

Sharing your story

Your personal experience can be one of the most powerful ways to help others understand the impact of Parkinson's.

Whether you are living with Parkinson's, caring for someone or supporting a family member, your story can help decision-makers understand the challenges people face and why better access to services and support matters.

You don't need to be an experienced speaker or writer. Your story, told in your own words, is what matters.

What makes a good advocacy story?

1. Introduce yourself

Briefly explain your connection to Parkinson's. You might mention how long you've been living with the condition or your experience as a care partner or family member.

2. Explain how Parkinson's affects everyday life

Share one or two examples that help others understand your experience. This might include changes to daily activities, employment, relationships, caring responsibilities or independence.

3. Talk about the support you need

Have you experienced difficulties accessing specialist healthcare, obtaining reliable information or finding support close to home? Explain what happened and how it affected you or your family.

4. Explain what would make a difference

Think about what could improve your experience or that of others in your community. For example, better access to Parkinson's Specialist Nurses, timely advice or more coordinated care.

5. Finish with a clear message

Explain what would make a difference to you and others affected by Parkinson's. If you're speaking with an MP, you might ask them to support greater NSW Government investment in specialist Parkinson's services.

A few tips to remember

- Keep your story focused on two or three key points.
- Use everyday language rather than medical terminology.
- Include a specific example that illustrates your experience.
- Be honest about the challenges, but share only what you feel comfortable discussing.
- You don't need to speak on behalf of everyone living with Parkinson's. Your own experience is valuable.

Putting your story into action

Your story can be shared in a letter or email to your local MP, during a meeting, through local media or on social media.

You can also use your experience to support Parkinson's NSW's advocacy for greater government commitment to Parkinson's services.