



# *Looking Ahead with Parkinson's*

A Guide to Future Care Planning



*Life brings uncertainty for all of us. In Parkinson's disease (PD), where future changes can be hard to predict, this uncertainty can feel magnified. Taking control where we can, by planning for the future, for example, can be empowering.*

For some, planning ahead brings comfort, ease and increased engagement in day-to-day life. For others, it may bring worry and concern. Listen to yourself and honor your preferences. One size doesn't fit all when it comes to life, Parkinson's, or planning for life with Parkinson's.

You may feel it's better to minimize thoughts about the future and take it one day at a time. Perhaps you want to tackle a few essentials or rely on trusted loved ones to help.

Or, you might be eager to take action. You may have recently been diagnosed with Parkinson's, or you may be considering deep brain stimulation (DBS) or another procedure. Aging parents, a young family, or the loss of a loved one might be additional prompts. Whatever your reason for wanting to plan, it's never too early to start.

In this guide, movement disorder experts, people living with Parkinson's, and care partners offer practical steps for future planning in Parkinson's. We hope it's a valuable resource for you and your loved ones.

# About This Guide

## **WHAT'S IN IT:**

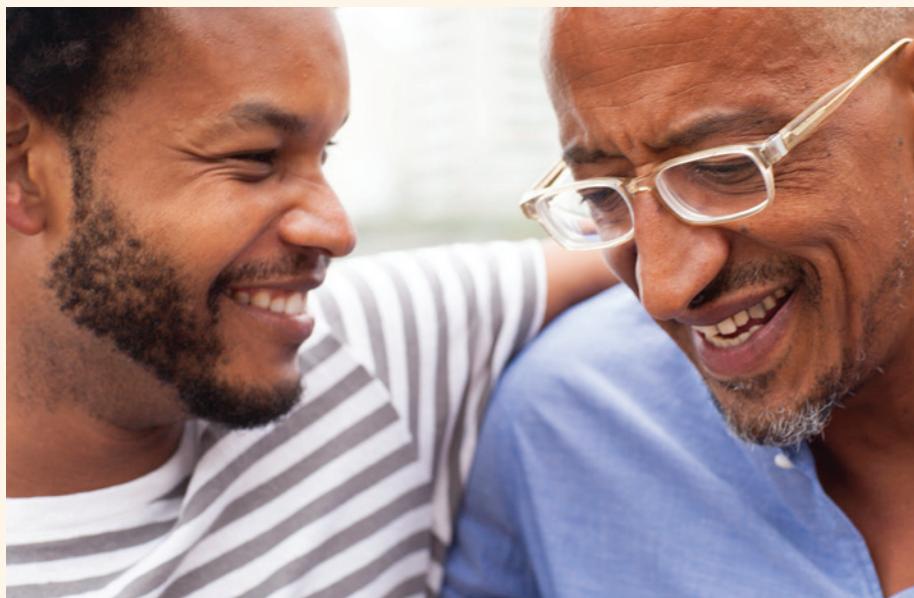
Information and tips for thinking and talking about the future and making end-of-life care plans.

## **WHO IT'S FOR:**

People and families with Parkinson's who want to be proactive in their care.

## **HOW TO USE IT:**

How it best works for you! You might want to skim the steps, read it cover to cover, or go through it with a loved one or family member. Or you may want to set it aside now and come back when you're ready to think about these topics in more detail.



# *Three Steps for Future Planning*

Planning for care around the end of life can feel overwhelming. Life can hold many unknowns and uncertainties. And it's hard to imagine how our lives will change in the years or decades to come. Before you dive in to planning, take a moment to check in with yourself. Does now feel like the right time? If so, what feels like the right approach? Some prefer to gather their thoughts and complete documents and then talk with loved ones. Others do the opposite. Still others take a different route. When you're ready, consider the three steps below as a guide. It's not necessary to do them in order or to do them all at once. Use the information in a way that's most helpful to you and your planning.



*Step 1*  
**NAME YOUR VALUES**



*Step 2*  
**WRITE DOWN PLANS**

*Step 3*  
**TALK WITH LOVED ONES**



## *Step 1*

### NAME YOUR VALUES

Your values are what are most important to you. Soania Mathur, MD, co-chair of The Michael J. Fox Foundation Patient Council, says, “To me, values are the fundamental beliefs that guide our attitudes or actions.” They’re what determine how — and with whom — you spend your time. Values might include spending time with family, independence and optimism, among many others.

If you haven’t already, write down your values. Reflect on what and who matter most to you; when you feel most yourself; when you’ve been most proud or happiest, or most disappointed or sad; and why. This helps you determine your values.

Many online tools can help. Some contain lists of values; others have questions to guide you in finding yours. (See resource #1 on [page 21](#).) You also can journal or chat with a trusted friend, family member or advisor.



# HOW VALUES GUIDE CARE DECISIONS

**BY DAVID IVERSON**  
**MJFF PATIENT COUNCIL MEMBER EMERITUS, AGE 73**  
**OAKLAND, CALIFORNIA**

Too often when we think about end-of-life planning, it becomes a bit too focused on checking off boxes about whether we want “extraordinary measures” at the end of life. I think that’s too simplistic. My own answer to the question of whether or not I’d want to be intubated (have a breathing tube) or resuscitated (have CPR) is, “It depends!” It depends on my values — and whether I might still be able to do what matters most to me. If I’m in dire straits, but a particular procedure would give me six months to have fun with my grandkids, cheer for my favorite team, go for a hike, and hug my wife and daughter, then — you bet, I want the procedure. But if it would give me six months in bed, where I couldn’t think straight or recognize my loved ones, then I say, “no thanks.”



It's also important to address the fact that what we think or want today may not be what we think or want tomorrow. We probably need to timestamp our values statement and tell our loved ones whether we want them to abide by that values statement even if we later lose our thinking and memory or say over and over again, “I don’t want to die.”

Each of us should write out the values we want our loved ones to be guided by if we can't make choices ourselves. But we also should talk with our loved ones about our values — and how they may change over time. I don't think we can rely on just a written statement. There is nuance, emotion and clarity that conversation can reveal, and which often is much more telling than the written word.



*“To me, values are the fundamental beliefs that guide our attitudes or actions.”*

— **SOANIA MATHUR, MD**  
**MJFF PATIENT COUNCIL CO-CHAIR, AGE 50**  
**TORONTO, CANADA**



## *Step 2* WRITE DOWN PLANS

It's crucial for all of us, regardless of age or health status, to write down our plans and wishes for later life. For people with Parkinson's or other medical conditions, this is especially important. Kirk Hall, MBA, who's been living with Parkinson's since 2007, urges others with PD to make plans as early as possible. Potential Parkinson's symptoms, such as changes in memory, motivation or handwriting, might make the process more difficult for some later on. Kirk has said, "Make a plan and then live life with the peace of mind that comes from knowing you can activate that plan when you need to."

Written plans are called advance directives. Advance directives allow you to name someone you trust to make care and treatment decisions on your behalf if you ever become unable. They also allow you to describe what treatments you would or wouldn't want in this situation. For example, some don't want cardiopulmonary resuscitation (CPR) if they are terminally ill or near the end of life.

Advance directives can include one or more of the following:

### **+** **Health Care Power of Attorney**

A health care power of attorney (POA) also may be called a health care proxy, health care agent, or medical power of attorney. This is someone you appoint to make medical and care decisions on your behalf if you ever become unable. For example, people with significant memory and thinking changes (dementia) or those who have suffered a stroke or brain injury may have difficulty processing the information necessary to make decisions about their care.

Your health care power of attorney should be someone who understands what matters most to you and who will direct your care in a manner consistent with your wishes and values. While many people name their spouse or another family member, you don't have to choose a relative. You should choose someone who knows you well, whom you trust, and who is comfortable with the role and responsibilities of a health care POA.

You may never need your health care power of attorney. You continue to make your own decisions unless the time ever comes when you can't. A health care power of attorney is a back-up plan, one that protects you if life brings unexpected or unwanted changes.

### **+** **Living Will**

A living will is a document that describes what care and treatments — such as CPR, a breathing machine or a feeding tube — you do or do not want near the end of life. You can put as little or as much detail as you wish in a living will. Some people check the form's boxes to indicate whether they'd want certain treatments and trust their health care power of attorney to take care of anything that's not specified. Others write thorough instructions for if, when, and how long they want to try a breathing or feeding tube, antibiotics, or IV water and nutrition, as well as where and how they want to live their last days. Many, for example, say they want to be at home, surrounded by loved ones, rather than in a hospital. Your doctor and other experts can help you understand your options, such as choosing hospice near the end of life, and make plans consistent with your goals. (See [page 16](#) for more.)

In a living will, you also can describe your wishes for after death. These may include organ or brain donation as well as a funeral and burial. (Read more on [page 17](#).)

Depending on your situation, you may want to complete other legal documents as well. These could include:

**+ A Do Not Resuscitate (DNR) Order**

Also called a Do Not Attempt Resuscitation (DNAR) order, this document indicates that, if your heart and lungs stop working, you do not want to receive CPR or be placed on a breathing machine. Your doctor can tell you more about what this means and also must sign the form with you. A DNR does not affect any care other than medical treatment that includes CPR or a breathing tube. Without a DNR, medical professionals are required to provide these treatments.

**+ Portable Medical Orders (POLST)**

People who are seriously ill or near the end of life may want to consider a POLST. (This form has different names in different states, including MOLST, MOST and others.) A POLST tells first responders what you do or don't want in the event of an emergency and offers more options than a DNR. You can specify whether you want to have CPR, go to the hospital, go to the intensive care unit (ICU) if necessary, or whether you'd prefer not to have CPR or to stay at home. (See resource #2 on [page 21](#).)



*“Make a plan and then live life with the peace of mind that comes from knowing you can activate that plan when you need to.”*

— **KIRK HALL, MBA**  
**NEUROPALLIATIVE CARE ADVOCATE, AGE 71**  
**HIGHLANDS RANCH, COLORADO**

**TIPS FOR COMPLETING ADVANCE DIRECTIVES****+ Revisit your values**

Your personal values influence what care and treatment plans will support you in living well through the end of life. On this topic, one person wrote, in a *New York Times* article, “After family, I value clarity of mind and the capacity to make decisions. To live well is to continue to possess the ability to converse, to read, to retain what I learn, and to coherently reflect and understand. I do not want my life prolonged if I undergo a marked lessening of my cognitive powers or severe, distracting pain.”

Here are some questions to think about:

- What are your hopes for the next five, 10 or 20 years?
- What worries you most?
- What are your cultural, spiritual and religious beliefs and how can they be honored?
- What makes life “worth living”? (Feeling and giving love, interacting with others, etc.)
- If you are no longer able to live on your own or at home because of memory or movement problems, for example, where would you like to live? What would the best place and best care look like?

A free, online resource — the Go Wish game — can help you define values around the end of life. (See resource #3 on [page 21](#).) This game involves sorting cards with statements that many people say are important in the last weeks or months of life. Examples include keeping a sense of humor, not being connected to machines, or talking about what death means. You can play the game alone or with others, which might offer a more natural opportunity to discuss difficult topics.

**+ Talk with your doctors**

Your doctor can explain more about advance directives, such as how and when they’re used, and what different treatment options, such as CPR, mean. They also can help you understand terms like “life-sustaining measures” or “terminal illness.”

Your physician can help direct what you might personally want to consider when crafting future care plans. Based on your medical conditions and symptoms, for example, they might be able to share some common or likely scenarios. You might ask, “Knowing me and my Parkinson’s and/or other conditions, what should I think about as I plan for my future?”

**+ Plan to update, as necessary**

You should complete documents based on your current values and update if or when your values or health condition change. Review your documents once a year to ensure they reflect your current wishes.

**+ Filter decisions through a “Parkinson’s lens”**

As Parkinson’s progresses, it can bring new or increased symptoms, such as swallowing, balance or thinking changes. While these don’t happen to everyone, taking the possibility into account can help you make the best plan for your future. It allows you to describe which treatments you would or wouldn’t want should these situations occur. (Some decide they don’t want any treatments; others want every available support.) You also can detail how long to try certain treatments or how other medical conditions or symptoms might impact your decisions. For example, some say having significant dementia would affect which treatments they’d want.

You can’t plan for every possibility. But you can consider the scenarios that are most likely for you and which among them are most likely to have the greatest impact on your quality of life. And a health care power of attorney who understands you, your perspectives and your wishes can help take care of anything else.



## STEP 1   STEP 2   STEP 3

Just as Parkinson's can bring symptoms that require different treatments, different treatments can affect Parkinson's. Being in the hospital, having surgery or experiencing other medical conditions, for example, could worsen PD symptoms and make it harder to benefit from treatments or fully recover. It's important to consider this as you outline future goals and plans.

### +

#### **Fill out forms for your state**

Each state has different advance directive forms. You should complete a form for the state where you live and receive health care. (If you split your time between two states, fill out forms for both.) You can ask your doctor or search online for the correct documents.

Even though these are legal documents, you don't need a lawyer to complete them. But you should involve a health care professional, such as your primary care physician or neurologist, who can help explain forms and direct personal considerations. You'll also need two witnesses, other than your health care power of attorney and doctor, to sign.

### +

#### **Get support**

There are many resources to help you create and discuss advance directives, including online tools and health care providers, such as social workers and palliative care experts. (See resources #4, 5 and 6 on [page 21](#).)

### +

#### **Share copies**

A copy of your advance directives should go in your medical record so that all your providers know and follow your wishes. Keep copies for yourself, too, to share with hospital providers, family members and others.

### +

#### **Keep your documents safe**

Put all information related to later- or end-of-life care (advance directives and other pertinent documents) together in a secure place. Claudia Garrido-Revilla, an MJFF Patient Council Member, compiled her plans in a binder she calls her "book of life." This holds her advance directives, bank account numbers and passwords, and specific wishes related to her parents, children and other valued areas of her life.

Make sure your powers of attorney, trustees and designated family members know where to find your documents, account numbers, passwords and other pertinent information.

### +

#### **Review regularly**

Review your advance directives at least once a year and with any significant changes, such as marriage, divorce, or a health change, such as a new medical diagnosis. This ensures your documents accurately reflect your values and wishes, which can, of course, shift over time.

You can change your health care power of attorney or living will at any time while you are able to make decisions.

## AM I GOING TO DIE FROM PARKINSON'S?

This is a natural, fair, and common question. Bret Parker, JD, co-chair of The Michael J. Fox Foundation Patient Council, has said, “When I was diagnosed with young-onset PD, I knew nothing about the disease. My first question to the doctor was, ‘Am I going to die from this?’”

Doctors often say that a person dies with — not from — Parkinson's disease. That's true for many people, who have a nearly normal lifespan with PD. But Parkinson's is variable from person to person, and those with advancing disease may experience complications. For example, some people experience swallowing problems and lung infection (pneumonia). Others have balance problems and falls. Still others, significant thinking changes. Each of

these symptoms brings different support and care needs. These could include hospital visits or a change to safer, more supervised living. Or, in the case of severe and frequent pneumonia, antibiotics or a breathing tube. Not everyone experiences a complication. But many say knowing about the possibilities guides conversations with doctors and loved ones, allows them to be proactive and plan ahead, and enables the best support throughout their Parkinson's journey.

Kirk Hall has said, “Parkinson's or not, I'm going to die. Choosing to accept this allowed me to make plans for the future and the most of every day by focusing on who and what matter most to me.”



→ *“When I was diagnosed with young-onset PD, I knew nothing about the disease. My first question to the doctor was, ‘Am I going to die from this?’”*

— BRET PARKER, JD  
MJFF PATIENT COUNCIL CO-CHAIR, AGE 53  
NEW YORK, NEW YORK



## *Step 3*

### TALK WITH LOVED ONES

For some people and families, talking about later and end of life is the toughest part of preparing for the future. Before you start conversations, make a plan for your discussions. Think about whom you want to talk with and how. Are they more emotion-driven or matter of fact? Is it better to be “casual” or more direct? Consider these tips:

**+ Decide how to broach the topic**

For many, current events offer a good opening to this sensitive subject. The coronavirus pandemic, for example, brought end-of-life care planning to the forefront of many minds. You also could use personal experiences, such as seeing how a friend or loved one lived their later years, as a starting point to talk about how you'd like something similar or different.

Claudia Garrido-Revilla chose a different approach with her young-adult son. She began by talking about a family heirloom, which led to reminiscing about her late father and then sharing her own plans. Claudia has said, “Starting with our history held my son’s attention. It was like we were having a regular conversation and it kept him from immediately worrying that I was seriously ill or dying.”

**+ Meet somewhere without distractions**

Get together in a comfortable, quiet place where you won’t be interrupted. Turn off the TV, phone notifications and other potential distractions so you can focus on the discussion.



*“Starting with our history held my son’s attention. It was like we were having a regular conversation and it kept him from immediately worrying that I was seriously ill or dying.”*

— CLAUDIA GARRIDO-REVILLA  
MJFF PATIENT COUNCIL MEMBER, PATIENT ADVOCATE  
AND COMMUNITY VOLUNTEER, AGE 56  
PEORIA, ILLINOIS

## STEP 1   STEP 2   STEP 3

### +

#### Plan more than one conversation

It's helpful to talk through these topics over time, through multiple conversations. That limits pressure to get through everything at once and allows time to reflect between discussions.

### +

#### Ask for help

Social workers or palliative care providers can help you think through your approach or facilitate discussions between you and your loved ones. (For more on palliative care, see [page 14](#).) Online resources also offer tools and tips for talking about end-of-life care with others.

(See resources #5, 6 and 7 on [pages 21–22](#).)

Some also write letters to their loved ones and/or health care power of attorney. A letter can complement your planning documents (which could feel a bit impersonal) by allowing you to share more about your values, beliefs and wishes; what inspired you to make certain decisions; and life reflections or lessons you'd like to others to know.

(See resource #8 on [page 22](#).)

You can share your letter before, during or after a conversation. (Sharing prior to talking may help foster discussion.) Be sure to keep a copy with your living will and other documents, too.





# WHAT IF MY LOVED ONE HASN'T YET SHARED PLANS?

For Care Partners and Family Members

As a care partner or family member, you may want to bring up end-of-life care planning with a loved one. You may be unsure if they've made plans, or they may not have shared plans in significant detail.

Many people don't know how to ask about end-of-life care planning, or they worry they'll offend or upset their loved one. If you wish to talk with your loved one about end-of-life care planning, consider these tips:

## **+ Keep it casual**

You might try to raise the topic during a regular visit or weekly phone call. For example, "I've been thinking about my future and wonder if you have? Would you be open to talking about your plans?" Some people avoid bringing this up around a doctor visit or change in symptoms so that the conversation doesn't seem tied to a change in health status. (But you can, of course, bring it up then if that feels more natural or appropriate.)

## **+ Remind them you care**

At the beginning of and throughout your conversation, reinforce the reason for the conversation. Tell them you love them, and you want to support and care for them how they most want to be supported and cared for throughout their life.

## **+ Lead by example**

All of us, no matter our age or health status, can — and should — plan for the future. Designate your health care power of attorney and make a living will and then tell your loved one about your thought process and decisions. Share, too, why it was important for you to make these plans and why you want to discuss your plans with them.

You also can download advance directive forms from the internet for your loved one. And ask if you can help them complete or sign as a witness (if you are not their health care power of attorney).

## **+ Make it interactive**

Free online resources, such as the Go Wish game or the Conversation Project, include activities you can complete together. (See resources #3 and 7 on [pages 21–22](#).) You each could complete a worksheet or card sorting exercise on your own and then discuss or do the exercises together.

# What Is Palliative Care?

Palliative care is extra support for living with and managing disease such as Parkinson's. It's not "giving up;" stopping treatment; or hospice, which is for people who have a prognosis of six months or less. (For more on hospice, see [page 16](#).)

Palliative care is a whole-person approach to care that addresses physical, emotional and spiritual sources of discomfort. It can help people understand their diagnosis and manage troublesome symptoms, clarify personal values, and make health care decisions consistent with their wishes and goals. This care is available throughout Parkinson's disease, from shortly after diagnosis through advancing symptoms.

In many cases, your Parkinson's doctor will deliver broad and person-centered care, helping to:

- ✚ Ease bothersome symptoms, such as depression, hallucinations or walking problems
- ✚ Offer emotional and spiritual support
- ✚ Facilitate communication with loved ones and care teams
- ✚ Avoid or manage burnout, for families and care partners
- ✚ Set or clarify care goals for now and for the future

Some people and families may need or want support in addition to what their Parkinson's doctor can offer. Reasons for seeking extra support, particularly in advancing disease, may include care partner burnout, multiple hospitalizations over a short period of time, and others. In these cases, palliative care specialists may be able to help.

Palliative care specialists include a team of professionals — doctors, nurses, social workers, spiritual advisors and volunteers, among others — who work with you, your loved ones and your Parkinson's doctor. This team aims to help improve your quality of life, ease bothersome symptoms, and lessen care partner stress and anxiety. They also can help craft or re-evaluate care goals and plans and facilitate discussion with family and care teams.

Care partner and family support is an important and unique part of palliative care. Malenna Sumrall, PhD, a palliative care clinic volunteer, has said, "When I was caring for my husband who lived with Lewy body dementia, our palliative care neurologist was the first doctor to ask how I was doing. That was a huge sigh of relief. I have seen the same relief on the faces of so many when they realize what's available through palliative care."

If you are interested in learning more about or engaging with a palliative care specialist, speak with your Parkinson's doctor. They may be able to adjust their approach to meet your needs or refer you to a palliative care specialist. Palliative care services can be provided at home or in a clinic or hospital, and either in person or through telemedicine. (See resource #6 on [page 21](#).)



## MYTHS ABOUT PALLIATIVE CARE

There are many misconceptions about palliative care, including that it:

- + **Is only for the end of life**

That's hospice, which is comfort care for people who have a prognosis of six months or less. (Read more on [page 16](#)) You can engage palliative care specialists at any point in Parkinson's, even early on.

- + **Does not apply to Parkinson's**

Palliative care was initially established for people with cancer. But it's appropriate for anyone with a serious or lifelong condition, including PD.

- + **Means giving up or stopping treatment**

Palliative care is *more* care and *more* treatment. It's extra support, added to your current medications and current care team.



# What Is Hospice?

Hospice is comfort care for people who have a life expectancy of six months or less. Like palliative care, it is medical, emotional and spiritual care provided by a team of experts, including a physician, social worker, spiritual counselor and others. Also like palliative care, hospice aims to increase quality of life, decrease symptoms, and clarify and coordinate goals of care for both a patient and their loved ones.

A significant difference between hospice and palliative care is that with hospice, therapies aimed at prolonging life (such as chemotherapy for cancer, for example) are stopped in favor of therapies aimed at promoting comfort and relieving symptoms. For people with Parkinson's, most or all PD medications, which aim to lessen symptoms, may continue during hospice care.

Because Parkinson's is difficult to predict, it can be difficult to know when hospice may be an option. It may help to engage palliative care specialists early on to learn about hospice, and to let your doctors know you are open to considering this care toward the end of life. Jennifer Brokaw, MD, relayed the story of her dear friend with Parkinson's who chose hospice:



→ “*After her Parkinson’s diagnosis at age 67, my dear friend Rosemary was dedicated to staying mobile and strong. Two years later, she was diagnosed with advanced liver cancer, and the cancer doctors wanted to start aggressive chemotherapy. Rosemary said, ‘Why would I do chemo? Just to get stiffer from Parkinson’s? I can’t afford stop moving, and the cancer therapy would force me to abandon all I’m doing.’ She chose hospice instead. It was a brave choice, one that matched her life and care goals.*”

— JENNIFER BROKAW, MD  
EMERGENCY MEDICINE PHYSICIAN AND  
END-OF-LIFE CARE PLANNING ADVOCATE  
SAN FRANCISCO, CALIFORNIA

# Other End-of-Life Considerations

Planning for later and end of life may extend beyond care and finances. Some people also are interested in donating organs or expressing wishes for a funeral or other arrangements.

## + **Organ and Brain Donation**

Many people wish to donate their organs after death. Donating organs, such as the heart, lungs or other tissues can help people living with disease. You can indicate wishes in your living will and register to be an organ donor online or at your local department of motor vehicles. Make sure to also discuss your wishes with loved ones, who can carry them out. (See resource #10 on [page 22](#).)

Many also wonder about brain donation. Brain donation is different than other organ donation in that it's solely for the advancement of scientific research. Studying the brains of people who lived with Parkinson's and other brain conditions helps researchers learn more about why disease happens, how it changes over time, and how to develop new and better treatments.

Any adult — with or without brain disease — can donate their brain. There typically is no cost to you or your family and donation does not interfere with funeral or burial plans. If you wish to donate your brain, talk with your doctor and loved ones. Your doctor can help you understand the process, where you can donate, and what steps you can take now to plan. (See resource #11 on [page 22](#).)

## + **Funeral and Burial Plans**

Making funeral and burial arrangements in advance can be a way to honor your personal values and lessen stress for loved ones and family members. You can describe your preferences, make plans, and even pre-pay (or save money in a separate account) for these arrangements. (See resource #12 on [page 22](#).) Questions to consider may include:

- Do you prefer burial or cremation?
- Have you identified a final resting place, such as a family burial plot or another meaningful location?
- Would you like your loved ones to have a funeral, memorial service, or celebration of your life? If so, do you have a desired location or structure? Which loved ones, friends, family and others would you like to attend? Are there people you'd want to speak, songs you'd like played, or words — yours or others — read? (Some people like to write their own obituary, which can be published online or in a newspaper, as a way to tell their life story; others ask close friends or family to take care of this writing.)

# DON'T FORGET FINANCIAL PLANNING



As you think about care for later and end of life, also think about future financial needs. A financial advisor and/or an estate planning lawyer can help you think through potential needs and complete required documents. Financial planning allows you to:

## **+ Prepare for potential costs**

Parkinson's and other medical conditions can bring care or living costs — not all of which are covered by insurance or retirement funds — in later life. A financial planner can help you understand options, such as long-term care insurance, investments, and others, to help with these costs, should they occur.

## **+ Name someone to manage finances, if necessary**

A financial power of attorney is someone who can handle your bills, property, investments, business and other financial assets if you become unable. You continue to make all money-related decisions as long as you are able. Just like a health care power of attorney, this is a security measure, just in case.

## **+ Create a will**

A will, also called a last will and testament, is a legal document in which you detail how you'd like your assets shared after death — with loved ones and/or organizations, institutions or causes that are important to you. A will also allows you to appoint guardians for younger children, if applicable, should something unexpected happen. If you don't have a will, state laws determine how assets are divided.

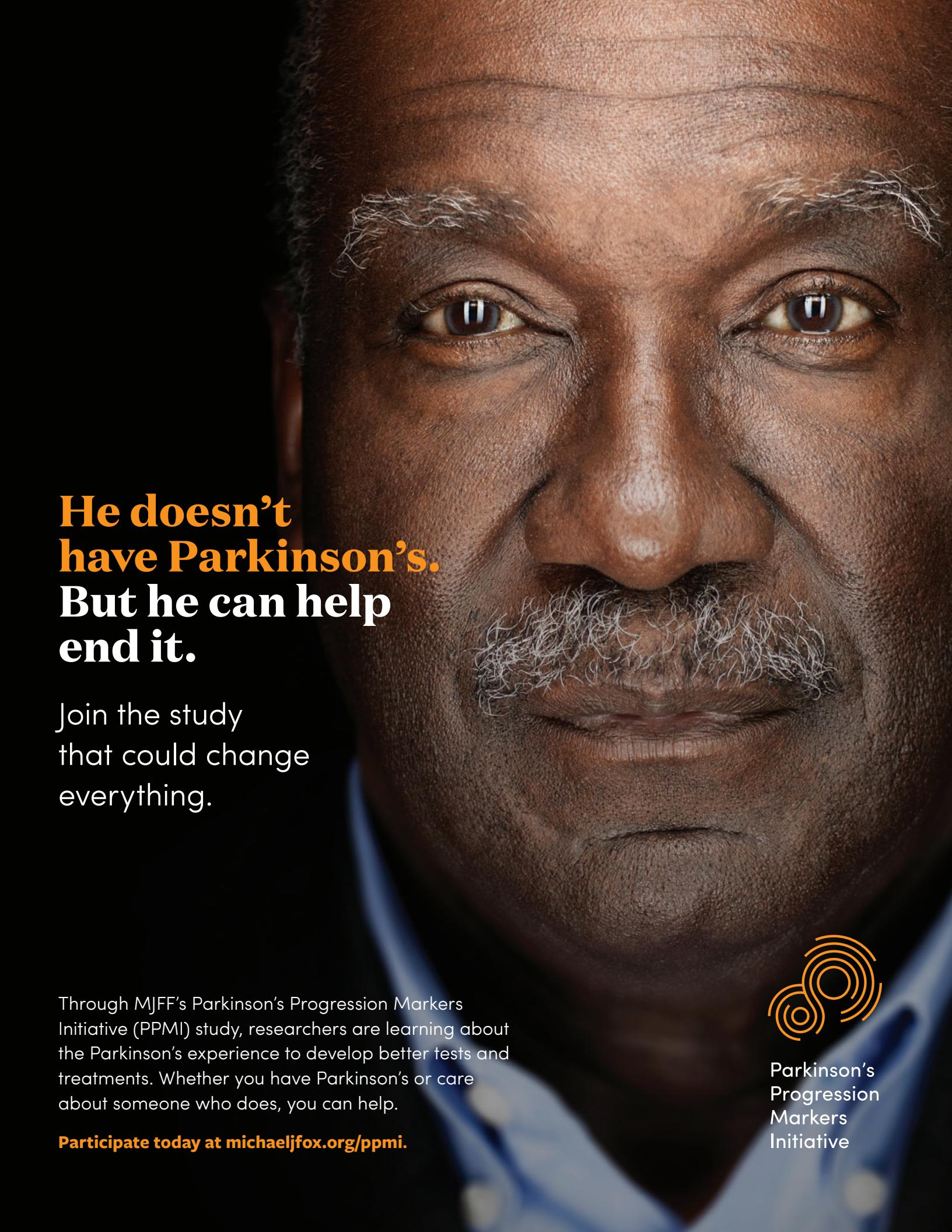
For more financial planning information and resources, see [page 23](#).





## *Take One Step at a Time*

Planning for the future with Parkinson's may not be easy. But it's an important and valuable way to take control of your health care journey, ease stress and worry, and help you and your loved ones make the most of each day together.



**He doesn't  
have Parkinson's.  
But he can help  
end it.**

Join the study  
that could change  
everything.

Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments. Whether you have Parkinson's or care about someone who does, you can help.

**Participate today at [michaeljfox.org/ppmi](http://michaeljfox.org/ppmi).**



Parkinson's  
Progression  
Markers  
Initiative

# *Future Care Planning Resources and Providers*

Many resources and health care providers offer information and help with end-of-life care planning. Here, we list tools and health care team members that many people with Parkinson's and their doctors find helpful. Ask your personal physician and others you trust for recommendations specific to you and your needs.

## **1. LIFE VALUES INVENTORY**

A free, online tool to help define your values. (This is only one example, there are many other tools that list values and help you clarify yours.)

↗ [lifevaluesinventory.org/the-process.html](http://lifevaluesinventory.org/the-process.html)

## **2. PORTABLE MEDICAL ORDERS (POLST)**

Information on what a POLST form covers, when to consider, and how to complete documents, as well as a link to state-specific forms.

↗ [polst.org](http://polst.org)  
↗ [polst.org/state-programs](http://polst.org/state-programs)

## **3. GO WISH GAME**

A free, online tool to help you describe what is most important to you near the end of life.

↗ [codaalliance.org/go-wish](http://codaalliance.org/go-wish)

## **4. PREPARE**

A free, online resource to help with advance directives and end-of-life care planning.

↗ [prepareforyourcare.org/index.php/welcome](http://prepareforyourcare.org/index.php/welcome)

## **5. SOCIAL WORKER**

A professional who provides supportive counseling and education about managing disease; connects people to community resources, such as support groups; and assists with future care planning.

↗ [onlinetherapy.com/social-workers](http://onlinetherapy.com/social-workers)

## **6. PALLIATIVE CARE SPECIALISTS**

A team of experts who can, at any time in disease — not only near the end of life — help manage troublesome symptoms and coordinate communication and align goals of care between a patient, family and their health care team.

↗ [getpalliativecare.org/provider-directory](http://getpalliativecare.org/provider-directory)  
↗ [nhpco.org/find-a-care-provider](http://nhpco.org/find-a-care-provider)

# *Future Care Planning Resources and Providers*

*(continued)*

## **7. THE CONVERSATION PROJECT**

A free, online resource with tools and tips for talking with loved ones about later and end-of-life plans.

↗ [theconversationproject.org](http://theconversationproject.org)

## **8. LETTER OF YOUR LIFE**

Guidance on writing a letter to loved ones as a complement to end-of-life planning documents.

↗ [michaeljfox.org/legacyletter](http://michaeljfox.org/legacyletter)

## **9. HOSPICE**

Information on end-of-life and hospice care and how hospice differs from palliative care.

↗ [hospicefoundation.org/Hospice-Care](http://hospicefoundation.org/Hospice-Care)

↗ [nia.nih.gov/health/what-are-palliative-care-and-hospice-care](http://nia.nih.gov/health/what-are-palliative-care-and-hospice-care)

## **10. ORGAN DONATION**

Resources on how organ donation works, who is eligible, what organs can be donated, and how to sign up.

↗ [organdonor.gov](http://organdonor.gov)

## **11. BRAIN DONATION**

Answers to questions about brain donation, information on arranging donation, and a link to register.

↗ [neurobiobank.nih.gov](http://neurobiobank.nih.gov)

↗ [nia.nih.gov/health/brain-donation-gift-future-generations](http://nia.nih.gov/health/brain-donation-gift-future-generations)

## **12. FUNERAL PLANNING**

Information and tips for making arrangements in advance.

↗ [aarp.org/home-family/friends-family/info-2020/funeral-planning-tips.html](http://aarp.org/home-family/friends-family/info-2020/funeral-planning-tips.html)



# Financial Planning Resources

Many resources and experts provide information and guidance on financial planning. Here, we list a few tools that many find useful. Talk with your loved ones and trusted advisors about which tools may be best suited to you.

## A GUIDE TO MAKING YOUR WILL

Answers to common questions and steps to creating a will.

↗ [michaeljfox.org/will-guide](https://michaeljfox.org/will-guide)

## FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

Information on completing a will and other legal documents, considerations for children and insurance beneficiaries, and more.

↗ [michaeljfox.org/estateplanning101](https://michaeljfox.org/estateplanning101)

## LETTER OF INTENT

A non-binding form that allows you to indicate your desire to name The Michael J. Fox Foundation for Parkinson's Research as a beneficiary in estate plans.

↗ [michaeljfox.org/intent](https://michaeljfox.org/intent)

The graphic features a light gray background with three large, overlapping white circles in the lower right corner. In the upper left, there is a logo consisting of three orange concentric circles. To the right of the logo, the text "Parkinson's Progression Markers Initiative" is written in a serif font. Below this, a paragraph of text describes the PPMI study. Further down, another paragraph explains the purpose of PPMI, followed by a statement encouraging participation and a call to action at the bottom.

Parkinson's  
Progression  
Markers  
Initiative

Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments.

PPMI gathers data and samples over time from volunteers around the world — both with and without Parkinson's — to increase understanding of symptoms and progression; find measurements in the earliest stages (even before motor symptoms); and advance treatments to slow, stop or prevent disease.

Whether you have Parkinson's or care about someone who does, you can help.

Find out how and join PPMI, the study that could change everything, at [michaeljfox.org/ppmi](https://michaeljfox.org/ppmi).

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The information in this guide was accurate at the time of publication in January 2022. For the latest in Parkinson's care and research, visit [michaeljfox.org](https://michaeljfox.org).

The medical information contained in this article is for general information purposes only. The Michael J. Fox Foundation has a policy of refraining from advocating, endorsing or promoting any drug therapy, course of treatment, or specific company or institution. It is crucial that care and treatment decisions related to Parkinson's disease and any other medical condition be made in consultation with a physician or other qualified medical professional.

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