

## The views of adults with Huntington's disease on assisted dying: a qualitative exploration

Short title: HD VIEWS ON ASSISTED DYING

Laurence Regan

Nancy Preston

Fiona Eccles

Jane Simpson

All: Division of Health Research, Lancaster University, Lancaster, Bailrigg

Lancaster LA1 4YT

Corresponding Author: Jane Simpson, Division of Health Research, Lancaster University,  
Lancaster, LA1 4YT, UK.

Email: [j.simpson2@lancaster.ac.uk](mailto:j.simpson2@lancaster.ac.uk)

Telephone: 01524 592858

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# HUNTINGTON'S DISEASE VIEWS ON ASSISTED DYING

## Abstract

**Background:** Assisted dying is frequently debated publicly and research often includes the views of health professionals on this issue. However, the views of people with life-limiting conditions, for whom this issue is likely to have a different resonance, are less well represented.

**Aim:** The purpose of this study was to explore the views of people who live with the inevitability of developing Huntington's disease, a genetically transmitted disease which significantly limits life, on assisted dying.

**Design:** Using thematic analysis methodology, individual semi-structured interviews were conducted.

**Setting/participants:** Seven participants (five women and two men) who were gene positive for Huntington's disease took part in the study.

**Results:** Four themes were extracted: 1) Autonomy and kindness in assisted dying; the importance of moral principles; 2) Huntington's disease threatens life and emphasises issues relating to death; 3) Dilemmas in decision-making on assisted dying: "There are no winners"; and 4) Absence of explicit discussion on dying and Huntington's disease: "Elephants in the room".

**Conclusions:** Our findings suggest that talking to patients about assisted death may not cause harm and may even be invited by many patients with Huntington's disease. The perspectives of those who live with Huntington's disease, especially given its extended effects within families, add significant clinical and theoretical insights.

**Keywords:** Huntington Disease; Suicide, Assisted; Euthanasia; Neurodegenerative Diseases; Qualitative Research

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### **What is already known about the topic?**

- Assisted dying has not been widely studied among people with life-limiting conditions, although available evidence suggests it is more supported among patients than professionals.
- In the Netherlands (where assisted dying is legal) from 2007 to 2011 6-10 people with Huntington's disease had their request for assisted death fulfilled each year.
- No research has been carried out on the views of people with the Huntington's disease gene mutation about assisted dying in a country where this is currently not legal.

### **What this paper adds?**

- Participants with the Huntington's disease gene mutation express some similar reasons to those in the wider community as to why assisted death should be legal: respect for individuals' autonomy and compassion
- However, the familial aspect of the disease also gives participants a very vivid representation of a future self and this further reinforces their views
- Fears for the loss of self, as well as fear for pain or symptom acceleration, seem to be main drivers for favouring assisted dying.

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### **Implications for practice, theory or policy?**

- Clinicians need to feel able to initiate frank conversations about death and understand why assisted dying could be favoured by people with the gene mutation, with an emphasis on feelings around a projected future self and the loss of current self.
- Theories around the self can be usefully incorporated into our theoretical knowledge of what factors are important in considering assisted dying.

### **The views of adults with Huntington's disease on assisted dying: a qualitative exploration**

#### **Background**

The term assisted dying encompasses both assisted suicide and voluntary euthanasia; in either case assistance is provided from a third party to end a person's life.<sup>1</sup> In many European countries legalisation is opposed by a range of professional bodies representing doctors and nurses, and also by palliative care organisations, although this does vary by country and by specialty.<sup>2-4</sup> In contrast, wider public support is evident for the adoption of legalisation to allow assisted dying.<sup>5</sup>

Most research is conducted on the views of physicians, nurses and carers on assisted dying rather than people with life-limiting conditions, who are perhaps the most immediately affected by the issue.<sup>6</sup> However the existing research on patient views, while suggesting diverse and complex attitudes<sup>7, 8</sup> does indicate that people who have life-limiting conditions generally favour assisted dying<sup>9</sup> but there is a mixed picture as to the impact on their bereaved relatives.<sup>10</sup>

One condition which is particularly pertinent to this debate is Huntington's disease, a genetic neurodegenerative condition characterised by motor and coordination problems and in later stages cognitive impairment. It is an inherited condition, more common in populations of European descent, where it is estimated to affect up to 13.5 people per 100,000<sup>11</sup> and is caused by an increased number of trinucleotide repeats in the huntingtin gene.<sup>12</sup> This mutation is autosomal dominant so each child of an affected person has a 50% chance of inheriting it. Of the major neurodegenerative diseases, Huntington's disease is unique in this respect as individuals with a diagnosis will usually have seen a parent affected by the condition. Symptoms vary but during the condition's later stages, the individual usually has dementia, marked decline in physical and cognitive functioning and requires full nursing care.<sup>13</sup> Individuals may live for many years knowing they carry the mutated gene and therefore will develop the disease,

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although diagnosis is not formally given until physical symptoms appear.<sup>12</sup> Age of diagnosis of Huntington's disease is typically around 35-55 and life expectancy from time of diagnosis is approximately 20 years.<sup>12</sup> Consequently, many people with the Huntington's disease gene are aware that they will functionally decline years before symptoms manifest. In addition genetic anticipation can occur, i.e. decreasing age at onset and severity for the next generation, further increasing concerns.<sup>12</sup>

Data on those people with Huntington's disease who are seeking assisted dying are limited due to its lack of legality in most countries. However, in the Netherlands, in line with the Euthanasia Act,<sup>14</sup> assisted dying is possible in the absence of any effective treatment and 6-10 requests from people with Huntington's disease were granted each year between 2007 and 2011.<sup>15</sup> However, little is known of how assisted dying is understood and positioned by individuals with Huntington's disease, with only one previous study on the topic in the Netherlands.<sup>15</sup> The authors of this grounded theory study based on interviews with 14 patients reported that the most important frame of reference was experience with an affected parent, underlining its specific familial effects. This experience influenced the perceived threshold of an acceptable life and end-of-life wishes. However, participants varied on a continuum from those who had specific end-of-life wishes (and advance directives) to those who had no specific wishes, thought their views might change with time and/or were still hoping for a cure. Understanding of the legal process for advance directives (including assisted dying) was poor and participants were often reluctant to discuss the issue with their physicians.<sup>15</sup> However, there is no existing research in countries where assisted dying is unavailable. Findings could encourage healthcare staff to allow people to explore these ideas in a contained manner.

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Consequently, this study aimed to answer the question: what are the views of people who live with Huntington's disease on assisted dying?

### **Method**

#### **Design**

Individual semi-structured interviews were conducted and analysed using thematic analysis. This approach is theoretically flexible and focuses on drawing patterns of meaning.<sup>16</sup> It lends itself to exploratory research<sup>17</sup> and there is a robust precedent for its use in healthcare research.<sup>18</sup> It has previously been used to interpret Huntington's disease patients' experiences of predictive genetic testing.<sup>19</sup>

#### **Procedure**

The project was reviewed by Lancaster University's Faculty of Health and Medicine Research Ethics Committee and ethical approval was granted by Lancaster University's Research Ethics Committee, reference number FHMREC15026. A purposive recruitment strategy was employed, with potentially interested participants able to contact the first author directly from adverts on relevant social media sites (such as Huntington's disease charities). Approximately 18 people inquired about the research and, of these, seven met the following inclusion criteria: participants had a self-reported confirmed diagnosis of Huntington's disease or were pre-symptomatic with a positive test for the mutated gene; they were aged 18 or over; and they spoke English to a sufficient level to be interviewed.

#### **Participants**

Seven people participated in the study, five women and two men aged 27-47 years ( $M = 35$ ). Four participants had children, three were single, three were married and one was separated. All participants identified as British and were either pre-symptomatic or had begun to experience

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symptoms but were at a very early stage of the disease trajectory. Participants were assigned a pseudonym to maintain anonymity.

### **Interviews**

All participants provided written consent. Five interviews were conducted by the first author (male, trainee clinical psychologist, no prior or existing relationships with participants) by phone and two interviews face-to-face, based on participant preference. Sampling ended due to pragmatic considerations rather than data saturation. An interview schedule was used to guide questioning but allowed the interviewer to follow areas of interest to the participants and be receptive to new ideas. Interviews lasted 37- 66 minutes ( $M = 47$ ) and were recorded, then transcribed verbatim. All identifiable information was anonymised.

### **Analysis**

Inductive thematic analysis was used to analyse the data from the interviews. The aim of analysis was to identify patterns of meaning across the dataset about participants' views on assisted dying. Analysis was entirely data-driven, with no pre-existing theory or framework applied. The five steps of thematic analysis as outlined by Braun and Clarke <sup>16</sup> were used; (1) familiarising self with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, and (5) defining and naming themes.

The analysis initially involved familiarisation with the data through transcription. Each transcript was read and re-read to increase familiarity with and immersion in the data. The transcripts were systematically annotated, with points of interest or particular significance noted and returned to at later phases of analysis. The generation of initial codes was then achieved through line-by-line coding of each transcript by the lead author. Consideration was then given to how codes could be compared and grouped according to patterns across the data that were



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relevant to the research question; thus emerging themes were identified. The transcripts were constantly re-examined to ensure that the themes still related to the original texts.

### **Results**

Four themes were identified in the analysis of the interview data: 1) Autonomy and kindness in assisted dying: the importance of moral principles; 2) Huntington's disease threatens life and emphasises issues relating to death; 3) Dilemmas in decision-making on assisted dying: 'There are no winners'; and 4) Absence of explicit discussion on dying and Huntington's disease: 'Elephants in the room'.

#### **Autonomy and kindness in assisted dying: the importance of moral principles**

This theme summarises the two central beliefs expressed by participants that were framed in terms of moral perspectives: that an individual has a right to autonomy and that assisted dying is as an act of kindness.

Participants viewed assisted dying as a way of taking control of their situations and exercising their right to autonomy:

...just be able to be in control of your final moments rather than it controlling you  
(Claire).

Assisted dying was considered a conditional right, with participants acknowledging that safeguards must be in place to protect people and prevent abuse. Although they demonstrated awareness of arguments against assisted dying, overwhelmingly participants believed that personal autonomy was paramount and that individuals were best placed to make such decisions about their own deaths provided they had the capacity.

[The] biggest concern is people in a vulnerable position, you know, if they're really ill and they're not able to make their own decisions. But surely if someone is sound of

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mind... and people can understand that person's wishes, I think quite strongly that it should be their right. (Mary).

Most participants feared prolonged suffering at the end of their lives and talked about a point beyond which life would not be meaningful or when suffering would be too much to bear and all participants emphasised the importance of choosing that point for themselves.

I do have intent or a desire to take my own life at some point to prevent myself from being at a point of suffering and losing my dignity with this condition. (Anna).

Relieving suffering through assisted dying also embodied an act of kindness. Reflecting on the death of a relative Claire felt assisted dying 'would have been kinder to her'. Conversely, to leave someone with suffering was thought to be 'a great cruelty' and a violation of that person's right to autonomy and dignity (Anna). Peter compared assisted dying and sedation at end of life as methods of ending suffering and acts of compassion:

It is effectively assisted dying by the back door.(Peter)

Assisted dying was also considered a kindness to families, as the alternative would be for them to bear the burden of witnessing participants suffering, potentially for many years, or for participants to request assisted dying from families, also considered a terrible burden.

### **Huntington's disease threatens life and emphasises issues relating to death**

Huntington's disease strongly informed participants' views on assisted dying: discovering they had inherited the mutated gene or being diagnosed formed their beliefs or reinforced their existing beliefs.

My thoughts changed when I was diagnosed with Huntington's, I suppose. I hadn't thought about it until then, or thought enough about it... I have become more aware, and I've become more understanding about why people would want that right. (Lola).

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Participants reported that these views had remained stable over time. Consequently, they spoke about Huntington's disease changing their future self-representations, suggesting that suffering went beyond physical pain to their very self-concept.

People shouldn't have to die alone and a shell of what they were. Nan was a vegetable by the end of it, bless her, she was literally just a case. There was nothing left inside. We were just keeping her alive but what for? She wasn't getting any joy out of life. (Claire).

This vivid language demonstrates how previously distant possibilities such as suffering, loss of functioning and death became more proximal for participants. They reported having to question previous assumptions about themselves, the world and the future.

Potential loss of role, personality and meaning were considered the most disruptive aspects of the disease and therefore more relevant in deciding the point at which assisted dying would be desired over loss of physical functioning:

I think the idea of the physical symptoms scares me a lot less than it used to and the fear of the mental symptoms scares me a lot more. (George).

Physical functioning seemed important mainly in an interpersonal context, for example, in not being able to communicate.

Obviously just like being able to function, get out and have conversations with people... cos it can massively affect your relationships with people. (Dawn).

The point at which assisted dying would be desirable was therefore connected to loss of self for participants.

Medicalisation of both Huntington's disease and dying contributed to this threat to sense of self; participants felt that their psychological, social and existential needs were ignored at the

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expense of their physical needs. Anna noted the incongruence between progress as defined by medicine and what participants ascribed meaning to:

But they have in no way been able to sustain her quality of life. And, as a result I don't see it as a triumph that she is still breathing. And that doesn't look like progress to me...

(Anna)

Participants spoke about formative experiences of witnessing family members dying with Huntington's disease. Their views on assisted dying were embedded in these family experiences. For example, although Peter was in favour of legalisation of assisted dying, he would never consider this for himself. This was because he saw that his father still had a sense of self and quality of life despite the severity of his symptoms.

He's been bedridden for the last 5 years now, can't speak, can't eat, can't do anything for himself. But he still has a certain quality of life. I took him out in my car the other week for a trip out. But he actually put his arm around me. So he's still in there but he just can't communicate as well... I can sort of observe what's happening to him and make decisions based on that. And that helps inform me [about assisted dying]. (Peter).

Anticipating their disease trajectories, participants adapted their perspectives on life and plans for the future. Some participants spoke about a life-affirming aspect of Huntington's disease and reported 'a new way of looking at life' (Lola).

I guess part of me, knowing my diagnosis, has made me seize the day a bit. It sounds a bit corny, but it's kind of about making the most of all the good days, being thankful, being mindful, taking notice of things that bring me great joy. And that sense of responsibility of living a good life has also made me think about that moment when that good life is becoming diminished. (Anna).

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Anna anticipated that she would be unable to maintain her quality of life as a result of Huntington's disease symptoms in the future, at which point she would desire assisted dying. Huntington's disease therefore had become part of the biographical narratives of participants and influenced their views on assisted dying.

### **Dilemmas in decision-making on assisted dying: 'There are no winners'**

This theme encapsulates the personal and practical dilemmas inherent in participants' situations, in particular around their stance on assisted dying. Assisted dying was considered to be an imperfect solution to a real world problem; until a cure was found assisted dying was thought to be necessary. The only alternative was to live with suffering or commit suicide by other means.

I don't want it there just as an escape route but for those who genuinely do need it. And the only way out is either continue as you are until something happens to you or starve yourself or have to take your own life (Claire).

Another dilemma across participant accounts was the conflicting views of family. Often there were multiple stakeholders in decision-making and participants reported times where different views and rights came into conflict.

I just don't wish to go through that process of decline. I don't wish it for my mother, but I appreciate that other people are taking those decisions... I think my dad would feel very guilty if there were to be any intervention to end my mum's life sooner than it naturally would (Anna).

Linked with first theme, *Autonomy and kindness in assisted dying*, freedom of choice was most important for participants. However, this was frequently balanced with the wants and needs of family.

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It might be, for example, it is not worth it for me directly but for whatever reason I still keep my wife company. And you might drag it out another year or something... I guess it wouldn't be just about me, but at the same time it is not about many people other than me. (George).

Another predicament identified by some participants is that the point at which suicide may be desirable would be the point at which it was no longer an option for them because they would be too impaired physically or cognitively.

Sometimes with the assisted dying thing I think, "Well, it's pretty easy. All I have to get myself is a packet of paracetamol or whatever, and plan things in advance." And the day I think that, I am going to be in a position where I can't take my own life. (George).

Similarly, Anna acknowledged this tension and wondered at what point she should document her wishes formally.

When I read the Huntington's disease literature and it talks about kind of losing the ability to initiate decisions or take action – so, again, that alerts me to, well hang on a minute, if I'm declining gradually, am I losing the ability to make those decisions? So do I need to make that decision long before I'm symptomatic in order to ensure that I don't miss my opportunity? (Anna).

Claire contemplated going to Dignitas (a Swiss assisted dying organisation) in the future assuming no change in the legal status of assisted dying in the UK. However, she highlighted the difficulty of being well enough to travel but ill enough to warrant treatment.

To do that you have still got to be well enough to travel so it is a Catch-22 situation. You have got to be well enough to travel but then you have to be poorly enough to warrant going somewhere like the clinics. (Claire).

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Additional considerations for her were having the funds to travel to Switzerland and the place of death being a strange country, without many of her family and friends.

Anna also discussed how she felt the conservative proposals to changes in UK legislation were not appropriate.

They talk about people within six months at the end of their life. With Huntington's that's not applicable. That wouldn't be of any benefit, because the decline is such a long, drawn-out process. I don't think any doctor can predict where six months off death is for somebody with Huntington's. Because in my experience of my mum's condition, she has been awful for years and close to death for years yet sustained by tiny amounts of food and nutrition (Anna).

It can be seen here how contemporary debate on assisted dying was irrelevant to participants, as they felt it excluded the complexities inherent in conditions such as Huntington's disease or dementia.

### **Absence of explicit discussion on dying and Huntington's disease: 'Elephants in the room'**

Emergent in the data was the idea that both assisted dying and Huntington's disease were difficult and often unmentionable topics of conversation. Although many participants described their families as supportive, there was reportedly little discussion about death or wishes for end-of-life care. Participants considered the cultural taboo of death as one of the reasons behind this reticence.

I said to my mum before about the fact that I think it should be somebody's free choice to choose something like that, but not in depth. I suppose I don't want to say that sort of stuff. It's a bit morbid isn't it, to your parents? (Laughs). (Lola).

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Views on end-of-life care were also often not talked about explicitly with healthcare professionals. Participants spoke about the need for a balancing act between feeling supported and feeling distressed or offended by conversations about end-of-life issues.

It is a really difficult balance. And I know that's the same with family and friends as well as medical professionals. It's kind of like people wanting to talk to you about it enough so that you feel heard, but not wishing to distress you by bringing it up at times when it feels uncomfortable. (Anna).

Consequently, some participants were unaware of end-of-life options. For example, two participants had not heard of advance directives. Some participants felt this reticence was inadequate and put the onus on healthcare professionals to facilitate conversations about assisted dying. Others thought it more acceptable because of the difficulty of the subject.

I wouldn't know when the right sort of age to start talking about dying is. It's a tough one. Some people could be seriously offended by it. (Laughs)... But then I probably would start talking about it quite early on because you never know how quick Huntington's is going to affect some people. (Lola).

More implicitly, participants communicated that Huntington's disease itself was also not talked about. Participants largely felt left to manage by themselves and some reported feeling lonely with their Huntington's disease:

Because I am symptom free, I'm also kind of doctor free... I guess there's time when I feel a bit adrift maybe with it; kind of like a bit left alone with it'. (Anna).

Some participants talked about not having open discussions with families, instead having 'hushed conversations' (Anna) or implicit understandings. For some this was an active choice. For example, George described a significant period where he chose not to disclose to his mother



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that he was gene positive as: 'it's just extra time to worry more.' For other participants, the uncommunicativeness within their families was not their decision. For example, Dawn acknowledged that her father did not talk about Huntington's disease and withdrew from the family:

I think that was more that he didn't want us to see him declining, so he kind of distanced himself. (Dawn)

### **Discussion**

#### **Main findings**

Participants emphasised the right to autonomy and perceived assisted dying as an act of kindness; these were very much seen in the context of their moral reasoning. Their views were strongly shaped by knowing they would develop Huntington's disease (or their symptoms would increase) which they had witnessed in relatives. They feared not only the loss of physical function, but especially emphasised a fear of a loss of self. Decision making in assisted dying was described as a difficult and complex process, with family as important stakeholders, but discussing it with family remained very difficult and equally the opportunity for open discussion with medical professionals was lacking.

#### **Strengths and limitations**

This is the first study to look at the views of assisted dying in people with the Huntington's disease gene mutation in a country in which it is not legal and highlights the importance of the familial aspect of Huntington's disease in shaping participants' views. All participants were at an early disease stage, and it is not known if views change as the disease progresses. Additionally, there is a high potential for selection bias as participants self-selected into the study. However, efforts were made in advertising and interviewing to approach the issue neutrally. It might also

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be useful to make the distinction between clinician assisted suicide versus euthanasia in future research on participant views.

### **What this study adds**

Participants all thought that the law should provide for assisted dying and reasons were similar to those expressed without a life limiting illness and outside the UK. For example, in a comparative analysis of the attitudes of 33 countries to euthanasia<sup>20</sup> two dominant arguments were identified in favour of assisted dying. The 'autonomy argument' proposes that individuals should have the ultimate right to make decisions about their life and death<sup>21</sup> and is consistent with the discourse of individual choice and autonomy used by participants in this study.

Similarly, the discourse of compassion employed by participants here is consistent with the 'death with dignity argument',<sup>21</sup> which argues that euthanasia relieves suffering. However, participants also drew on the inherent familial experience of Huntington's disease.<sup>22</sup> As well as being rooted in the past, in terms of having witnessed their own affected family members' end-of-life experiences, support for assisted dying was framed by participants' projections, informed by these familial experiences, about their likely futures and in particular their future self.

Consistent with the Netherlands study by Booij et al.,<sup>15</sup> most participants wanted to discuss Huntington's disease and end-of-life issues but lacked certainty on how and when to do this appropriately.

A strong theme throughout the transcripts was one of autonomy and control and this is consistent with theories around the prominence of uncertainty in living with a chronic illness and subsequent attempts to regain some element of control.<sup>23</sup> Clearly with a condition such as Huntington's disease, attempts at control are more limited in terms of the progression of the disease so controlling death becomes more pertinent. Participants identified a lack of choice and

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autonomy in proposals for legalisation of assisted dying. For instance, restricting assisted dying to those with less than six months to live (e.g. <sup>24</sup> ) excludes many people with chronic, life-limiting conditions such as Huntington's disease where the trajectory is less certain.

Moreover, the concept of the self, prominent in chronic illness research, <sup>25</sup> is also relevant here in relation to decisions to end life. Bury <sup>26</sup> described the phenomenon of biographical disruption, whereby chronic illness causes unavoidable disruptions in a person's previously anticipated life plan. Although Bury's work is not without criticism, <sup>27</sup> some elements of his theory, such as reciprocity (worrying about not being able to undertake the usual share of tasks or activities) appear in the current study; the notion that caring for someone with Huntington's disease at the later stages of their life represented a significant investment by carers - and one which could not be repaid. Perhaps this then had implications for their views on dying. <sup>23</sup>

Another relevant extension of Bury's work is that of biographical repair. <sup>28</sup> While this might seem counterintuitive given the seriousness of the condition and the lack of effective treatments, participants seemed to use the issue of assisted dying to maintain aspects of their self which they valued: the need to demonstrate autonomy and to fight for what they felt was right and to be able to decide and influence a major decision in their life – how to die.

Although it is important to provide more resources to help people in distress and desiring death, improving palliative care, while perhaps being the preferred solution for clinicians, would not appear to eliminate the case for assisted dying among patients. The loss of self – rather than symptom severity – is the issue participants here felt was key in diminishing quality of life. <sup>23, 29</sup> Clinicians should aim to have honest discussions including issues relating to the self, as opposed to narrower reassurances of the availability of effective symptom management. Specifically, communication with patients could be improved by informing them of the existence of advance

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directives. Battin's<sup>30</sup> concept of the least worse death may be salient here, in that patients might value a discussion of all the care options, including that of assisted dying.

Further research could usefully include interviews with people with life limiting illnesses such as Huntington's disease in later stages of their illness, to see if there are changes in views given the more immediacy of death. Moreover, more research on the family's conceptualisation of assisted dying would be useful. Some research on family views of individuals who request assisted death has been conducted,<sup>31</sup> and this has also emphasised the primacy of issues relating to the self, but the essentially familial nature of Huntington's disease, and the notion of shared selves in genetic illnesses<sup>22</sup> makes further research here compelling.

### **Authorship**

Laurence Regan conceptualised the study, applied for ethics approval, conducted the interviews, provisionally analysed the data and wrote the first draft of the paper.

Nancy Preston supervised the analysis and revised the paper critically for content.

Fiona Eccles revised the paper critically for content.

Jane Simpson supervised the whole study, wrote the second draft of the paper and revised it for content.

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### **Declaration of Conflicting Interests**

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The Authors declare that there is no conflict of interest.

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