

Welcome to your Support Group Manual

When Sydney man Don Gration was diagnosed with Parkinson's in 1979, he and wife Joan found there were few sources of information about the disease and no support or advice available from others in the same situation.

The couple founded what they described as 'a mutual self-help society' called The Parkinson's Syndrome Society of Australia. It was really the first Parkinson's Support Group, and the forerunner of Parkinson's NSW.

Today our name is different, and our remit is broader, but the Support Group model endures.

Support Groups function within their local communities or geographic areas but they are not autonomous; they are part of Parkinson's NSW and supported by employees of our organisation.

You represent your Group participants and community to Parkinson's NSW. You also represent your Group and Parkinson's NSW to your community.

As the words on the Parkinson's NSW logo say, we're *IN THIS TOGETHER*.

That's why this *Support Group Manual* and the accompanying *Support Group Guidelines* are so important.

These documents will help to clarify and standardise how we work together for mutual benefit.

The *Guidelines* are a blueprint for effective governance and legal compliance, because your Group is representing a registered charity.

This *Manual* provides you with the tools you require to operate an effective, sustainable Parkinson's NSW Support Group.

It is designed for frequent reference and includes contact details for more information on each topic if required.

We believe you will find this resource useful and would welcome your feedback on how it might be expanded or improved to better meet your needs.



Jo-Anne Reeves
Chief Executive Officer

Vision – Our aspiration

Quality of life now, as we work towards a community free of Parkinson's.

Mission – Our focus

To enhance the quality of life of people living with Parkinson's.

Purpose – What we do

To connect people living with Parkinson's with life-enhancing support and services.

Services

Parkinson's NSW services for people living with Parkinson's include an InfoLine staffed by experienced Registered Parkinson's Nurses, community-based Parkinson's Specialist Nurses, counselling, exercise physiology, education, and social work.

We also offer advocacy for people living with Parkinson's under the age of 65 who are applying for funding under the National Disability Insurance Scheme (NDIS).

Parkinson's NSW is a Registered Service Provider of the National Disability Insurance Scheme delivering the following services:

- Support coordination – implementing all of the supports funded by a person's NDIS Plan and teaching them how to manage their supports.
- Coordination of supports – helping people to develop greater independence and the ability to self-direct their supports over the longer term.
- Speech pathology.
- Physiotherapy.
- Exercise physiology.
- Group skills training.

Parkinson's NSW is also applying to become Approved Services Provider for My Aged Care. This will enable us to deliver a similar range of services within the NSW aged care system.