

Exploring invisible symptoms and how poetic methods may help those experiencing them to be heard and seen

What do researchers mean by ‘seen’ and ‘unseen’ symptoms of Parkinson’s?

What Can’t Be Seen?

Many symptoms of Parkinson’s are invisible—unseen by others but deeply felt by those living with them. These symptoms shape daily life in powerful ways. Naming them is important. When we don’t name something, we can’t examine it or build a relationship with it that allows for understanding or growth.

Common Invisible Symptoms in Parkinson’s:

- Fatigue – A deep, consuming tiredness that doesn’t go away.
- Anxiety & Depression – Emotional changes that may precede or accompany physical symptoms.
- Sleep Disturbance – Vivid dreams, insomnia, acting out dreams (REM sleep behaviour disorder).
- Cognitive Changes – Difficulty focusing, memory lapses, or brain fog.
- Pain – Neurological discomfort, muscle stiffness, or joint pain.
- Autonomic Issues – Digestive problems, low blood pressure, bladder issues.

Voices from participants in *Placing Unheard Voices* on invisible symptoms:

“People only notice the shake, not the six hours of exhaustion that follow.”

“I’m not lazy. I’m navigating brain fog and fatigue.”

“I dream loudly. Sometimes I wake up fighting.”

Reflection Prompt from *Placing Unheard Voices*

What's one thing others don't see about your experience with Parkinson's?
Write it down and consider how you could give it a voice.

Poem of the Unseen

Hands once all mine
you see
but you don't know
my hands are not my
nights
You don't notice
my voice
You think I am quiet
but inside
I am louder
than a river
and powerful
I hold a storm still
in the deepest of night's chill



Making the Invisible Visible

To speak the invisible is to reclaim it.

Creative expression helps surface the parts of illness that are not easily seen. This is empowering for people with chronic illness—it offers agency over one's story and increases visibility.

If you're engaging with poetry in your own research or reflection, begin by reading and writing as much as you can. As you do, consider these questions:

- How can you write poems or metaphors that express your inner world?
- What kinds of visuals, textures, or imagery could represent what you feel—emotionally and physically (e.g., pain, fear, strength, joy)?

Tip: Choose concrete metaphors to ground your expressions in sensory detail.