HDBUZZ

Self-determination on the HD journey: the role of Advanced Care Planning

Advanced Care Planning is a tool that can allow people living with Huntington's disease to compassionately engage with loved ones about their future care, taking thoughtful steps at their own pace while they're able, to ensure their wishes are met.

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Here, we cover a report on Advanced Care Planning (ACP) prepared by clinical researchers at the University College London, reminding us there are things that can be done **right now** to improve the lives of people living with HD. Until we have drugs that slow the progression of HD, peace of mind can be some of the best medicine.

Facing the challenges of HD doesn't have to be done alone

Anyone dealing with Huntington disease (HD) knows that it comes with many physical and mental challenges, and these can affect everyone differently. For some, symptoms may eventually call for life changes such as moving to a long-term care facility.

Communicating care preferences early on with your family can ensure the wishes of you or your loved ones are met as Huntington's disease advances.

As the ability to make decisions can be lost in the later stages of HD, it can help to express care preferences early on to ensure that one's wishes are respected. Because each person's journey with HD is unique, individualized and tailored care plans are crucial.

The best way to navigate these challenges is by openly discussing preferences with loved ones and healthcare providers. To support this, a team of clinicians have published a guide to help individuals and families plan ahead, empowering people with HD to retain a sense of autonomy and extend their independence, even after they can no longer make decisions independently.

What is Advanced Care Planning?

ACP is a process that helps individuals reflect on, understand, and communicate their concerns, preferences, and wishes for future medical care. While thinking about future health decisions can feel overwhelming, many people find value in discussing these matters, once they are ready.

Although doctors might have concerns that these conversations may cause undue stress, studies have shown that many individuals appreciate the chance to talk about their future care, as long as it is done in a personalized and context-specific way.

> **“ACP is a process that helps individuals reflect on, understand, and communicate their concerns, preferences, and wishes for future medical care ”**

ACP can empower people with HD and extend their autonomy by ensuring that their choices are respected even when they may no longer be able to communicate them. It also reassures healthcare providers that the care they deliver aligns with a person’s values and wishes. For caregivers, knowing a person’s preferences can reduce feelings of helplessness, as they can act in ways that truly honor the individual. Documenting these preferences can even support legal aspects of care, such as appointing a power of attorney.

A roadmap for Advanced Care Planning

Previous studies have found that ACP is often underutilized in clinical practice, despite its benefits. Doctors have to approach ACP with sensitivity, recognizing that not everyone may be ready or willing to discuss future care decisions, while balancing this sensitivity with the benefits gained from setting things up in advance.

Addressing these challenges, a team of clinical researchers at the Huntington’s Disease Centre at University College London have developed a system to offer ACP to all patients who express interest. Their approach ensures that each person with HD has the opportunity to initiate ACP discussions whenever they feel ready.

People don’t need to make every decision at once when beginning ACP. Initial conversations can focus on exploring goals and values, providing a foundation for more specific plans later on. ACP is an ongoing, flexible process that accommodates changing views–these discussions are documented and reviewed regularly to reflect any updates in a person’s preferences.

Resources around Advanced Care Planning for Huntington's disease can help people make thoughtful decisions on a timeline that works for them.

Putting it on the record

In the case of the Huntington's Disease Centre at University College London, ACP can eventually lead to some key documents. An *Advance Statement* captures personal wishes and preferences for end-of-life care or when decision-making capacity is lost. While not legally binding, it guides future care decisions and can include things like religious beliefs, preferred care locations, opinions on certain treatments, and funeral preferences.

Another option is an *Advance Decision to Refuse Treatment (ADRT)*, a legally binding document where an individual can specify refusal of certain treatments, like artificial ventilation or resuscitation, if they lose capacity.

A *Lasting Power of Attorney (LPA)* allows a trusted person to make decisions on the individual's behalf if they become unable to do so themselves. Given that each country has different regulations, it is important to discuss options with a healthcare team. This report offers a framework for healthcare teams to support ACP, helping to personalize and honor people's wishes across different countries and settings.

What can be done now?

> **"The best time to plant a tree was 20 years ago. The second-best time is now. "**

A Chinese proverb goes, "The best time to plant a tree was 20 years ago. The second-best time is now." Similarly, the report highlights that while many people delay starting ACP and can still benefit from it, starting earlier is also an option.

HD is a long journey, allowing people ample time to approach ACP thoughtfully, ensuring that they're ready to engage in these discussions. Recognizing that decisions don't have to be made all at once and progressing at a comfortable pace can offer peace of mind.

More resources on ACP

- HDA video on Advanced Care Planning
- Huntington's Disease Society of America's Family Guide Series

- Huntington Society of Canada’s guide on Future Planning

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