

Exploring why support matters and how to offer support

## Support matters

People with Parkinson's are often overlooked or misunderstood—in the health system, at work, and even at home. In *Placing Unheard Voices*, participants spoke about experiencing invisible symptoms and how many had chosen to 'pass'—to hide their diagnosis—because they were told they looked too well to have Parkinson's or were advised to seek another opinion.

Another major reason for 'passing' was a lack of social support. Many participants felt wary about sharing their vulnerabilities due to previous experiences of being dismissed or unsupported. They described this lack of support as frustrating, isolating, and deeply concerning.

*“There is very little social support to navigate work, healthcare, parenting, relationships—and we badly need it. Our families need it too—urgently.”*

Regardless of age at diagnosis, participants described a widespread lack of social support services—intensified by financial strain, especially for those diagnosed younger.

Social science research has been slow to consider these everyday social realities. More studies are needed to understand how social factors shape the experience of Parkinson's and how everyday interactions impact quality of life.

## Thoughtful support makes a difference. But what does support really mean?

We often talk about social support, but don't always pause to define what it means to each person. It can look very different depending on context, timing, and personal needs.

## Advice from participants in *Placing Unheard Voices*:

- Ask, don't assume – Everyone's experience is different.
- Be patient – Speech and movement may slow, but understanding goes a long way.
- Respect boundaries – Some people may want help; others value independence.
- Stay flexible – Symptoms fluctuate. What's possible one day may not be the next.
- Don't disappear – Even if you don't know what to say, your presence matters.

The following research poem offers a few reminders drawn from participant reflections:

Try not to say –

“But you don't look sick.”

“You're too young for that.”

“Have you tried...”

“My uncle had that and...”

Support isn't fixing –

my condition is progressive,

incurable,

but if you're standing

beside me

when the road gets uneven,

I know I can

make it up that road.

