Fight Parkinson's

Understanding Parkinson's

Fight Parkinson's™
Together we can

Understanding Parkinson’s

Contents

Understanding Parkinson’s

If you or a loved one has been diagnosed with Parkinson’s, it’s important to remember you are not alone.

Fight Parkinson’s is here for you and is a leading source of specialised health information and advice services.

Free Health Information line: 1800 931 031
Website: fightparkinsons.org.au

What is Parkinson’s?

Parkinson’s is a progressive neurological condition that affects people from all walks of life. It is a complex condition with many symptoms. Some known as 'motor symptoms' affect movement, while others known as 'non-motor symptoms' affect other areas such as mood and thinking. Some are a combination of both.

The name ‘Parkinson's disease’ comes from the British doctor Dr James Parkinson, who first described the symptoms in 1817. Many people prefer to use the shorter term 'Parkinson's' rather than 'Parkinson's disease'.

It is quite a common condition, with an estimated 219,000 Australians living with Parkinson’s. The average age of diagnosis is 65 years, however younger people can be diagnosed with Parkinson’s too. This is referred to as Young Onset Parkinson’s.

Parkinson’s can be a difficult condition to diagnose and is not able to be identified on an x-ray, CT or MRI scan or by a blood test.

The symptoms of Parkinson’s are caused when the body’s production of dopamine, a neurotransmitter we need for smooth coordinated movement, is disrupted.

With Parkinson’s, a protein called Alpha Syncline accumulates around dopamine producing cells and over time less dopamine is produced which effects affects the body’s movement

Recent research has identified a biomarker or protein detectable in spinal fluid and some changes visible on a highly specific scan, that are able to diagnose Parkinson’s however these tests are not yet readily available as a diagnostic tool. It does however provide hope to improving future research into new treatments.

For most people a Parkinson’s diagnosis comes following examination by a Neurologist or General Practitioner where the symptoms of Parkinson’s are detected.

The symptoms of Parkinson’s present when the body’s production of Dopamine, a neurotransmitter we need for smooth coordinated movement, is disrupted. A protein called Alpha Syncline accumulates around the cells which produce dopamine and over time there is less dopamine produced which affects body movement.

What causes Parkinson’s?

Currently there is no known cause or understanding of why a person develops Parkinson’s for most people who are diagnosed. For a very small percentage of people diagnosed there is a genetic cause.

There are many theories as to the causes and it is generally thought that multiple factors are responsible. Through ongoing research, our understanding of the possible causes of Parkinson’s is increasing all the time.

While the cause of Parkinson's remains unknown, we do know that people diagnosed with Parkinson's have low levels of a brain chemical called dopamine, which helps the brain to communicate with the body.

Over time, people with Parkinson's have less dopamine, making it harder for the brain to communicate effectively with the body, resulting in symptoms such as difficulty with movement.

How does it affect people?

Parkinson’s affects each person differently and symptoms can often vary.

Common motor symptoms affecting movement:

- Shaking or trembling in a part of the body, such as the hand, leg or head, usually when the person is resting
- Leg, neck or face muscles may look or feel stiff, sometimes the person may feel frozen and unable to move
- Movement can slow and people may take small steps or shuffle when walking
- Balance problems or difficulty keeping good posture

Common non-motor symptoms:

- Sleep difficulties and fatigue
- Depression and reduced engagement in daily life
- Constipation
- Difficulty with speech
- Difficulty swallowing
- Cognitive challenges, e.g. difficulties multi-tasking

Parkinson's can impact many daily activities including:

- Bodily movements e.g. walking, rolling over in bed or getting out of a chair
- Spoken and written communication e.g. difficulty speaking, writing and typing
- Personal care tasks e.g. eating, dressing, showering, toileting and shaving
- Household tasks e.g. cleaning, cooking and laundry
- Travel e.g. driving and public transport
- Daily errands e.g. shopping
- Engaging in social activities

Parkinson’s does not cause death and people can continue to enjoy a long and fulfilling life.

It may take many years for symptoms to progress to a point where they cause significant impairment. When they do, many of these symptoms can be managed with treatment and support.

Who gets Parkinson’s?

Any adult can get Parkinson’s. It is one of the most common brain conditions in Australia and:

- is more common among people aged over 60 years
- it can affect adults of any age
- it affects both men and women from all cultures and lifestyles
- it is not contagious, meaning that you cannot catch it or pass it on to someone else
- it is not usually hereditary

How is it diagnosed?

Parkinson's can be difficult to diagnose and everyone will present with different symptoms. Tests may be carried out to rule our other causes for the symptoms, for most people the diagnosis occurs when the treating Doctor or a Neurologist is able to detect physical symptom associated with Parkinson's.

A recent advance has been the detection of a protein Biomarker detectable in spinal fluid which can provide a diagnosis of Parkinson's, This test is not readily available and is largely used in clinical research.

Some early symptoms people may notice include changes in movement, a tremor, changes in handwriting or slowness.

Research now suggests symptoms including constipation, acting out dreams, loss of sense of smell and mood changes may be apparent several years before movement changes are noticed.

Currently there are no treatments which cure Parkinsons, however there are many treatments available to reduce the impact of Parkinson's

The symptoms of Parkinson's can be treated with a range of medications, seeking help from a range of health care professionals (such as a physiotherapist) who will help in developing a regular exercise regime and supporting independence. Some people may also benefit from Deep Brain Stimulation surgery.

Can Parkinson's be cured?

Unfortunately, we do not yet know of any way to cure Parkinson's or to slow its progression. New and better treatments and medications are being researched, providing hope for the future.

Can Parkinson's be treated?

Medical treatment for Parkinson's

The following information gives a basic outline of the common medical treatments for Parkinson's. It explains how medications treat symptoms and help people to live safely and independently.

Medication is the primary treatment for Parkinson's. The medications used to treat Parkinson's works to restore dopamine in the brain to a more normal level, in order to address the motor symptoms. It is important to take prescribed Parkinson's medications on time, every time!

There are many different medications prescribed for Parkinson's. None are perfect, however research into treatments is improving the options all the time.

Common treatments for Parkinson's

Levodopa is the main treatment for Parkinson's. It works by converting into dopamine in the brain. Levodopa medications contain other drugs – Carbidopa, Benserazide or Entacapone – to help it reach the brain.

* Brand names: Sinemet, Madopar, Kinson, Syndopa Stalevo. (Stalevo contains entacapone – see COMT Inhibitors.)

Dopamine Agonist medications make the cells that use dopamine work more efficiently. They have a longer lasting effect than Levodopa and can be used with Levodopa to help it to work for longer.

* Brand names: Cabaser, Apomine, Sifrol, Neupro Patch

MAO Inhibitors, particularly Selegeline, reduce the breakdown of dopamine in the brain, allowing lower doses of Levodopa to be more effective.
* Brand name: Eldepryl, Selgene, Azilect, Xadigo

COMT Inhibitors, particularly Entacapone, help Levodopa to reach the brain, allowing Levodopa treatment to be more effective.

* Brand name: Comtan, Ongentys

***Note: Brand names change from time to time and substitute, or generic brands are also available.**

Side-effects

Taking Parkinson's medication can cause side-effects including:

- Nausea
- Involuntary movements
- Worsening of constipation
- Low blood pressure
- Confusion and hallucinations
- Impulse control disorder, increased desire to gamble, have sex, eat of peruse your hobbies (Dopamine Agonists only)

Side-effects can usually be treated and it is recommended to discuss your experiences with your treating doctor.

Managing Parkinson's medication

Each person with Parkinson's has different medication needs and it can take time to find what works best.

Parkinson's symptoms can have a greater impact on your life as the condition progresses. Medication needs will change as Parkinson's progresses. It can help to monitor or keep a diary of symptoms and when they occur so your treating doctor can determine the most effective timing and dosage. It's important to avoid changing times or doses without talking to your treating doctor.

Some treatments for conditions other than Parkinson's can cause problems for people taking Parkinson's medication. It's a good idea to keep an updated list of all medicines you are prescribed to show to your treating doctor or a pharmacist before starting or stopping any medicines.

When going to hospital it is essential that hospital staff understand that Parkinson's medication is required to be administered at the specific time prescribed for the patient - not just at routine drug rounds. It is advised that the admitting doctor record the prescribed dose and times on the patient's drug chart.

Surgery for Parkinson's

Some people with Parkinson's may benefit from Deep Brain Stimulation (DBS). Surgery may be considered when symptom control with medication fluctuates or is unpredictable.

Speak to your treating doctor about the suitability of DBS in treating your Parkinson's symptoms.

Tips for visiting a doctor:

- Write a list of concerns or symptoms to discuss during your appointment.
- Create an updated list of all your current medications.
- Be honest about the symptoms you are experiencing.
- If you don't understand something, ask your doctor to repeat it or explain it a different way.
- Write down anything important or ask your doctor to write it down.
- Bring a family member or other support person to your appointment.

If you speak a language other than English, it's very important to have an interpreter present. You can ask for an interpreter when booking your appointment. Translation services for medical appointments are usually free of charge

Building your health team

Fight Parkinson's advocates for high quality care for people diagnosed with Parkinson's.

Our organisation strives to provide accessible information and services to support the unique needs of people with this condition.

Aligned with the European Parkinson's Disease Standards of Care Consensus 1. established in 2011, we firmly advocate for the following rights of individuals with Parkinson's:

- Referrals to doctors specialised in Parkinson's
- Accurate diagnosis
- Access to support services
- Continuous care
- Assistance managing their illness

A Neurologist is the most suitable specialist doctor to diagnose and provide comprehensive management of Parkinson's. They possess the expertise to determine the most effective medications and appropriate dosages for individuals with a Parkinson's.

Regular visits to a Neurologist , every few months, are crucial as they will adjust the prescribed medication based on your specific symptoms and any potential side affects you may experience.

Parkinson's is a complex condition with symptoms unique to each individual. To support best management of Parkinson's it is best done with a comprehensive team of healthcare professionals, working in collaboration with you and your carer/family.

In addition to your GP and Neurologist, there are other healthcare professionals with areas of speciality who can help to optimise your function and quality of life.

This team of various healthcare experts should work to manage your symptoms and improve your overall quality of life. The care should be person centred and family friendly, this means they listen and work with you to set your personal health and wellbeing goals.

Ideally, you should see this team regularly and they will each act in conjunction with your treating doctor, who you may only see every three to six months.

Some of the main healthcare professionals involved in managing Parkinson's include physiotherapy, occupational therapy, speech pathology, psychology, Parkinson's nurses, dieticians and social workers.

Preventative action to maintain your function is an important step in managing Parkinson's symptoms.

Forming a team of healthcare professionals builds a foundation to proactively manage your Parkinson's.

Early assessments provide a baseline to gauge your daily function and wellbeing. Regular assessment can also help monitor your Parkinson's progression. This allows you to plan and make informed decisions regarding your health, career and financial position.

There are several avenues to access healthcare professionals to assemble your team. Some possible avenues include:

- **Medicare**-subsidised Chronic Disease Management Plan: Benefit from a plan that is supported by Medicare, which assists in managing chronic conditions
- **Private Providers**: Explore private health insurance or Government-funded plans/packages to access a range of healthcare services
- **Community Health**: Engage with community health organisations that offer a wide array of healthcare resources and support.
- **Specialised Clinics or Rehabilitation Programs**: Explore both public and private specialised clinics or rehabilitation programs that cater to your specific needs.

Finding a Neurologist

Selecting a Neurologist can feel overwhelming as it is an important decision. To aid in this process, consider the following questions:

- Does the doctor have expertise in Parkinson's?
- Do I feel comfortable discussing personal matters with this doctor?
- Is our communication effective and comfortable?
- What options are available when choosing a treating doctor?

Fight Parkinson's offers a list of specialised Neurologist s who focus on Parkinson's and includes general Neurologist. While this list is not exhaustive, it is a valuable resource that serves as a starting point.

Fight Parkinson's aims to provide the necessary support and guidance to help you navigate your Parkinson's journey with confidence.

The Role of the General Practitioner (GP)

Contact with your Neurologist can be infrequent and that means GPs play a pivotal role in treatment and management of Parkinson's.

Your GP serves as the primary healthcare provider, taking charge of your overall wellbeing.

GPs offer essential support in addressing symptoms, treatments and various life matters that may intertwine. GPs are typically the key source for referrals to other healthcare professionals who may help with symptom management.

It is advisable to regularly consult the same GP, preferably one who is receptive to learning about Parkinson's.

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[1] European Parkinson's Disease Standards of Care Consensus Statement, 2011 (EDPA Consensus Statement) https://www.epda.eu.com/latest/resources/the-european-parkinsons-disease-standards-of-care-consensus-statement/ (accessed Dec 2022)

Coping with a Parkinson's diagnosis

Individual reactions to being diagnosed with Parkinson's are varied.

This information offers insights into the diverse range of responses that can arise when someone is diagnosed with Parkinson's, providing valuable advice for coping with the diagnosis and moving forward.

Navigating the changes that accompany living with a chronic condition is a unique experience for each individual. While there is no 'one-size-fits-all' approach, it is important to try to keep a positive mindset during this adjustment period.

Fight Parkinson's recommends a proactive, practical approach, utilising credible, sensitive and appropriate information and support.

Some people will want to learn as much as they can about the condition. Others will prefer to take in only what they need.

After receiving a Parkinson's diagnosis, people usually experience a full range of emotions, filled with ups and downs that can last varying lengths of time.

Upon initial diagnosis, it's normal to feel sad, angry, helpless, alone and scared. These emotions are all part of the natural grief response. Give yourself, or your loved one, permission to experience these emotions.

The impact of diagnosis on partners, family and friends

When a loved one is diagnosed with Parkinson's, it can impact their spouse, partner, family and friends greatly. While they might not be the ones experiencing symptoms, they will be living with Parkinson's also as they share your journey.

Partners and family members will also experience their own unique emotions as they work towards acceptance. They may feel sad or helpless for their loved one, or scared about the future and the impact that Parkinson's may have on their own roles and responsibilities. They may even feel angry and resentful at times.

These are natural reactions when experiencing a diagnosis of a chronic condition such as Parkinson's, as is the sense of losing control, being unsure of the future and reconsidering certain goals or dreams.

It is important to give partners, family members and friends their own space to process the diagnosis, as they need to experience their emotions in their own way. It is important to continue to communicate openly with each other about the impact of the diagnosis.

Tips for coping with a Parkinson's diagnosis

Maintaining your identity

After receiving your diagnosis, it's important to remember that you are not defined by your condition. You have many important roles in your life and many dimensions to your identity. These roles may include being a spouse, partner, parent, sibling, child, accountant, golfer, artist or community volunteer. It is valuable to prioritise and embrace the aspects that define you who you are.

Be flexible

Parkinson's will require some changes to your overall lifestyle. This could include changes in your hobbies, daily activities or usual responsibilities. While acknowledging and embracing these changes can be challenging, it becomes easier when approached with flexibility and adaptability.

If certain tasks become more challenging, try to find modifications so you can continue to enjoy the activities rather than avoiding them. For example, if you enjoy camping in a tent, you might consider different bedding or opting for a caravan instead.

Always consider other options available to you. You'll often find that with an open and flexible mind there is usually a workable solution. An Occupational Therapist can help with strategies to retain or adjust activities that are important to you.

Disclosing your Parkinson's to others

When you feel ready, consider sharing with others that you have Parkinson's. Provide insights for your close network what life is like as you navigate the symptoms of Parkinson's. Sharing your experience can foster understanding, empathy and support from those around you.

The more you speak about your diagnosis, the less daunting it can become. With time, you'll find that while Parkinson's is now a part of your life, it no longer dominates your thoughts.

Many people aren't familiar with Parkinson's and its effects. If you feel comfortable, it may be beneficial to share your experiences of living with Parkinson's. You might choose to simply share that you have a Parkinson's diagnosis and, while it has affected certain aspects of your life, it does not define who you are.

Talking to Children

Children can be very perceptive and often pick up on symptoms. While it's a very personal choice of how much to explain to a child, focussing on providing reassurance and how you manage your current symptoms can assist with understanding.

Disclosing at work

Legally, for most occupations you are not obligated to disclose your Parkinson's diagnosis to your employer unless your symptoms present a potential risk to your own safety or to others in the workplace. It can, however, be beneficial to inform your employer, as making minor adjustments may enhance both your productivity and safety.

Symptoms

Some Parkinson's symptoms, such as fluctuations in ability to control facial expression may cause confusion to others. Helping people to better understand the condition can help to clarify why you may be able to do something well at times, or not so well at others.

Legal obligation

You are legally required to report any permanent or long-term illness that is likely to affect your ability to drive safely to your local licensing authority. You can refer to our Information Sheet, Driving and Parkinson's for more information.

Seek support

Don't be afraid to ask for help. Family and friends will want to help but may not know how to go about it. They will appreciate knowing what they can do to provide you with support.

Professional support can also make a positive difference for your wellbeing and mental health. Following a diagnosis, you may find you suddenly have a lot of overwhelming thoughts. Seek professional help from a counsellor for you and/or your loved ones can assist in adjusting to the diagnosis.

A counsellor has expertise in helping a person to work through their thoughts in a constructive way. Often, individuals find talking with a counsellor provides an opportunity to talk openly without fear emotionally burdening a loved one.

Peer Support can be a way for people living with Parkinson's to meet others in a similar situation. Fight Parkinson's has a range of peer support opportunities available. Visit our Information Sheet Benefits of Peer Support for further information.

Don't hesitate to seek information and support from Fight Parkinson's. From providing expert guidance in navigating the healthcare system to finding the best support for your Parkinson's journey, our team is here to help.

Maintain a sense of humour

Living with Parkinson’s can be frustrating and stressful at times. Try not to forget your sense of humour when things don’t go to plan. Ensure you find time to have fun, catch up with friends and Parkinson's laugh.

The importance of outlook

A positive and healthy attitude is vital to ensuring your quality of life is maintained and maximised. Where you can, try to maintain activities and continue to participate in social circles and/or clubs that you enjoy.

Stay active, eat well and laugh when you can. Maintaining a healthy lifestyle can help to ensure that Parkinson’s doesn’t consume your life and will put you in the best possible position to start and continue the journey that lies ahead.

Remember that Fight Parkinson’s is your leading source of comprehensive and evidenced-based Parkinson’s information, advice, support and services.

Reach out to our Health Team for any enquiries or to discuss any concerns you, your family members or friends may have regarding Parkinson's. Our Health Team can direct you to appropriate resources based on your needs. We are here to provide support and guidance every step of the way.

Living with Parkinson's

Understand your condition

Understanding Parkinson's is the first step to managing the symptoms that may occur.

Parkinson's is a complex condition that affects many areas, including movement. The symptoms you may experience are due to a breakdown of messages from the brain to the body.

Parkinson's has many symptoms that can affect each person differently and often vary across different days.

Seek expert health advice

It's very important that people with Parkinson's see a specialist doctor such as a Neurologist.

Other health workers can provide support, information, treatment and therapies to help with daily living, including:

- **Physiotherapist**: for advice on movement and exercises to help make tasks easier and safer.
- **Occupational therapist**: for practical advice and equipment to make every-day tasks such as eating, dressing and writing, easier.
- **Speech therapist**: for advice on communication, such as ways to make your voice louder and clearer and on managing swallowing difficulties.
- **Counsellor, psychologist, psychiatrist or social worker**: for support in coping with the emotional effects of Parkinson's.

Look after yourself

Keeping yourself healthy will help you manage living with Parkinson's. It will also give your body the best chance to cope with symptoms. Eating a balanced diet and exercising regularly helps keep your muscles flexible and strong, helping with balance, posture and movement.

One of the best exercises for people with Parkinson's is regular walking. You may also consider getting involved with a local strength training program. Speak with your treating doctors about starting to exercise and seek some guidance from a physiotherapist or Exercise physiologist to find the exercise which is best for you.

Exercise regularly

Exercising regularly is beneficial when you have Parkinson's. Some research indicates that regular exercise may slow the progression.

To ensure you remain safe while exercising it is recommended that you:

- seek support from a Physiotherapist or Exercise Physiologist to develop an exercise plan which is safe, and that you will enjoy,
- include strength, balance and aerobic activities and
- exercising for 45 minutes, 3-4 times a week.

Fight Parkinson's can assist you to find a Physiotherapist or an Exercise Physiologist who can assist you to start exercising.

There are also Parkinson's specific exercise programs in some locations, you can contact Fight Parkinson's to find out if there is a program close to you.

Prioritise Healthy Digestion

Constipation is a common problem for people with Parkinson's. The muscles responsible for bowel movement slowdown, which can lead to constipation. Way to help ease this symptom can include:

- Drink at least two litres of fluid per day unless you need to restrict fluids due to another medical condition.
- Eat plenty of fibre, found in fresh fruit and vegetables, or consider using a supplement such as psyllium husks.
- Stay as active as you can. Regular exercise can help to keep your bowel moving.

If constipation continues, talk to your doctor.

Prioritise healthy sleep

Parkinson’s can be tiring, so it’s important to get enough sleep. Sometimes, however, the condition and the medications used to treat it can lead to sleep disturbances. Some people even find that after a good night’s sleep, their symptoms improve the next morning.

Some strategies you can try to improve your sleep include:

- try to maintain a regular sleep routine
- avoid napping during the day
- try relaxation methods such as mindfulness, deep breathing and meditation
- avoid unnecessary stimulation before bed, e.g., don’t watch TV or exercise before bed and minimise light and noise in your bedroom
- restrict stimulating drinks such as coffee before bedtime

If these methods are not working, seek further advice from Fight Parkinson's or talk to your doctor about medications that may help.

Learn and utilise movement strategies

Sometimes moving in a different way or even thinking differently about movement can help people with Parkinson's manage their movement symptoms.

For example, for shaking or tremors:

- Try moving the body part that is shaking to a different position
- Hold onto something to give you more stability
- Press a shaking arm against your body

For walking difficulties (such as shuffling or feeling stuck in one spot) try the following:

1. Stop walking or stop trying to walk
2. Relax and take a full breath
3. Think about taking big steps
4. Begin to walk again

You can also try to look straight ahead or visualise a spot on the floor and try to step over it and count each step as you lift your feet.

A physiotherapist can provide techniques that may suit your individual situation.

Take precautions against falls

People with Parkinson's are at an increased risk of falling due to challenges with walking, balance and muscle weakness. Some medications can also increase the chance of falls due to lowering blood pressure.

Here are some simple strategies you can use to avoid falling:

- Wear comfortable, firm-fitting flat shoes with soles that grip.
- Make your home and surroundings as safe as possible.
- Think about different and/or safer ways of doing things that suit your abilities.

If you are experiencing issues with your balance or mobility, contact your treating doctor or Fight

Parkison's free Health Information line for assistance in determining how to reduce your risk of falls.

Look after your emotional wellbeing

It's common for people with Parkinson's to experience sadness or depression. Similarly, some people may experience feelings of nervousness or anxiousness.

It's important to talk about this with your treating doctor as this may be a symptom of Parkinson's, a response to receiving your diagnosis or a side-effect of medication.

Parkinson's brings many stresses and challenges, and it is important to get emotional support even if you do not feel depressed. It can help to meet or talk with other people who are going through the same experiences. There are also many organisations that can connect you with someone to talk to over the phone or in person.

Where to go for help

Parkinson's Information and support

Fight Parkinson's has specialist healthcare professionals who can provide support and information over the phone, online or in person. Information is available in many languages and a free interpreter service is available.

Fight Parkinson's free Health Information Service. The Fight Parkinson's multidiscipline Health Team staff the free Health Information line for anyone who is seeking Parkinson's advice, support and information about best practice management of Parkinson's. To access this free phone line call 1800 931 031.

Fight Parkinson's support groups run in many metropolitan and regional areas. Support groups are available for individuals living with Parkinson's, as well as family members and caregivers. These groups provide an opportunity to connect and engaging with others who share similar experiences. In these groups you will meet people at all stages of Parkinson's. Meeting someone with symptoms which are more advanced can be confronting when you are recently diagnosed.

If you are interested in attending a Support group meeting, Fight Parkinson's can assist you in connecting with your local group.

Young onset Parkinson's support groups provide information and support for people diagnosed at a younger age. Connecting with other individuals who are managing similar challenges, such as balancing family responsibilities or maintaining employment, can provide valuable support and insights for those living with Parkinson's. Contact Fight Parkinson's for more information.

Other **specialised peer support** or activity-based groups are available. Depending on your needs and interests, you may be suited to a more focused peer support group. Our Health Team can discuss the range of group options including:

- Therapeutic groups such as DBS or Infusion therapy
- Activity based groups including painting and singing.

Parkinson's information and education available online. The Fight Parkinson's website provides access to online events and seminars as well as self-directed learning options to maximising access to information wherever you may be.

Contact Fight Parkinson's for further details on upcoming sessions and programs.

Available resources for daily living

Movement Disorder Clinics provide specialist programs and advice to teach people with Parkinson's strategies to help improve or maintain mobility and activities of daily living. Reach out to Fight Parkinson's to find the nearest clinic in your area.

My Aged Care facilitates support and services to individuals aged 65 years or older. See **www.myagedcare.gov.au** or phone 1800 200 422.

National Disability Insurance Scheme provides support and services to eligible individuals who are aged under 65 years. Visit www.ndis.gov.au or phone 1800 800 110.

Services Australia provides payments and services for people in need, including people retiring or accessing aged care, people living with a disability, those looking for work and for those who care for others. Visit www.servicesaustralia.gov.au.

Local organisations who can also assist you:

- local councils / shires
- community health centres
- neighbourhood houses / community centres
- recreation and leisure services
- migrant resource centres

Resources as care needs increase

There are many available services that help people continue to live in their own home as they get older or as their care needs increase. Services include:

- help with personal care, such as bathing, dressing and eating
- home delivered meals and other food services
- assistance with housework, laundry, shopping and transport
- allied health services to improve or maintain independence and daily function, including physiotherapy, occupational therapy, speech pathology and podiatry

Services and supports may be provided through private providers, community health centres, community organisations or approved aged care and disability providers.

To explore service options in your area, contact My Aged Care on 1800 200 422 (if aged 65 years or older) or the NDIS on 1800 800 110 (if aged under 65 years).

Your local doctor can also be helpful in suggesting appropriate therapy or service options and in developing Allied Health or Mental Health care plans.

If you are unsure, contact the Health Information Service at Fight Parkinson's 1800 931 031 to discuss options relevant to your situation.

Help for carers

People who care for someone with Parkinson's need help and support too. There are services available that can help carers.

Carer Gateway is an Australia-wide network that provides free services and support for carers. Carer Gateway offers peer support, counselling, education, information about carer services and entitlements as well as access to emergency respite. Information is also available in other languages. Phone: 1800 422 737 or see www.carergateway.gov.au.

Centrelink: Most people who care for someone at home can receive financial assistance with a Carer Allowance. Some carers may be eligible for a Carer Payment. Phone Centrelink on 132 717.

Further information & support:

Fight Parkinson's: 1800 931 031 or info@parkinsons.vic.org.au | fightparkinsons.org.au

If you need an interpreter, phone: 131 450 and ask for an interpreter in your language to connect you to Fight Parkinson's. This is a free service.

Benefits of Peer Support

Living with Parkinson's or caring for someone with Parkinson's is full of challenges, but you don't have to feel alone. Fight Parkinson's currently operates numerous peer support groups.

A Peer Support Group (PSG) is an informal gathering of people who share similar experiences, situations or problems. Parkinson's peer groups are ideal for people living with Parkinson's, their carers, friends and family members. Meetings are informal and friendly and new participants are always welcome.

PSGs offer participants a chance to connect with others while offering each other emotional and practical support. Besides helping you feel less alone, a PSG gives you a chance to share your feelings and hear the experiences of others.

PSGs encourage knowledge-sharing. Learning from the experiences of others living with Parkinson's, as well as using professional resources, can help participants gain valuable insights and discover additional approaches to managing the symptoms of Parkinson's and overcoming challenges.

Peer groups can help you renew a sense of hope in dealing with changes to your lifestyle and offer you the chance to make new friends.

What to expect

Fight Parkinson's PSGs are not therapy groups. They are run by volunteers who may be a health professional from the local area, a person living with Parkinson's or a carer.

PSGs appeal to a range of people for a variety of reasons. While there are opportunities for people to be involved in the planning of meetings and activities, other participants prefer to simply enjoy the company.

The groups vary, from the number of participants to the age and interests of the individuals. Some groups run in person, others run online and some use a hybrid model.

Peer group meetings typically involve:

- group discussions and sharing experiences, information, practical tips and advice on living with Parkinson's
- connections to the Fight Parkinson's Health Team
- social activities and day excursions
- guest speakers discussing topical and relevant subjects. These may include occupational therapists, social workers and doctors

When you join a PSG meeting, you may meet people who have had Parkinson's for longer than you. You'll meet people who have had different experiences and symptoms from yours. Don't be afraid of these differences! No two people with Parkinson's are the same and it's important to remember that everyone's journey is unique.

To find out where your nearest Parkinson's PSG is, contact Fight Parkinson's.

Note: While participants may discuss their experiences of Parkinson's during meetings, it is important to remember that everyone has different symptoms and will respond differently to treatments. Professional advice must be sought before altering any treatment.

Employment and Parkinson's

Parkinson's is a progressive neurological condition, characterised by both motor (movement) and non-motor symptoms.

Whilst the average age of diagnosis is 65, Parkinson's can affect adults of any age. It is estimated that 1 in 5 people living with Parkinson's are aged under 50 or of working age, often referred to as Young Onset Parkinson's.

In addition to rigidity and tremor, visible symptoms that may affect employment include decreased facial expression, microphonia (quiet voice) and micrographia (small handwriting). Other less visible symptoms include slower thinking and challenges with problem solving.

The impact an individual's Parkinson's has on their employment will depend on the nature of the work and symptoms experienced. Mild symptoms, such as a slight tremor may not affect employment at all.

Many people diagnosed with Parkinson's will be keen to remain in the workforce. In addition to the financial benefit of employment, work is often strongly associated with an individual's sense of identity, independence, self-esteem and social connection.

With medication and support following diagnosis, together with understanding and adjustments from colleagues and employers, productive and rewarding employment can be possible.

Disclosure:

Individuals with Parkinson's may face the dilemma of whether to disclose their diagnosis to their current or prospective employer. Generally speaking, there is no legal obligation to disclose your diagnosis.

If you are requested to complete a pre-employment health questionnaire or medical examination, you do not have to disclose your condition unless it is relevant to the job. It is important to disclose your condition if your ability to perform your duties is affected and is especially critical if your symptoms have the potential to create an unsafe workplace for you or others.

For some, disclosing a diagnosis may be a positive step. It may explain visible problems, reduce stress levels arising from attempting to disguise symptoms and enable simple changes to assist with productivity and safety.

Parkinson's and employment discrimination:

It is illegal for your employer to discriminate on the grounds of a Parkinson's diagnosis and employers should take reasonable steps to support you. Examples of reasonable steps may include changes to your work environment, greater flexibility with work hours or allowing more breaks. If you are requesting some workplace modifications, you will need to disclose your diagnosis with your employer.

In addition to Federal legislation, each State and Territory have specific rulings to address the needs of both the employer and employee in cases where disability impacts employment. Individual advice should be sought from the relevant authority. Workers' compensation legislation may apply in some circumstances.

Disability Employment Services:

Disability Employment Services (DES) is a government-funded employment service that may support people with Parkinson's in seeking or maintaining employment, including funding towards necessary workplace modifications (Employment Assistance Fund) and developing practices that support both employees and employers.

Employees or employers can explore these options through the national website; Job Access; www.jobaccess.gov.au or by calling 1800 464 800.

Managing symptoms at work:

- **Incorporate regular breaks**: Pace yourself as fatigue can impact both work and leisure time. Scheduling regular breaks may help focus your attention and improve productivity.
- **Manage stress and anxiety**: Recognise the causes of stress and the parts of the day when you feel anxious. Seeing a psychologist or counsellor may help or you may consider trying some relaxation strategies.
- **Allow sufficient time**: Bradykinesia, characterised by slowness of movement, may mean you require more time and effort to complete tasks, leading to fatigue. To manage this, consider adjusting your schedule and allowing extra time for tasks. Open communication with your employer about your needs can be highly beneficial in maintaining deadlines and schedules.
- **Consider the environment**: Some work environments can involve lots of distractions which can be challenging for individuals whose ability to multi-task is impaired. Completing one task before starting another, minimising distractions and maintaining an uncluttered work environment can assist.
- **Consider how you work**: Changes in mobility and hand function, sustained body positions, repetitive tasks, pain and fatigue may all contribute to challenges with managing work duties. An occupational therapist may be able to suggest workplace modifications, assistive technology or strategies to help. Reduced speech volume and vocal changes may impact telephone and office dialogue. Speech therapy may be beneficial in maintaining optimum communication.
- **Perform complex tasks when at your best**: Consider scheduling important tasks when you feel your best and your medication is working well. Plan by allowing more time to complete tasks or by breaking them down so they seem more manageable.

Seeking professional guidance and support:

Some individuals will benefit from more customised strategies and therapies to help them maintain, improve or adjust work-related skills, duties and roles. Allied Health may be particularly useful for addressing concerns relating to communication, mobility, mood, productivity and safety.

If an individual is under 65 years and eligible for the National Disability Insurance Scheme (NDIS), they may be able to pursue funded therapies, assistance or work-place modifications to help them achieve their work-related goals. These supports are generally greater than what may be provided by an employer or by the DES.

As an alternative, individuals may be able to pursue other, government-subsidised supports and therapies or access privately funded therapy options.

Planning:

Initially, symptoms may be mild and major lifestyle changes may be avoided. This can allow for a period of adjustment and to plan with realistic expectations.

You should seek professional legal and/or financial advice before making any changes to your working hours or consider premature retirement. It's important to know that hasty decisions to reduce your hours or terminate your employment may affect access to certain employment benefits, insurances or superannuation entitlements.

Further Information:

Job Access: www.jobaccess.gov.au or call 1800 464 800

National Disability Insurance Scheme (NDIS): www.ndis.gov.au or call 1800 800 110

Driving and Parkinson's

Living with Parkinson's can affect many drivers, but it doesn't necessarily mean that you will be unable to drive.

Parkinson's is a progressive neurological condition, characterised by both motor (movement) and non-motor symptoms.

Most people wish to continue driving for as long as possible. Driving can be important for maintaining social interactions and independence, as well as providing a sense of freedom and enjoyment.

Part of your responsibility as a driver is ensuring you remain capable of driving safely. Your safety when driving may be impacted by illness, disability, certain medical conditions or medications. It is a legal requirement to report your Parkinson's diagnosis to the licencing authority who issued your driver's licence.

You may need to have more regular health checks to ensure your Parkinson's is well managed. To continue driving, there may need to be some conditions or restrictions placed on your licence.

The complexity of driving

Driving is a complex task that requires perception, good judgement and reasonable physical capability.

Cognitive abilities such as attention, scanning, memory, concentration, spatial awareness, coordination, anticipation and responsiveness are used in combination with one's physical ability to safely enter and exit the vehicle, fasten a seatbelt, steer, perform head checks and manage foot and hand controls.

Symptoms and driving

Some symptoms of Parkinson's that may influence driving ability or make driving more challenging might include:

- Slowed movements
- Muscle rigidity
- Involuntary movements
- Changes in hand dexterity
- Motor fluctuations
- Fatigue
- Anxiety
- Concentration difficulties
- Difficulty with multitasking

Your legal responsibilities

Reporting your condition to your licensing authority

All states and territories in Australia have agreed to the rules surrounding health and driving.

You are legally required to report any permanent or long-term illness that is likely to affect your ability to drive safely to your local licensing authority. A diagnosis of Parkinson's falls into this category. Failure to report your diagnosis may jeopardise your insurance cover and potentially put lives at risk.

Reporting a condition does not necessarily mean your licence will be taken away.

Process for reporting

To report your condition, a medical report needs to be submitted (most commonly online) to your local licensing authority

Only certain health professionals can make a formal recommendation regarding your fitness to drive; these professionals are listed in your State or Territory road transport legislation ('Assessing Fitness to Drive'; Appendix 3.2).

Your treating healthcare professional will assess your health and ability to drive safely and submit a medical report indicating whether you meet the medical standards to drive a vehicle, as specified in a national publication; 'Assessing fitness to drive' (Austroads Assessing Fitness to Drive).

The health professional confirms:

- your medical condition/s
- whether you meet the medical standards to drive
- whether you undergo an on-road driving assessment

The health professional most commonly able to submit a medical report is your local doctor. You may like to book a longer consultation than usual to discuss this.

What If I drive a commercial vehicle?

It is important you also inform your treating healthcare professional if you drive a commercial vehicle, such as a truck or public passenger vehicle. Even if you don't meet the health standards to drive a commercial vehicle, you may still be able to continue driving a private vehicle.

Can someone report concerns about your ability to drive safely?

If a family member or someone in your community has concerns about your ability to drive safely, they can report their concerns to your State or Territory licensing authority. This can be done anonymously and will likely result in a request for you to submit a medical report.

Motor vehicle insurance

In addition to notifying the licensing authority in your State or Territory, it is recommended that you check the "duty of disclosure" clause of your motor vehicle insurance policy.

It is difficult to say how disclosing your diagnosis will impact your insurance premium, as all insurers are different, but make sure you check the fine print of your policy.

The licensing authority will determine next steps

The driver licensing authority considers the advice provided in the medical report and will make the final decision about your licence status. They will inform you of any further steps required. Possible recommendations may include:

- Continue driving, with the requirement to submit periodic medical reports
- Undergo a specialised occupational therapy driving assessment
- Suspension or cancellation of licence

What happens if I need an on-road driving assessment?

You may be required to have an **occupational therapy driving assessment**. This is with a specialised Occupational Therapist (OT) who has an extra qualification as a driving assessor.

There are two parts to this assessment:

- Off-road: Medical history, driving history, vision and hearing checks and road law knowledge

- On-road: Dual-control car, with an instructor in the front passenger seat and OT Driving Assessor in the rear passenger seat

The OT Driving Assessors role is to evaluate your ability to continue to drive safely, legally and independently. They provide advice on how your Parkinson's could impact your driving and make recommendations for how to manage and monitor any issues identified.

Some possible recommendations may include periodic reviews, driving at certain times such as daylight hours only or off-peak times, driving locally within a certain radius of home, or modifications to the vehicle such as alternative controls. Some recommendations may result in a conditional licence.

In more rare instances, if there are significant safety concerns, an OT can recommend a licence suspension or cancellation.

Can I appeal a decision?

Information about appealing licence decisions is available through your State or Territory licensing authority.

Accessible Parking Permits

Accessible Parking Permits enable people with certain conditions, disabilities or impairments to park in accessible parking bays or to park in standard parking bays for double the time displayed on the parking sign.

You may be able to apply as a driver, a passenger or as both.

Depending on your State or Territory, these may also be referred to as disability parking permits.

All application enquires should be directed to your relevant State or Territory Authority (refer below for weblink).

Further Information:

Austroads - www.austroads.com.au

'Driving and health: Your questions answered' publication: Austroads: Driver Patient Fact Sheet

Assessing Fitness to Drive for commercial and private vehicle drivers (2022): Austroads Assessing Fitness to Drive

State and Territory licensing authorities:

Australian Capital Territory
Access Canberra
www.accesscanberra.act.gov.au

New South Wales
Transport for NSW
www.rms.nsw.gov.au

Northern Territory
Motor Vehicle Registry
www.nt.gov.au

Queensland
Department of Transport and Main Roads
www.tmr.qld.gov.au

South Australia
Department for Infrastructure and Transport
www.sa.gov.au

Tasmania
Department of State Growth
www.transport.tas.gov.au

Victoria
VicRoads Medical Review
www.vicroads.vic.gov.au/licences/medical-conditions-and-driving/medical-review

Western Australia
Department of Transport
www.transport.wa.gov.au

Australian Disability Parking Scheme:

Australian Disability Parking Scheme; State and Territory websites

Parkinson's Research

Fight Parkinson's supports and encourages ethical research which contributes to the knowledge about Parkinson's and to development of evidence-based therapies and treatments.

Research is vital to discover more about Parkinson's including its symptoms and possible causes. Research plays an essential role in developing new treatments and discovering a cure.

Fight Parkinson's plays an important role in funding and supporting research into Parkinson's. The Fight Parkinson's Research Committee considers current research projects and requests for research support and is made up of scientists, clinicians and people living with Parkinson's.

We support research:

- that provides insight into Parkinson's and furthers our understanding of the condition to find a cure for Parkinson's and Atypical Parkinson's
- to assist people in both managing symptoms and living with Parkinson's
- that enhances the quality of life and independence of those living with Parkinson's
- Research which is co-designed with people living with Parkinson's and Atypical Parkinson's (PSP, MSA and CBS)

Through donations and bequests, supporters can help fund valuable research projects. In addition, the Parkinson's and wider community can play a vital role directly by participating in various studies.

Impactful examples of Parkinson's research studies include:

- Treat-to-target: objectively monitor motor symptoms via watch technology to assess whether a person with Parkinson's has appropriate treatment and to judge the effect of changes to therapy at subsequent visits.
- Designing Evidence-Based exercise Programs for people living with Progressive Supranuclear Palsy (PSP)
- ParkinDance: a two-year, randomised control trial looking at the specific dose of physical activity, in the form of dance, needed to have a positive benefit on the symptoms of Parkinson's.
- ParkinSong: a controlled trial of singing-based therapy for Parkinson's disease which therapeutically informed, intensive effort singing increased vocal intensity, MEP, and voice-related quality of life.

Research into Parkinson's is ongoing. There are projects currently taking place throughout Australia and internationally, varying in scope, area of interest and level of participant involvement.

Fight Parkinson's Research Agenda

Developing a strong Australian research agenda is central to Fight Parkinson's mission. Fight Parkinson's has developed a research platform to provide clear direction for increased investment within the research sector through scholarships, fellowships and strategic partnerships, to:

- better understand the impact of living with Parkinson's
- raise awareness with respect to the benefits of research investment
- seek participation from the Parkinson's community in research trials
- increase reporting of research with the community (including donors and supporters) of outcomes, results and breakthroughs
- contribute to innovative, world leading research that advances the search for a cure

Participating in research

Participation in Parkinson's research is important to further the understanding of the condition and ultimately to improve the quality of life for those who are living with Parkinson's now and into the future.

Both people with and without Parkinson's can participate in Parkinson's-related research projects.

Participation in research projects may include the process of diagnosis, development of new therapies and quality of life studies.

Prospective research participants will be provided comprehensive information to explain what is involved.

Our Health Team may be able to assist with information and advice on current research opportunities.

If you are interested in becoming involved in research, the Australian and New Zealand Clinical Trials Registry (ANZCTR) is a helpful resource which provides an online registry of clinical trials taking place in Australia and New Zealand.

You can search the register and refine your search to trials related to Parkinson's and Atypical Parkinson's - www.anzctr.org.au.

You may also wish to discuss research and clinical trial opportunities with your treating Neurologist.

Donations for research

With your support, Fight Parkinson's can invest in research projects that improve the quality of life for people with Parkinson's. Fight Parkinson's relies on generous support from individuals, corporations, the government and community groups to support research that improves the quality of life for people with Parkinson's and advances the search for a cure.

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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