

## Preparing for Your Future: Advance Care Planning and Parkinson's Disease

## What is Advance Care Planning (ACP)?

• Advance care planning supports people at any age or health stage understand and share their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences.

ACP prepares people for future medical decisions and assigns a surrogate to decide on the person's behalf in the case that they lose capacity. ACP includes the completion of an advance directive (AD), such as the assignment of a health care power of attorney (HCPOA), or the completion of a living will, or both.

## How Can I Talk with My Doctor about ACP?

- 1. **Revisit your goals of care.** It can be helpful to re-visit your goals for your future care (advance care planning) and related documentation at least annually. It is also important to check in as life events happen or things change.
- 2. **Ask for clarification**. Ask your medical team questions if you want to learn more about what could happen with your PD in the future or if you do not understand something when discussing current or future care plans. Questions to be asked can include:
  - a. What do different choices mean medically , such as on advance directives and MOST/POLST forms?
  - b. What is the extent of health care power of attorney's rights and obligations?
  - c. What can a health care power of attorney to ensure their decisions will be respected by medical personnel?
- 3. **Make sure your healthcare providers and family know your values**. It is hard to know what may happen in the future or to make "the right choice" with future plans. It is easier to state what is most important to you and make sure your decisions are consistent with them.
- 4. **Help your family be your voice.** The goal of advance care planning is to make sure care is directed by your voice and values. By having these conversations, you give a gift to your family who can now relax knowing your wishes. They can be your voice and not your decision-maker.

## Are There Resources Online That Can Help Guide Me?

Yes, there are resources that can help you think through your goals of care and complete documents. In the resources listed below you will find different versions of the same documents. Keep in mind that you should have only one of each (e.g., one Living Will, one Healthcare Power of Attorney designation).. You can choose what type to complete based on what is legal in your state and what is recognized and preferred by your medical provider.

- 1. Five Wishes: Provides a booklet to express your wishes regarding:
  - Who you want as your health care power of attorney
  - What kind of medical treatment you would want or not want
  - How comfortable you want to be

- How you want other people to treat you
- What you want your loved ones to know
- 2. <u>Prepare for Your Care</u>: Provides forms to complete based on the state where you live. There are also videos that can help you complete these forms.
- 3. <u>The Conversation Project</u>: Provides several guides for contemplating and making decisions about ACP.
- 4. <u>Ariadne Labs</u>: Have resources to help with having conversations related to wishes for care, including a workbook ("What Matters to Me") to help you talk to your healthcare team about what is most important to you.
- 5. <u>Charting a Course for Parkinson's Care</u>: Helps you consider the possible progression of Parkinson's and what you can do to live well throughout your journey.
- 6. <u>State-Specific Healthcare Proxy (HCPOA) Documents</u>
- 7. <u>State-Specific MOLST/POLST Forms</u>
- 8. **Faith-Specific Documents:** Please note that if you are considering using these documents that you should confer with an elder law attorney about what is legal and accepted in your state.
  - <u>Catholic</u>
  - <u>Jewish</u>
  - Islamic
  - Jehovah's Witness
- 9. <u>Estate Planning and Parkinson's</u>: Explains what documents everyone should have and includes a guide for talking with your attorney.