Fight Parkinson's

Health Professionals guide to caring for someone living with Parkinson's

Fight Parkinson's™
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Introduction

Parkinson's is a progressive neurological condition which has no known cause and no cure. There are an estimated 220,000 people living with Parkisnon's in Australia, with 20% of people diagnosed before the age of 60.

Each person living with Parkinson's will have unique symptoms which fluctuate throughout the day.

The treatments for Parkinson's are time critical, with medication needing to be administered ***on time, every time***.

Each person living with Parkinson's will have a highly personalised treatment regime.

Parkinson's occurs when dopamine producing cells in the brain and nervous system die. This cell death is thought to relate to accumulation of a misfolded protein called alpha synuclein forming a Lewy body.

The lowered levels of Dopamine cause a range or motor, autonomic and non-motor symptoms, with tremor, stiffness and loss of coordination often identified as early symptoms.

Parkinson's symptoms and rate of progression will vary from person to person.

Main physical symptoms

Bradykinesia or Slowness of movement – initiating movements become difficult and movements are slower to perform. Lack of co-ordination can also be a problem.

Muscular rigidity or stiffness – is a common early sign in people with Parkinson's. Symptoms might include problems turning around, getting up from a chair, turning over in bed or fine finger movements such as fastening a button. People with Parkinson's may have stooped posture.

Facial expressions can be reduced due to muscle rigidity which makes reading emotions difficult.

Stiffness can at times be painful. Muscular stiffness can also worsen other conditions such as Arthritis. In some cases muscles can become very stiff and this is known as Dystonia.

Tremor – Approximately 70 percent of people with Parkinson's experience a tremor. The tremor is classified as a resting tremor. The tremor is often more noticeable when a person is resting and may increase when anxious or excited.

Autonomic Nervous System – Symptoms

Orthostatic Hypotension – Parkinson's can impact on Blood pressure. Some people with Parkinson's can have large swings in BP. This is commonly postural with BP dropping with movement, typically sitting to standing. The person may experience symptoms such as dizziness which can contribute to falls. They may develop fluid retention and daytime drowsiness and then experience a diuresis and become

wakeful when lying down as BP increases when prone. A single BP measurement may not always reveal the problem. It is necessary to record BP lying down and standing up. Encouraging adequate hydration and considering a bolus of fluid prior to breakfast and lunch can help minimise this symptom.

Constipation – The nerves controlling bowel motility contain many dopamine producing cells which are also affected in Parkinson's, slowing peristalsis causing constipation and in some cases gastric stasis. Constipation is a common symptom and needs to be proactively assessed and managed. Encouraging water intake, increasing dietary fibre and considering a bulking and lubricating aperient will assist.

Bladder Function – The pathway between the bladder's detrusor muscles and the brains micturition centre is impacted by the loss of Dopamine causing frequency and urgency.

Anorgasmia and erectile difficulties – Fluctuating blood pressure and lower levels of dopamine can also make achieving an orgasm more difficult for male and females and it is common that males will experience difficulties in achieving and maintaining an erection.

Non-motor symptoms

There are several non-motor symptoms in addition to motor or movement symptoms. These include fatigue, cognitive change sleep problems, depression and anxiety, and constipation. These often have a greater impact on quality of life for people living with Parkinson's.

Depression and Anxiety – Depression is increasingly considered to be part of Parkinson's disease, and people will often develop symptoms of depression as their Parkinson's develops, as well as a reactive depression to the diagnosis of Parkinson's. Depression in Parkinson's needs to be screened for and treated carefully as many anti-depressants will worsen the symptoms of Parkinson's.

Anxiety is also a common symptom of Parkinson's, resulting in excessive worry, over reacting, fear and racing heart.

Compulsive and Impulsive Behaviours – Some people may develop disinhibited behaviours, or complain of an increased sex drive; this is known as hypersexuality. Developing a difficult to control urge to gamble can also occur in advanced disease or in response to some medication.

Hallucinations, Delusions and Psychosis – Some people with Parkinson's can develop visual hallucinations or delusions. This can be a result of taking anti-Parkinson medication for many years or from a condition closely related to Parkinson's called Lewy body dementia. Sometimes an infection or anaesthetic can exacerbate this problem.

It is important to remember that someone experiencing hallucinations does not have a psychiatric illness like schizophrenia, and should always be encouraged to discuss this symptom with their treating Neurologist.

> Extreme caution needs to be taken if considering treatment with Anti-psychotic medication, as these medications can worsen Parkinson's symptoms.

Management of Parkinson's

Multidisciplinary care

Considering the complexity of Parkinson's a team approach is best practice in care delivery. Key team members are Occupational Therapy, Physiotherapy and Speech Pathology, and other health care members may need to be involved as the persons symptoms progress. All health care professionals will need to work together to deliver comprehensive care.

The role of Medications

Medication is the main treatment to help control the symptoms of Parkinson's.

Medications does not slow the progression of the condition.

Medication therapies for Parkinson's replace the dopamine which is no longer being produced treating symptoms, support its uptake or slow the breakdown of Dopamine. Every person will have an individualised medication regime. To get the best control of symptoms medication needs to be given on time every time.

There are several categories of drugs for Parkinson's treatment. Patients are often prescribed medication from many categories listed and all have to be given at specific times.

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

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

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

Some people report hallucinations.

Side effects are able to be treated and you should speak to your doctor about any concerns.

Dopamine Agonists

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

- Sifrol (Pramipexole) 0.125mg; 1mg; 1.5mg
- Sifrol ER (Extended release pramipexole) 0.375mg; 0.75 mg; 1.5mg; 2.25mg; 3mg; 3.75mg; 4.5mg
- Simipex (Pramipexole) 0.125mg; 0.25mg; 1 mg (generic medication)
- NEUPRO (Rotogotine) 2mg; 4mg; 6mg; 8mg (transdermal patch)

- Cabaser (Cabergoline) 1mg; 2mg

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

This medication can also cause some people to develop compulsive behaviours, examples include gambling, compulsive eating or increase sex drive.

In addition to these side effects Cabaser has an ergotamine base and can cause fibrosis in lungs, kidney and retroperitoneal areas and regular assessments for this need to occur.

If you experience a side effect while taking a Dopamine Agonist you should not stop this medication abruptly- your neurologist will assist you in reducing the dose over time.

Monoamine Oxidase type B Inhibitors (MAO-B Inhibitors)

These medications make your nerve cells make better use of the Dopamine in your brain by blocking an enzyme called Monoamine Oxidase type B which otherwise would break Dopamine down.

Selegene, Eldepryl (Selegiline Hydrochloride) 5mg this medication is usually is taken twice daily. It is important not to take the second dose later than midday as it can cause sleep disturbance.

- Azilect (Rasagaline) 1mg taken once daily
- Xadago- (Safinamide)- 50-100mg once daily

Side effects – indigestion, headaches, and depression.

These medications may interact with commonly used antidepressants, Pethidine, decongestants, cold remedies and also some natural medications such as St John's Wort.

Check with your pharmacist before taking any medication.

COMT inhibitors

These medications block the COMT enzyme making the Levodopa last longer. They can be useful to boost levodopa if you are experiencing end of dose wearing off. COMT inhibitors come also be in a tablet combined with levodopa (Stalevo)

- Comtan (Entacopone) 200mg – always taken with a dose of Levodopa
- Stalevo Levodopa/carbidopa/entacopone 50, 75, 100,125, 150, 200.
- Ongentys (Opicapone)- 50mg- Long acting COMT inhibitor taken once a day an hour before or after the last dose of Levodopa.

Side effects – 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 anti-viral agent. It is not fully known how this drug 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) 100mg

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

Anticholinergic medication

These medications block the action of acetylcholine a brain chemical which sends messages in the brain from your nerves to muscles. They are not commonly used they but may have the effect of reducing tremor and muscle stiffness.

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

Side effects – dry mouth, blurred vision, constipation, urinary retention, confusion and memory loss.

Infused therapies for Parkinson's

- Movapo (Apomorphine Hydrochloride) 20mg/2ml and 50mg/5ml solution for infusion 50mg/10ml Pen Fill Syringe for intermittent injection
- Apomine (Apomorphine Hydrochloride) 100mg in 20ml 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 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

Levodopa 20mg /ml Carbidopa 5mg/ml as gel solution

This medication is a gel form of Levodopa which is administered through a tube which has been placed into the stomach with a small 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 your stomach.

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

Medications to be avoided or used with caution

Parkinson's and its treatments can be complex. There are some commonly used medications which may worsen the symptoms by blocking the action of Dopamine or that interact possibly causing additional symptoms.

Commonly Prescribed medications which need to be avoided

- Metoclopramide – Maxolon, Pramin – used for nausea- Blocks the uptake of Dopamine worsening symptoms
- Prochlorperazine – Stemetil – used for nausea – blocks the uptake of Dopamine

worsening symptoms
- Promethazine – Phenergan, Avomine – used for colds and hay fever, blocks uptake of dopamine and worsens symptoms
- Haloperidol – Haldol, Seranace – used for mood disturbance – block the uptake of Dopamine
- SSRI/SNRI/St John's Wort- interact with Azliect and may cause serotonin syndrome

There is a comprehensive list of medications to be used with caution or avoided available at Fight Parkinson's.

Always check with your pharmacist for any interaction between prescribed, over the counter and complimentary / naturopathic / Chinese or herbal medications

Surgery for Parkinson's

Deep Brian Stimulation surgery

Deep Brain Stimulation surgery (DBS) may be appropriate for some people with the condition and is now considered 3-5 years post diagnosis.

This surgery involves placing electrodes into the part of the brain impacted by Parkinson's, electrical impulses are delivered through these electrodes stimulating the brain and retuning its electrical activity to a more normal state reducing the motor symptoms of Parkinson's. DBS is not suitable for everyone with Parkinson's however a good response to levodopa based medications is a key criteria. DBS may be a treatment considered at any point during Parkinson's, however increasingly is considered earlier.

If the person you are caring for has DBS there are some precautions with exposure to electromagnetic fields including MRI and Diathermy. Some people will have DBS which requires charging regularly. DBS may need to be turned off for certain procedures.

Companies which supply DBS have a consumer support line who can offer additional support.

Side effects – as this is a surgical procedure with an indwelling device the key adverse event is infection. Prophylactic antibiotic therapy may be considered prior to dental and surgical treatments. medications.

Medication Management

Get it on time

Timing of medication is vital for drugs to give effective control of Parkinson's symptoms.

Every effort needs to be made to ensure that medication is given to patients at the correct time.

Wherever possible people with Parkinson's should be allowed to self-medicate. For people who are self-medicating assessing concordance is important, if doses are being missed suggesting medication timer devices may assist.

Timings will often differ from usual ward drug rounds and patients will have very individual drug regimes, it is important to understand without medication the person with Parkinson's will have difficulty in moving or not be able to move. mobility.

Care Planning

Nursing assessment for people with Parkinson's is challenging as "on" and "off" periods, drug therapy and motor fluctuations will determine different needs at different times.

Below are some areas that should be considered when care planning:

Expert Patients and Carers

The person living with Parkinson's and their families will be able to describe the key symptoms of Parkinson's and the individualised management and medication response. This information will help you understand the patient's individualised needs and plan care. how they are affected by Parkinson's and what effect their medication has.

Drug administration

When people are nil by mouth, administering the drugs to ensure a stable drug regime before, during and after the surgery may be the main concern.

If taking tablets by mouth is impossible, consider alternative routes.

Using a Neupro (Rotigotine) patch or using Apomorphine on a short-term basis may be a consideration.

If Apomorphine is used it should be done in conjunction with domperidone (Motilum).

The best person to consult in regards to altered medication regimes is the patient's neurologist.

Most frequently when people are nil orally, they will receive a lower dose of medication - this will directly impact upon their motor function and as a result they will need more assistance.

Crushing medication may affect absorption and this should be avoided, if medcation needs to be crushed the Hospital Pharmacist needs to be consulted.

It is important to reintroduce the individual's Parkinson's medications as soon as possible once they are no longer nil by mouth, however a gradual increase to normal levels of medication is worth considering as your patient is likely to develop some dyskinesia when Parkinson's medications are re-introduced.

Mobility

People who have Parkinson's may walk slowly with a shuffling gait, have a stooped posture, may freeze (sudden unpredicted inability to move) and have a running 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 (most hospital corridors and rooms).

Some problems associated with mobility include difficulty in 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.

Communicating

People with Parkinson's can have a very quiet voice or speech can become slurred.

They may require more time to answer questions. Loss of facial expression and body language can also make communication more difficult, as often the visual fed back of a smile or grimace is not present.

Handwriting may become very small and hard to decipher (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 set up at meal times, as they may have difficult in taking the tops of individual portions (E.g. Jam's Milk).

Saliva can become thicker and stringy and may not lubricate swallow. 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.

Meals should ideally occur when you patient is "ON" this will make it easier for for the person to swallow safely

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

A referral to a speech and language therapist may be necessary. Fluid intake should be monitored to avoid dehydration.

Elimination

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

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

Constipation, in particular, will be worsened if your patient 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 nighttime care

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

Altered sleep patterns, sudden onset of day time sleep, fatigue and drug induced nightmares can also occur.

An inability to turn in bed may result in a need for pressure area care.

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.

Consideration should be given to using an alternating cell pressure relieving device.

It is often useful to use a Pressure Care score, such as a Norton or Waterlow score to assess risk.

Personal hygiene

A person with Parkinson's may require assistance due to reduced manual dexterity
Teeth cleaning and shaving can be particularly difficult.

Immobility and lack of stability may mean the use of shower seating rather than standing is required.

Motor Performance can fluctuate, from day to day and hour to hour so an assessment of the level of assistance some one needs should be carried out prior to tasks.

Ensuring the person with Parkinson's receives their mediation on time will help in reducing motor fluctuations.

Pain

Pain is a problem for many people living with Parkinson's and research suggests that people living with Parkinson's may have heightened sensitivity to pain.

Pain may be muscular pain which is worsened during periods when patients are wearing off Central Nervous system pain which may present at burning or tingling sensations can also occur. Pain may fluctuate with medication levels and be worse when they are low.

Cramping can also occur and will be painful. In some instances patients can develop Dystonia or involuntary contraction of the muscles which is also very painful.

Impulse Control Disorder

Dopamine Agonist medications can cause some impulsive behaviours, such as hyper sexuality, or an increased urge to gamble, engage in hobbies, eat compulsively or pursue another activity. These behaviours may be spread over a range of activities. This is a well-documented side effect of Dopamine agonist treatments with people being unaware of the impact these behaviours are having on others. The compulsive behaviour will reduce as the Dopamine agonist medication is reduced and may stop completely when ceased.
If a person has developed problematic impulse control disorder care must be taken to reduce Dopamine agonist treatment as the person can develop signiciant withdrawal symptoms called Dopamine Agonist Withdrawal Syndrome.

Anxiety, Depression and Psychosis

Feelings of anxiety, depression and hopelessness occur and may be worse when the drugs are not working and may improve when medication is back at a normal level.

Patients with Parkinson's may develop psychosis which often has a theme of persecution, paranoid delusions or marital infidelity. These thoughts are slow to evolve but can be very disruptive. Good communication within the team will help detect changes in behaviour early. To manage these symptoms assessing for any other intercurrent condition which may contribute to them and the addition of an atypical anti-psychotic will treat this symptom. If you detect that these are evident in your patient, you should ensure that they see their Neurologist.

Palliative and end of life care

In advanced Parkinsons the person living with Parkinson's is likely to have a high level of disability and have unpredictable fluctuations between on and off. This is likely to make them more prone to developing respiratory infections and hypostatic pneumonia. Supporting the patient to have a well-developed Advance Care Plan will assist in identifying points where treatment of intercurrent illness many be conservative or when Palliative care should be considered.

When the patient is nearing the end-of-life medications should not stop or be altered without consulting with a neurologist. If oral medication cannot be administered transdermal Rotigotine can be considered alongside long-acting muscle relaxants and analgesia. Multidisciplinary team member may also be important to assist managing positioning, communication and secretion management.

Appendix 1 – GLOSSARY

Common terms used to describe Parkinson's symptoms

Dyskinesia – involuntary writhing movements caused by an erratic response to long-term drug therapy.

Dyskinesias are a result of varying levels of Dopamine that are available'

Dystonia – painful fixed contractions of muscles.

Bradykinesia – decreasing speed and amplitude of self-paced repetitive movements e.g. poor writing, slow walking

'On' – is when the drugs are working and the symptoms are treated.

'Off' – is when the symptoms of Parkinson's are not controlled and a person can experience reduced mobility or immobility and require more assistance, this is often known as **freezing**.

'On/Off Phenomenon' – is when a person goes from 'on' to 'off' often quite quickly and without warning; like a switch being flicked.

'Wearing Off' – is the term used when drugs wear off before the next dose is due.

To continue our work in the community, we need your support. To donate over the phone, call us on (03) 8809 0400 or visit fightparkinsons.org.au to make a secure online donation.
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