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—from the outside is difficult. Whether you're a researcher, healthcare professional, friend, colleague, or family member, it can be hard to grasp the depth and complexity of someone else's experience. Even when you share a diagnosis, as I did with participants in Placing Unheard Voices truly understanding another person's experience takes care, attention, and humility.

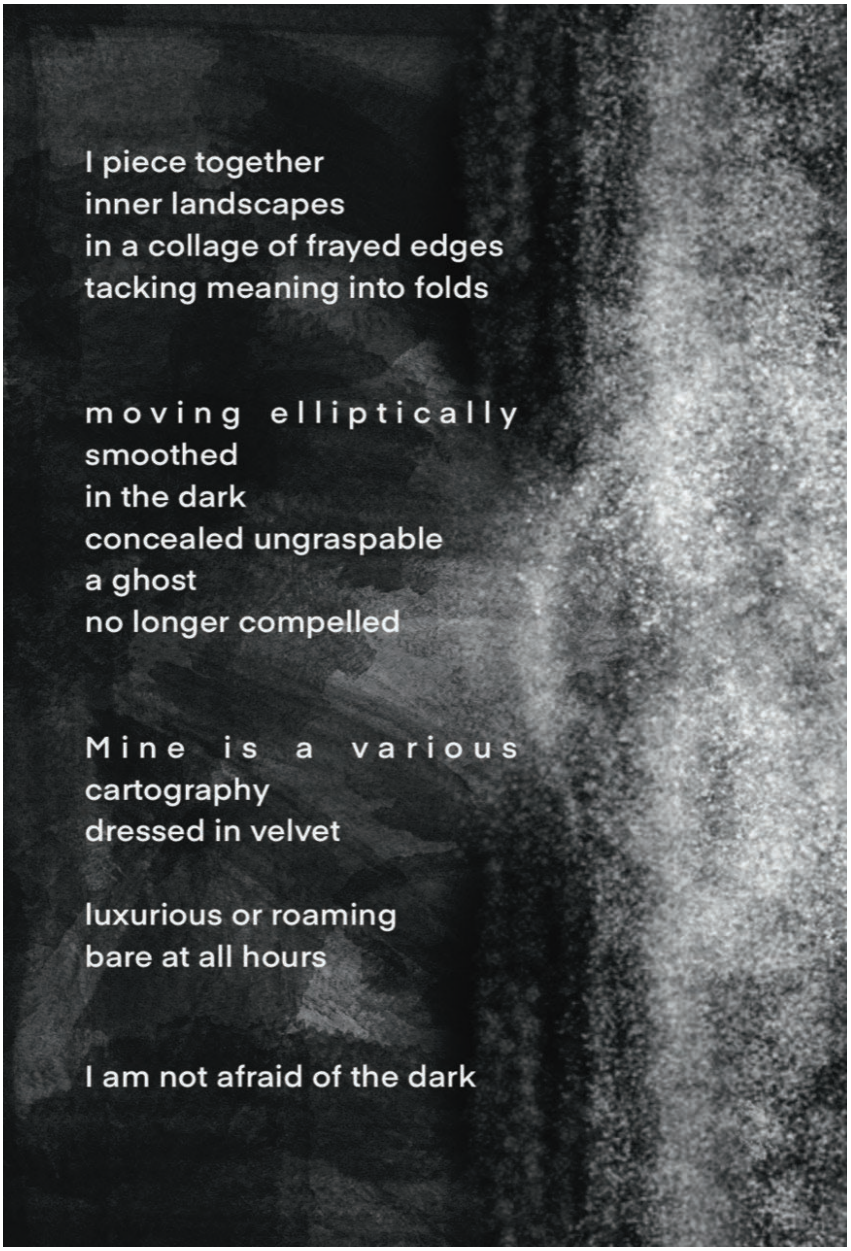
The unseen story of Parkinson's

There are many myths about Parkinson's—one of the most common being that it is defined only by tremors. Parkinson's presents a wide and shifting array of symptoms that vary from person to person and can change throughout the day. Living with Parkinson's means living with constant change—sometimes moment to moment.

Not all change is negative, of course. But when illness brings unplanned and unwanted changes, the impact can be physical, emotional, social, and symbolic. It can be profoundly disorienting. At times, language feels inadequate to describe what is happening. The poem shown here captures one of my own experiences of this.

Take my hands, for example. Some days they work fine at 10am, then 'go on holiday' until 5pm. Other days, I can type all day with no issue—then find I cannot type at all for days. This unpredictability makes planning difficult and meeting deadlines stressful. Over time, it can erode one's identity as a competent researcher, a reliable friend, or an effective colleague. When that happens, it takes real effort to stave off anxiety or depression.

If I had to summarise what Parkinson's feels like in everyday life, I'd say it's like standing at an edge, or being caught in wild, unpredictable weather. It can feel like the gradual loss of things that once defined you—physical, social, symbolic things that might not even be recognised as losses by others.



I piece together
inner landscapes
in a collage of frayed edges
tacking meaning into folds

moving elliptically
smoothed
in the dark
concealed ungraspable
a ghost
no longer compelled

Mine is a various
cartography
dressed in velvet

luxurious or roaming
bare at all hours

I am not afraid of the dark

Here are some poetic phrases participants used to describe what Parkinson’s feels like:

- **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**

These lines reveal the sensations and emotions of living with Parkinson’s.

For me, Parkinson’s is a weighty, layered experience that resists plain explanation. It is demanding to live with and even harder to describe. That is why poetry and art can help. They give us new ways to communicate depth and feeling—when words alone are not enough.