

# Advance euthanasia directives in Huntington's disease: A patients' perspective

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## Background & Aim

Huntington's disease (HD) has a poor prognosis. For HD patients in the Netherlands, one way of dealing with their poor prognosis is by drafting up an advance euthanasia directive (AED). Little is known about the perspectives of patients on their AED. The aim was to gain insight into patients' views and attitudes on their AED.

## Methods

A qualitative longitudinal study design was used. Twelve HD patients who received outpatient care were interviewed 1-6 times over a period of maximum 3 years. The semi-structured interviews focused on 1) thoughts towards the future, future care and end of life, and 2) discussing these topics with others. In the current study, we focused on the 9 participants who either had an AED or were thinking about drafting one up. These 9 participants were interviewed a total of 35 times.

## Results

We identified two themes through which we can describe patients' perspectives on their AEDs:

### 1) Personal character of the AED

The conditions that participants described as their reason(s) for euthanasia were generally not very specific for the person. Mostly these were general notions of unbearable suffering.

*"Getting dementia. If that happens, then I'm going to stop."*

*"I don't want to end up like a vegetable".*

Participants differed in the extent to which they were guided by examples of family members with HD in drafting up their AED. For some participants, these experiences played a major role. Other participants were particularly shocked by other patients in the waiting room or what they saw in videos on the internet.

*"Because I don't want that ending. Like my mother, who was ill. I don't want that."*

*"I've seen people that were in such bad shape, that scared me so much. In the waiting room in the hospital. And then I thought, this is not going to happen to me. [...] That was much worse than the way my grandmother had it."*

### 2) Awareness of the tentative character of the AED

Most participants realized that the content of their AED could change over time. They expressed doubts concerning their own willingness to initiate the request in the future, or the willingness of others to cooperate (e.g. the physician).

*"I can imagine that I would go on a bit longer, because of my daughter, but you never know."*

*"That would be a reason to consider: do I want to continue living or not. [...] It could very well be that I have found other things, another hobby or whatever, that I would think: I want to continue for 10 years. I can't say that ahead of time."*

In one participant, these doubts were so great, that it prevented her from drafting up an AED.

*"I find it very difficult to say which moment. No, I don't believe I can already."*

Despite the awareness of possible change over time, participants did not alter their AED during the follow-up period.

## Conclusions

These findings suggest that the AED usually contains general notions of unbearable suffering and that familiarity with HD in the family can play a role in drafting up an AED. Patients generally are aware of the tentative character of their AED, which underlines the importance of a continued dialogue between professionals and patients concerning patient's wishes. The results from this study can help physicians and other professionals in dealing with AEDs and in guiding patients that potentially want to draft up an AED.