

People with Huntington's want more openness around assisted dying

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Many patients feared prolonged suffering at the end of their lives. Credit: Lancaster University

Research has shown that better communication around assisted dying is needed between clinician and patients diagnosed with Huntington's

Disease.

This is the first study in the UK (where assisted dying is illegal) into the attitudes of people with the condition, which usually leads to dementia and inability to coordinate movement.

Because it is inherited, people with a diagnosis will often have witnessed the [suffering](#) of a parent. Assisted dying is legal in Holland where several Huntington's [patients](#) annually chose to die between 2007 and 2011.

Dr Jane Simpson of Lancaster University said: "Our findings suggest that people with the Huntington gene would welcome talking about assisted death but feel they are not able to do so."

Participants in the study spoke about the need for a balancing act between feeling supported and feeling distressed by conversations about dying.

Anna (pseudonym) said: "It is a really difficult balance. And I know that's the same with family and friends as well as [medical professionals](#)."

Many of them feared prolonged suffering at the end of their lives and saw assisted dying as an act of compassion towards their families.

They believed they were best placed to make such decisions about their own deaths provided they had the capacity.

Mary said: "If someone is sound of mind... and people can understand that person's wishes, I think quite strongly that it should be their right. "

Potential loss of role, personality and meaning were considered the most disruptive aspects of the disease which could lead to a decision in favour of assisted dying.

Dr Simpson said: "Fears for the loss of self, as well as fear for pain or symptom acceleration, seem to be main drivers for wanting the option of assisted dying to be available."

More information: Laurence Regan et al. The views of adults with Huntington's disease on assisted dying: A qualitative exploration, *Palliative Medicine* (2017). [DOI: 10.1177/0269216317741850](https://doi.org/10.1177/0269216317741850)

Provided by Lancaster University

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