

# FIELD NOTES #6



from the **Placing** Unheard Voices Study

**Exploring** what Parkinson's feels like and **how to relate to someone else's illness**

from your place in the world

## Understanding the lived experience of Parkinson's

Understanding what it means to live with Parkinson's or any illness, looking in from the outside, is a challenge whether you're a researcher, health professional, family member, friend, or colleague of someone managing illness. Even if you share a diagnosis – as I did with participants in *Placing Unheard Voices* – it is still tricky to put yourself in someone else's shoes at a deep level and comprehend the details and nuances of someone else's experiences.

### The unseen story of Parkinson's

Common myths about Parkinson's include the idea that it always entails tremors, or that shaking is all there is to Parkinson's. There is a startling array of possible symptoms associated with Parkinson's

and it is a condition that manifests differently for each person. It also changes shape throughout the day. That means living with Parkinson's is a life spent navigating constant change, sometimes moment to moment.

Change can, of course be productive and positive. Unplanned, and sometimes unwanted change driven by illness can be confronting. Illness is not just about physical change, but social and symbolic, change too making it a potentially profound experience. Isolation can accompany this kind of change, especially in those times when words are insufficient to explain what we are facing. The poem shown here illustrates my experience of this.

Another good example is my hands. These days my hands may work at 10am then decide they're on holiday until 5pm so that I have to work in the evening.



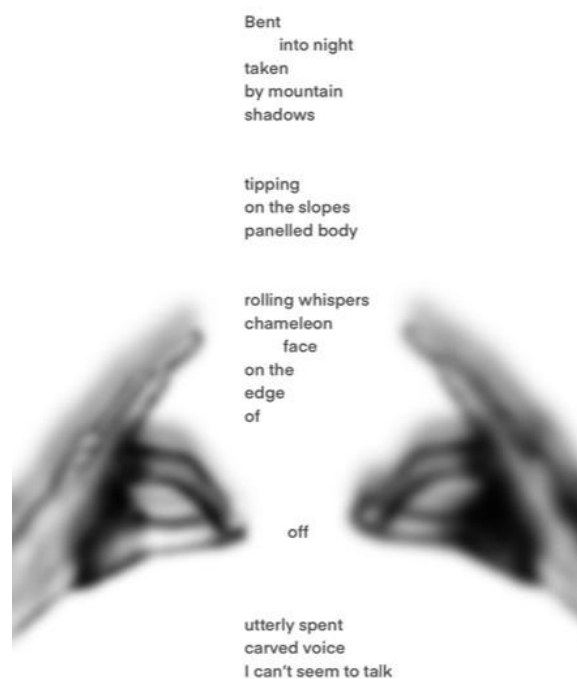
Or I may find I can type at the computer all day with no problem, until a few days later I cannot! Due to such unpredictability, planning things and meeting deadlines becomes stressful. In turn, my identity as an effective researcher and colleague, a reliable friend, can be destabilised. When that happens, it takes dedicated effort to avoid anxiety and depression.

If you asked me to summarise what this all means for daily life with Parkinson's, I'd say it can make Parkinson's *feel* like being on an edge or caught in wild weather that cannot be controlled. It is often a feeling of losing things that are important – things that are physical, social and symbolic and make us who we are. yet may not be recognised by others as important or a loss.

These poetic phrases used by participants in *Placing Unheard Voices* to describe the meaning of Parkinson's, hint at the emotional, social and symbolic sensations of life with Parkinson's:

- walking through deepening water.
- a violin string, stretched too tight.
- the weight of a body filled with concrete
- a heavy veil, stiff
- a flickering light
- caught in-between.

What are the implications of all this for how Parkinson's feels day to day? For me, Parkinson's becomes a weighty and complexly layered experience – difficult to explain in plain language and demanding to navigate. Poetry, music and art make it easier to convey the depth of the experience.



For More Reflections & Stories: Visit *Placing Unheard Voices* at [www.placingunheardvoices.org](http://www.placingunheardvoices.org)

