

Fight Parkinson's

When your Patient has
Parkinson's

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When your Patient has Parkinson's

Parkinson's Care Management Strategies and Key Considerations for Hospital / Respite Staff and Carers.

Symptoms and clinical updates

Parkinson's is a progressive neurological condition which has no known cause and no cure. It occurs when dopamine-producing cells in the brain and nervous system degenerate.

Parkinson's is a highly complex condition and each person diagnosed will have unique symptoms. Symptoms will fluctuate with medication levels so taking medication on time every time is essential throughout the day. This means each person requires a highly personalised treatment regime.

There are an estimated 57,000 Victorians living with Parkinson's and 219,000 nationally. Of those diagnosed with the condition, 20% are under the age of 60.

Main physical (motor) symptoms

Symptoms include muscular rigidity or stiffness which causes slowness of movement or Bradykinesia. People with Parkinson's may have difficulty initiating movement and experience problems turning around, getting up from a chair or turning over in bed. It also commonly affects fine motor activities such as fastening a button, handwriting and phone use.

Stiffness can at times be painful and can worsen other conditions such as arthritis. In some cases,

muscles can spasm and become very tight; this is known as Dystonia.

Facial muscles can also stiffen which reduces facial expression resulting in the person having a blank or expressionless face – it is important not to misinterpret this.

Another motor symptom is tremor at rest which affects approximately 70% of people with Parkinson's experience a tremor. It may increase when anxious or excited.

Common non-motor symptoms

Parkinson's has a range of non-motor symptoms or symptoms not related to movement. These symptoms affect the autonomic nervous system causing hyposmia, pain, bladder difficulties, constipation, loss of libido, blood pressure fluctuations and, in some people, excessive sweating. Many people also experience mood changes, causing anxiety and depression. Some people may also develop paranoid delusions while dopamine agonist medications used in Parkinson's can cause some people to develop compulsive behaviours. Parkinson's may also cause some mild cognitive impairment presenting as slowed thinking or difficulty multi-tasking.

Symptoms to monitor:

Orthostatic Hypotension – Parkinson's can impact blood pressure (BP). Some people with Parkinson's can have large swings of both high and low BP and may experience symptoms such as dizziness which can contribute to falls. It is recommended to monitor a sitting/lying and standing BP.

Constipation – Parkinson's affects dopamine-producing cells in the nerves controlling the gut, slowing down bowel muscles and causing the stool to become dry and hard to pass. Constipation needs to be proactively assessed and managed, ensuring adequate hydration, intake of dietary fibre and consideration of a bulking and lubricating aperient.

Bladder function – The nervous pathway between the bladder muscles and its regulation centre in the brain is impacted by the loss of dopamine, causing urinary frequency and urgency.

Mobility and falls – Falls occur frequently and are contributed to by slower movement, gait changes and changes in posture. BP fluctuations, and difficulties in managing multiple tasks also contribute to increasing an falls risk. Note: While a person with Parkinson's has an increased falls risk, it is important that opportunities for mobility and exercise are provided during a hospital stay.

Cognitive changes – Common issues can include word-finding difficulties, challenges with planning and organising tasks, difficulties performing multiple tasks at once (such as walking and talking), problem-solving challenges, visuospatial difficulties.

Depression and anxiety – Depression can be a symptom of Parkinson's and a reaction to living with Parkinson's. Mood may also fluctuate with medication levels, which needs to be considered when screening for depression. Beware that some antidepressants can worsen the symptoms of Parkinson's and some may interact with Parkinson's medications.

People with Parkinson's can also experience anxiety, which may worsen when medication levels are low.

Apathy – A lack of motivation to participate in activities, therapy sessions or completing daily routines is a common Parkinson's symptom. Encouraging someone to participate or engage in tasks can assist in overcoming this.

Compulsive behaviours and Impulse Control Disorder – Developing compulsive behaviours can affect people taking a class of medication called dopamine agonists. These medications are used for Parkinson's and some people with restless legs. The most common behaviour is compulsive eating, gambling or hypersexuality. These behaviours abate when the dopamine agonist medication is stopped. Note: These medications need to be reduced slowly to avoid a withdrawal syndrome.

Hallucinations, delusions, psychosis and delirium – Some people with Parkinson's can develop hallucinations which are commonly visual and range from misinterpretation of objects to seeing lifelike representations.

Some people who have had Parkinson's for several years may develop delusions and occasionally psychosis. This is thought to be related to long term medication use. Common themes are paranoia, persecution and marital infidelity.

People with Parkinson's are at a greater risk of developing delirium while in hospital which may be post-operative or related to infection.

Hallucinations, delusions and psychosis are slow to develop and can be easily treated with carefully selected atypical anti-psychotic medication.

Swallowing and communication – People with Parkinson's may experience both swallowing and

communication difficulties. These difficulties will be more obvious when medication levels are low.

Stiff facial muscles which cause hypomimia will also slow eating meals and will contribute to saliva becoming thick and sticky. Providing additional time to have meals in an environment with minimal distractions and encouraging your patient to take regular sips of fluid before and during meals will assist.

The muscles responsible for swallow are also used in communication, people with Parkinson's may experience slowed, slurred or faint speech. Stiff facial and arm muscles reduce facial expression and writing ability impacting nonverbal communication.

Treatments and management

The role of medication

Medication is the first and most common treatment for Parkinson's. The medications either replace dopamine or support maintaining dopamine levels.

Dopamine Replacement Therapy: Key dopamine replacement medications come in dispersible, tablet, capsule and long-acting preparations and contain levodopa to replace dopamine and carbidopa or benzseride which are agents to assist the levodopa to cross the blood brain barrier. Common trade names are Sinemet, Madopar, Kinson, Sinadopa.

Dopamine replacement medications have a very narrow therapeutic window so must be administered on time every time. Consuming

protein within 30 minutes of taking medication can affect the absorption of the medication. Dose adjustments need to be made frequently to maintain optimal symptom control.

Other medications are used so support dopamine levels or reduce the breakdown of dopamine.

Dopamine agonists

Pramipexole, Rotigotine, Cabergoline

- Stimulates dopamine receptors
- Optimises dopamine uptake
- Makes the cells that use dopamine work more efficiently.

MAO-B inhibitors

Safinamide, Rasagaline

- Reduces breakdown of dopamine
- Blocks the action of an enzyme called MAO-B
- Can help reduce the need for high doses of L-dopa.

COMT inhibitors

Entacapone, Opicapone

- Blocks the enzyme that breaks down L-dopa
- Helps L-dopa to reach the brain
- Enhances and prolongs the effects of L-dopa.

Infused therapies for Parkinson's

Infused therapies may be used when someone has had Parkinson's for some time. These therapies provide a continuous infusion of medication reducing the fluctuations in medication levels associated with tablet-based therapies.

Intra-Jejuneal dopamine – levodopa gel delivered directly into the Jejunum.

- Requires a PEJ

- Delivered during waking hours

Apomorphine – Dopamine agonist delivered sub-cutaneously or as an intermittent injection or infusion.

- Assists in smoothing motor fluctuations by reducing amount of L-dopa required
- Infusion sites need to be monitored.

Get it on time – every time!

The timing of administering medication is vital to effectively manage Parkinson's symptoms and maintaining the person's usual interval time between doses of dopamine replacement therapy is essential.

Self-medication allows the person to maintain control over their medications. It is also a valuable way for medical and nursing staff to assess concordance and discuss medication timer devices if the patient is missing or mistiming doses of medication.

Medication Precautions

There are some commonly used medications which may worsen Parkinson's symptoms by blocking the action of dopamine or interacting with other medications, possibly causing additional symptoms.

Commonly prescribed medications which need to be avoided:

Metoclopramide – Maxolon, Pramin – Used for nausea: Blocks the uptake of dopamine.

Prochlorperazine – Stemetil – Used for nausea: Blocks the uptake of dopamine.

Promethazine – Phenergan, Avomine – Used for colds and hay fever: Blocks uptake of Dopamine

Haloperidol – Haldol, Seranace – Used for mood disturbance: Blocks the uptake of dopamine.

SSRI/SNRI/St John's Wort - Interacts with Azliect: May cause serotonin syndrome

A comprehensive list of medications to be used with caution or avoided is available at Fight Parkinson's – please contact our Health Team on 1800 644 189 or 03 8809 0400.

Always check with your pharmacist for any interaction between prescribed, over the counter and complementary/ naturopathic/ Chinese or herbal medications. Avoid crushing medication as this may impact absorption and half-life.

For people needing to fast for procedures, check if medication can be continued. Without medication, their ability to move will be compromised.

The role of Deep Brain Stimulation (DBS)

DBS involves placing electrodes into the region of the brain impacted by Parkinson's and providing continuous electrical stimulation which suppresses the symptoms of Parkinson's. DBS is not suitable for everyone with Parkinson's; however, a positive response to levodopa-based medications is a key criterion for consideration.

The implanted DBS may interfere with ECG and cardiac monitoring while people with DBS should not have MRI's, if possible. If an MRI is required, the DBS should be turned off. The person or their family may be able to do this.

For people requiring surgery, DBS may need to be turned off and only bipolar diathermy should be used.

Multidisciplinary management

Multidisciplinary team members will often play an important role monitoring and managing care for someone who has Parkinson's, regardless of whether they are being managed by medication, DBS or a combination. Some examples may include:

Physiotherapist – To provide strategies for improving mobility, balance and preventing falls

Occupational Therapist – To provide strategies to maintain or improve function, safety and independence in daily activities

Speech Pathologist – To improve safety and comfort while swallowing, managing saliva and maintaining optimal communication abilities

Dietitian – To offer nutritional advice if loss of weight is noted.

Patients and carers are experts in their own condition

Talk with the patient and their carer about how they are personally affected by their Parkinson's symptoms and medications.

Mobility

A patient with Parkinson's may walk slowly with a shuffling gait, have a stooped posture, may freeze (sudden unpredicted inability to move) and have an altered gait of small, unsteady steps (called festination).

People living with Parkinson's frequently have an increased tendency to fall, especially in high traffic and obstructed areas (common in hospital corridors and rooms).

Some problems associated with mobility include difficulty rising from a chair or bed, problems

turning in bed and drug-induced dyskinesias that can cause immobility and instability. Low blood pressure and postural hypotension with dizziness on standing can also be a feature.

An inability to adjust position independently while seated or in bed should alert the need for pressure injury prevention and management strategies.

A Physiotherapist can help to review issues relating to mobility.

Communication

People with Parkinson's can have a very quiet voice with poor articulation. They may also require more time to answer questions.

Loss of facial expression and body language can make communication more difficult, as often the visual feedback or cue of a smile or grimace is not present.

Handwriting may become very small and hard to decipher; a condition known as micrographia.

It may be of use to involve a Speech Pathologist to assist in developing an effective communication strategy.

Eating and drinking

A person with Parkinson's may require assistance at mealtime due to reduced manual dexterity.

Check that your patient is well set-up at mealtimes, as they may have difficulty getting into a suitable eating position or taking the tops off individual portions - e.g. jam, milk and juices.

Time should be allowed for independent eating, which may be slow.

Chewing and swallowing can be affected and there may be a risk of choking/aspiration. Ensure patients are not attempting to eat while lying

down or if they have not had medication on time or are in an 'Off' state.

If your patient is on a lower level of medication than normal, consideration should be given to providing some additional assistance at mealtimes.

If your patient has dyskinesia, be mindful that they will have an increased calorie burn and may need dietary supplements or additional snacks.

Food and fluid intake should be monitored to avoid nutritional decline and dehydration.

A referral to a Speech Pathologist, Occupational Therapist or Dietitian may be necessary.

Elimination (bladder & bowels)

Help to promptly get to the toilet may be required due to mobility problems affecting ability.

Urinary urgency and frequency are common and constipation is a symptom of Parkinson's for many people.

Constipation, in particular, will worsen if the person has been on pain relief and if their fluid intake is less than usual.

Monitoring bowel movement and introducing the appropriate aperient will help in avoiding this problem.

Sleeping and night-time care

Sleep patterns may be affected by Parkinson's and its medication.

A person with Parkinson's will need the nurse call bell very close at hand as mobility is often reduced overnight due to lower levels of medication.

Altered sleep patterns, sudden onset of day-time sleepiness, fatigue and medication-induced

nightmares can also occur.

An inability to turn in bed indicates the need for vigilance surrounding pressure injury prevention and care.

Consideration should be given to using an alternating air pressure relieving mattress overlay or replacement system, ensuring that transfers are not compromised by the selected device.

Consultation with a wound consultant or pressure care expert (such as an Occupational Therapist) should be considered when selecting pressure care equipment.

It is often useful to use a pressure risk assessment tool, such as the Braden, Norton or Waterlow Scale, in conjunction with a comprehensive assessment.

Personal hygiene

A person with Parkinson's may require assistance with personal hygiene tasks due to stiffness, slowness of movement, cognitive challenges or reduced hand dexterity. Oral care, shaving and managing clothing fasteners can be particularly difficult.

An individual with reduced mobility, postural instability or who has difficulty multi-tasking may benefit from performing personal hygiene tasks whilst seated, where possible.

Motor performance can fluctuate from day-to-day and hour-to-hour so an assessment of the level of assistance someone needs should be conducted prior to tasks.

Ensuring that the person receives their Parkinson's medication on time will help reduce motor fluctuations.

If issues with personal hygiene are identified, a referral to an Occupational Therapist can help.

Pain

Pain is a problem in about 50% of people living with Parkinson's. It's normally experienced as muscular pain and is worsened during periods when an individual's medication is wearing off. Cramping can also occur and may be painful.

In some instances, individuals can develop dystonia or involuntary contraction of the

muscles which may also be very painful.

Pain can also be experienced because of postural implications of Parkinson's, such as back, shoulder or neck pain from sustaining a stooped posture or a sideward lean.



Fight Parkinson's is a leading source of specialised health information and advice services. Through research, education and support, we strive to improve the lives of people living with Parkinson's, PSP, MSA and CBS.

Any medial information provided is for general information purposes only. You should always talk to your treating doctor and qualified healthcare providers for personal medical and health-related instructions.

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Appendix 1 – MEDICATIONS

Levodopa

This is the main treatment for Parkinson's. It is the precursor to dopamine and is combined with a decarboxylase inhibitor which supports levodopa to cross into the brain.

This medication is started at a low dose and slowly increases. Levodopa never stops working - the dose will alter as Parkinson's progresses, keeping the level of dopamine topped up.

- Sinemet (levodopa and carbidopa) 100/25 mg; 250/25 mg
- Sinemet CR 200/50 mg controlled release (CR)
- Kinson (levodopa and carbidopa) 100/25 mg (generic medication)
- Madopar (levodopa and Benserazide) 50/12.5 mg; 100/25 mg; 200/50 mg
- Madopar HBS 100/25 mg Long Acting
- Madopar Rapid 100/50 mg 50/12.5 mg

Side effects can include nausea, dizziness and sometimes vivid dreams.

When you have been taking this medication for some time, you may develop some involuntary movement called dyskinesia.

Some people report hallucinations. Side effects can be treated and you should speak to your treating doctor about any concerns.

Feelings of anxiety, depression and hopelessness may occur when dopamine levels are low or when medications are wearing off. These feelings will often improve once Parkinson's medications are back at normal levels.

Dopamine agonists

These medications mimic the effect of dopamine on the dopamine receptors. Initially, they may be used on their own or as an adjunctive medication to dopamine replacement therapy.

- Sifrol (pramipexole) 0.125 mg; 1 mg; 1.5 mg
- Sifrol ER (extended release pramipexole) 0.375 mg; 0.75 mg; 1.5 mg; 2.25 mg; 3 mg; 3.75 mg; 4.5 mg
- Simipex (pramipexole) 0.125 mg; 0.25 mg; 1 mg (generic medication)
- Neupro (rotogotine) 2 mg; 4 mg; 6 mg; 8 mg (transdermal patch)
- Cabaser (cabergoline) 1 mg; 2 mg

Side effects – can include nausea, blood pressure changes causing dizziness, confusion and sleepiness.

This medication can also cause some people to develop compulsive behaviours (impulse control disorders). Examples include gambling, compulsive eating or increased sex drive.

In addition to these side effects, Cabaser has an ergotamine base and can cause fibrosis in lungs, kidney and retroperitoneal areas.

If an individual experiences a side effect while taking a dopamine agonist they should not stop this medication abruptly - their neurologist should be consulted to reduce the dose over time.

Monoamine Oxidase type B Inhibitors (MAO-B Inhibitors)

These medications encourage nerve cells to make better use of the dopamine in the brain by blocking an enzyme called monoamine oxidase type B which otherwise would break down dopamine.

- Selegene Eldepryl (selegiline hydrochloride) 5 mg: This medication is usually taken twice daily. It is important not to take the second dose later than midday as it can cause sleep disturbance.
- Azilect (rasagiline) 1 mg - taken once daily

- Xadago (safinamide) 50 - 100 mg - taken once daily, as prescribed.

Side effects can include indigestion, headaches and depression while sleepiness and insomnia can also occur. These medications may interact with commonly used antidepressants, pethidine, decongestants, cold remedies and some natural medications such as St John's wort.

Check with your pharmacist before taking any new medications, vitamins or supplements.

COMT inhibitors

These medications block the COMT enzyme, making the levodopa last longer.

They can be useful to boost levodopa if an individual is experiencing end-of-dose wearing off.

COMT inhibitors can also be in a tablet combined with levodopa (Stalevo).

The different types of COMT inhibitors are:

- Ongentys (opicapone) 50mg- taken once daily preferably at night one hour before or one hour after levodopa.
- Comtan (entacapone) 200 mg – always taken with a dose of Levodopa
- Stalevo (levodopa/carbidopa/entacapone) 50 mg, 75 mg, 100 mg, 125 mg, 150 mg, 200 mg.

Side effects include diarrhoea, discoloration of urine, hallucinations and headache.

This medication will boost levodopa so may cause involuntary movement or dyskinesia.

Amantadine

This medication is a glutamate antagonist and is an antiviral agent.

It is not fully known how this medication works

for Parkinson's; however, it does have an anti-Parkinson effect.

It is identified as being particularly beneficial for reducing dyskinesia; an involuntary movement related to dopamine.

- Symmetryl (amantadine hydrochloride) 100 mg

Side effects can include feelings of anxiety, insomnia, confusion and a mottled rash on the legs.

Anticholinergic medication

These medications block the action of acetylcholine, a brain chemical which sends messages in the brain from the nerves to muscles.

They are not commonly used but may have the effect of reducing tremor and muscle stiffness.

- Artane (benzhexol hydrochloride) 2 mg; 5 mg
- Benztrop (benzhexol hydrochloride) 2 mg
- Cogentin (benztropine Hydrochloride) 2 mg

Side effects can include a dry mouth, blurred vision, constipation, urinary retention, confusion and memory loss.

Infused therapies for Parkinson's

Apomorphine Infusions

- Movapo (apomorphine hydrochloride) 20 mg/2 ml and 50 mg/5 ml solution for infusion
- 50 mg/10 ml Pen Fill Syringe for intermittent injection.
- Apomine (apomorphine hydrochloride) 100 mg in 20 ml solution for infusion vial. D-mine pen for intermittent s/c injection.

This medication is a powerful dopamine agonist (see above) mimicking the effect of dopamine.

It is given as an injection or, more commonly, as an infusion delivered by a needle placed under

the skin into the fatty tissues.

An infusion of apomorphine can reduce motor fluctuations and reduce dyskinesia.

Side effects are the same as other dopamine agonists, however as it is given as an infusion or injection, skin nodules can form at the injection sites.

Note:

The consumables (injection materials) used to inject apomorphine need to be paid for by the individual.

The injection materials also cannot be interchanged between Movapo and Apomine.

Duodopa Infusion

- Levodopa 20 mg /ml carbidopa 5 mg/ml as gel solution

This medication is a gel form of levodopa that is administered through a tube placed in the stomach with a smaller inner tube extending into the duodenum.

The gel form of levodopa is administered as a constant infusion smoothing the highs and lows of dopamine which cause motor fluctuations.

This medication requires a small operation to place the tube into the stomach.

Side effects are the same as levodopa tablets. Problems with the tube including blockage, infection and pain have also been reported.

Appendix 2 – GLOSSARY

Common terms used to describe Parkinson's symptoms

Dyskinesia - Involuntary writhing movements caused by an erratic response to long-term medication therapy and as a result of varying levels of dopamine in the body.

Dystonia - Painful fixed contractions of muscles.

Bradykinesia - Decreasing speed and amplitude of movements - e.g., smaller handwriting, slow walking, reduced stride length, reduced facial expression or quieter voice.

'On' - When Parkinson's medications are working and the symptoms are treated.

'Off' - When the symptoms of Parkinson's are not controlled and a person can experience significantly reduced mobility. Some people experience an inability to initiate movement (also referred to as 'freezing') or become temporarily immobile.

During these periods, a person may also experience difficulty with communication, thinking, mood and swallowing.

People with Parkinson's will often require increased assistance and support at these times.

'On/Off Phenomenon' - When a person goes from effective symptom management to the resumption of Parkinson's symptoms ('on' to 'off') quite quickly and without warning; like a switch being flicked on or off.

'Wearing Off' - Term used when medications wear off before the next dose is due.

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