



### Recently diagnosed with Parkinson's

People who have been recently diagnosed with Parkinson's often feel confused. They may be overwhelmed with doubts and questions, feel emotionally distressed and not know where to find the answers they so desperately need.

Start with Parkinson's NSW. We exist to support people living with Parkinson's and their loved ones. We offer evidence-based information and advice through our **1800 HealthLine**, specialised nursing and counselling services, education events, website and social media.

### Living with Parkinson's

The Parkinson's NSW logo includes these words: In This Together. That's more than just a slogan. It's a promise that when you come to us for help, we will travel side by side with you on your Parkinson's journey.

We will ensure that you receive accurate information and can assist you to build your support network of medical, allied health and other professionals.

### Caring for someone with Parkinson's

Parkinson's NSW understands that caring can take its toll, so our support is here for you too.

Carers also have many questions when a Parkinson's diagnosis is received by your partner or family member. You will need information about how to help manage various symptoms and provide practical help and emotional support to your loved one.

## Our Vision

A Parkinson's community empowered every step of the way.

## Our Purpose

We support, enable and advocate for and with people living with Parkinson's and their communities.

## We're here to help you

When Parkinson's enters your life, you may feel uncertain about what the future holds for you and your loved ones. Receiving a Parkinson's diagnosis can be confronting. However, because we are here, no one has to face Parkinson's alone.

### Get in touch

☎ 1800 644 189

✉ [pnsw@parkinsonsnsw.org.au](mailto:pnsw@parkinsonsnsw.org.au)

💻 [www.parkinsonsnsw.org.au](http://www.parkinsonsnsw.org.au)



Connect with us



# Do you know someone living with Parkinson's?



# What is Parkinson's disease?

Parkinson's is a progressive, degenerative neurological condition. It affects the brain's ability to control movement and is also associated with many non-movement disorders including apathy, anxiety, and depression.

There is no cure, but there is hope and support available.

In Australia, every hour of every day someone is diagnosed with Parkinson's. Up to **212,000\*** Australians are living with the disease – however the Parkinson's community is more than double that number including family and carers as well.

The average age of diagnosis is **60**. However **18%** of people diagnosed are of working age and **10%** are under the age of **40**.

## What causes Parkinson's?

The causes of Parkinson's are not yet known. People living with Parkinson's have reduced levels of a chemical messenger in the brain called dopamine. This chemical facilitates smooth and easy movement. Parkinson's causes loss of dopamine over time – making movement more difficult.

## What are the main symptoms of Parkinson's?

Parkinson's has more than 50 symptoms. This makes it difficult to diagnose and complex to manage. Each individual experiences a different combination of symptoms at different times, and with different effects.

Some of the most common movement-related symptoms include shaking (tremor), stiffness (rigidity), slow movement (bradykinesia) and balance (postural instability). Not everyone develops all these symptoms. For example, about 30% of patients do not develop a tremor.

## Parkinson's NSW services

Whether you have received a Parkinson's diagnosis or are a carer, carer, or friend, you will need different services at different times. Parkinson's NSW offers a range of services and supports to accommodate a variety of needs.

\*Ayton, D., Ayton, S., Bush, A., and Warren N. (2018). Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism & Related Disorders*.



## HealthLine

The Parkinson's NSW HealthLine is the gateway to all our services. When you call, there will be an initial conversation to determine your concerns, needs and priority. Then you will be connected with the services you require in a timely manner. These services include Parkinson's Registered Nurses, counsellors, and NDIS advocates. You can also be linked with your local Support Group and other services in your area. Call the HealthLine on 1800 644 189.



## Counselling

No matter how you are affected by Parkinson's, our qualified counsellors can provide the support you need. Confidential face-to-face, phone and teleconferencing appointments are available. Contact the HealthLine to arrange an appointment.



## Support Groups

Living with Parkinson's can be isolating so meeting with others in the same situation can have a positive impact. Parkinson's NSW has a network of more than 70 Support Groups across NSW, as well as specialised Groups for people with early onset Parkinson's (under 60 years) and carers. Join a Group to share experiences, hear about new developments from knowledgeable speakers and health professionals and meet new friends.



## Information and Education

Parkinson's NSW education seminars are held regularly across NSW. Attending these will give you updates on the latest treatment options, research, programs, and services. Visit our website and follow us on Facebook @parkinsonsnsw for a full list of dates and locations.



## Community-based Parkinson's Nurses

We have Parkinson's Specialist Nurses in regional areas across NSW. These nurses can assist with the management of Parkinson's and provide information and emotional support. We are continuing to grow our network of nurses in regional areas.

## Support for Research

Parkinson's NSW helps to connect people living with Parkinson's with research participation opportunities. As a service delivery organisation, we particularly support research focused on the wellbeing of people living with Parkinson's at home in their community – including improving the effectiveness of Support Groups, exploring the value of multidisciplinary clinical teams, and developing more ways of delivering services to regional and rural areas – for example, through telemedicine.

## Raising Awareness

In addition to delivering services and support, Parkinson's NSW raises awareness of the challenges of living with Parkinson's. We advocate to State and Federal Ministers, publicise issues and breakthroughs, and partner with hospitals, clinics, Local Health Districts and Primary Healthcare Networks.

## Fundraising

Parkinson's NSW compensates for a lack of government funding by conducting online and in-person fundraising events throughout the year.

For people who want to help more, we provide guidance on setting up monthly donations, as well as birthday, anniversary, or in-memoriam donations and bequests.

## Living Well

Exercise – along with medication management and knowledge – is a particularly effective way for people living with Parkinson's to improve their quality of life.

Call the **Parkinson's NSW HealthLine** on **1800 644 189** or visit our website for updates on suitable programs available in your area.

## National Disability Insurance Scheme (NDIS)

Parkinson's NSW is a Registered NDIS Service Provider and your main point of contact for NDIS questions and information about requirements.

We will help you understand your options, support your preparation for entry into the NDIS, then link you with the services you require.