appointment to see your neurologist/movement disorder specialist or consider asking for a referral to see one of these specialists if you're not already.**

Use the following checklist to help you identify changing symptoms. (Tick all that apply)

- ☐ Are your tremors getting more severe or affecting both sides of your body?
- ☐ Are you aware of more involuntary movements of your face, arms, legs, or torso (known as dyskinesia)?
- ☐ Are you experiencing unpredictable movement changes that are causing you distress?
- ☐ Do you sometimes feel "stuck in your tracks" or that your feet are glued to the floor?
- ☐ Are you having problems swallowing such as coughing during or right after eating, feeling like food is stuck or not going down properly, or drooling more frequently?
- ☐ Is your medication working for shorter periods of time or are your symptoms returning more easily?
- ☐ Does your medication dose sometimes not work, or randomly stop working after you've taken it?
- ☐ Are you feeling more anxious or depressed lately?
- ☐ Are you unusually forgetful or easily confused?
- ☐ Has your sleep pattern changed – do you wake up often in the middle of the night or sleep more during the day than you do at night?
- ☐ Do you find yourself relying on the help of others more for everyday tasks such as writing, walking, bathing, dressing, eating, toileting, etc?
- ☐ Are you experiencing bladder/sexual dysfunction?

To learn more, visit:
www.parkinsonsprogression.com.au

For further information please talk to your healthcare professional.

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