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# PLANNING FOR THE FUTURE

## A GUIDE FOR INDIVIDUALS LIVING WITH PARKINSON'S

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## INTRODUCTION

Living with Parkinson's disease can raise many questions, not just about health care, but also about planning for the future. Thinking about legal and personal decisions ahead of time can feel overwhelming, especially when symptoms may change over time. You are not alone in feeling this way.

This resource is designed to help people living with Parkinson's disease in Ontario, as well as their families and caregivers, understand some common planning tools. The goal is not to tell you what choices to make, but to explain what options exist and how they operate.

Planning can give you more control over your future. It allows you to share your wishes, choose people you trust to help make decisions if needed, and reduce uncertainty or stress for loved ones. Many of these steps can be taken gradually and can often be updated as your circumstances or wishes change.

This guide provides general information only. It is not legal advice. Everyone's situation is different, and you may wish to speak with a lawyer or healthcare provider before making decisions.

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## **POWER OF ATTORNEY**

### **What is a Power of Attorney?**

A Power of Attorney is a legal document that lets you choose someone you trust to make financial or healthcare decisions for you if you are unable to make them yourself.<sup>1</sup> If Parkinson’s disease affects your ability to make these decisions in the future, having a Power of Attorney in place can help ensure that your wishes are respected and that the person speaking on your behalf is someone you trust.

When choosing your attorney, it is important to select someone who will act in your best interests, such as a spouse, family member, or close friend.<sup>2</sup> The person who gives this authority is called the “grantor.” A grantor does not have to name a singular attorney, and one or more individuals may be appointed under a Power of Attorney.<sup>3</sup> Where more than one person is appointed, the Power of Attorney may require them to act jointly, which requires that they all agree on decisions and will be jointly liable for

<sup>1</sup> Government of Ontario, “Make a power of attorney”, online: <<https://www.ontario.ca/page/make-power-attorney#section-1>>.

<sup>2</sup> “Make a power of attorney” (footnote 1).

<sup>3</sup> Government of Canada, “Powers of attorney and joint bank accounts”, online: <<https://www.canada.ca/en/employment-social-development/corporate/seniors-forum-federal-provincial-territorial/power-attorney-financial.html>>.

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each other's actions. Alternatively, if the Power of Attorney is drafted as "joint and several," each appointed person may act independently.<sup>4</sup>

## Types of Powers of Attorney

In Ontario, there are two types of Powers of Attorney: **Power of Attorney for Personal Care** and **Power of Attorney for Property**.<sup>5</sup>

### Power of Attorney for Personal Care

A Power of Attorney for Personal Care allows your chosen attorney to make decisions about your personal well-being if you are unable to do so yourself. This can include decisions about health care, where you live, what you eat, clothing, and other day-to-day personal matters.<sup>6</sup> If you do not have a Power of Attorney for Personal Care, family members may be able to make some health-related decisions for you. In those situations, the *Health Care Consent Act*<sup>7</sup> sets out a legal order of who may make certain healthcare decisions on your behalf, but this does not cover all personal care decisions.

### Power of Attorney for Property

A Power of Attorney for Property gives your attorney the authority to manage your financial affairs. This can include paying bills, collecting money owed to you, managing bank accounts and investments, and maintaining or selling your home.<sup>8</sup> If you do not have a Power of Attorney for Property, your family cannot automatically make financial decisions for you. Instead, they may need to apply to the court to be appointed as your guardian.<sup>9</sup> This process can be time-consuming and costly. The court will require proof that you are incapable of managing your property and that the proposed guardian is appropriate, which may include a formal capacity assessment by a physician or licensed capacity assessor.<sup>10</sup>

In some cases, if no suitable person is available or willing to act, and decisions must be made, the government may step in through the Office of the Public Guardian and Trustee.<sup>11</sup> This typically happens only as a last option.

<sup>4</sup> "Powers of attorney and joint bank accounts" (footnote 2).

<sup>5</sup> Government of Ontario, "Make a power of attorney", online: <<https://www.ontario.ca/page/make-power-attorney#section-1>>.

<sup>6</sup> "Make a power of attorney" (footnote 1).

<sup>7</sup> *Health Care Consent Act, 1996*, SO 1996, c 2, Schedule A, s 20(1).

<sup>8</sup> "Make a power of attorney" (footnote 1).

<sup>9</sup> "Make a power of attorney" (footnote 1).

<sup>10</sup> Government of Ontario, "Guardianship", online: <<https://www.ontario.ca/page/guardianship#section-0>>.

<sup>11</sup> Government of Ontario, "Office of the Public Guardian and Trustee", online: <<https://www.ontario.ca/page/office-public-guardian-and-trustee>>.

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## Creating Your Power of Attorney

To make a Power of Attorney, you must be mentally capable at the time you sign it. Under Ontario law, adults are presumed to be capable of making their own decisions unless it is shown otherwise. A person may be found incapable if they do not understand the information needed to make a decision, the consequences of that decision, or both.<sup>12</sup>

In Ontario, you must be at least 18 years old to create a Power of Attorney for Property and at least 16 years old to create a Power of Attorney for Personal Care.<sup>13</sup>

You can create a Power of Attorney on your own or have a lawyer prepare one for you. If your financial, personal, or business affairs are complex, speaking with a lawyer may be helpful. If you choose to do this yourself, the Ontario government has published a [guideline document](#) that contains the instructions and forms for establishing a power of attorney for property and/or personal care in the province. Additionally, Community Legal Education Ontario has created a [web tool](#) to help individuals create these documents.

Once your Power of Attorney is complete, there is no requirement to register it with the government. However, it may be a good idea to let trusted people, such as your attorney, family members, or caregivers, know that the document exists and where it is stored, in case it is needed in the future.<sup>14</sup>

For more information, the Office of the Public Guardian and Trustee has published a helpful [Q&A document](#).

## ADVANCE CARE DIRECTIVES

Creating an Advance Care Directive is a method through which you can formally clarify your wishes regarding personal health care decisions, as well as the management of your property. This section will be focusing on the creation of an Advance Care Directive on the subject of personal care decisions, to be utilized by your Power of Attorney for Personal Care or Substitute Decision Maker in order to advocate on your behalf at a point in the future when you are no longer capable of making these decisions for yourself. A Power of Attorney for Personal Care may also be referred to as a Substitute Decision Maker.

<sup>12</sup> Government of Ontario, “Mental capacity”, online: <<https://www.ontario.ca/page/mental-capacity>>.

<sup>13</sup> “Make a power of attorney” (footnote 1).

<sup>14</sup> Office of the Public Guardian and Trustee, “Powers of Attorney”, online (pdf): <[https://www.publications.gov.on.ca/store/20170501121/Free\\_Download\\_Files/300629.pdf](https://www.publications.gov.on.ca/store/20170501121/Free_Download_Files/300629.pdf)>.

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There are three pieces of law in Ontario that regulate how advance care directives should be created and used:

1. [Powers of Attorney Act, 1990](#)<sup>15</sup>
2. [Substitute Decisions Act, 1992](#)<sup>16</sup>
3. [Health Care Consent Act, 1996](#)<sup>17</sup>

Your Substitute Decision Maker will be able to advocate for wishes in relation to preferences for health care, nutrition, residence, and clothing.<sup>18</sup> If a Substitute Decision Maker is not assigned, your family may be able to make some (but not all) of these care decisions on your behalf.<sup>19</sup>

Typically, the Substitute Decision Maker role is assigned to a spouse, family member, or close friend of the patient.<sup>20</sup> If more than one Substitute Decision Maker is appointed (for example, one or more of the children of the patient), these individuals may be required to act *jointly* in making personal care decisions.<sup>21</sup> You may also elect to assign the Substitute Decision Maker role to the Public Guardian and Trustee.<sup>22</sup>

When selecting an individual to assume the role of your Substitute Decision Maker, it is important that you speak with them to ensure that they are comfortable with the responsibilities of the position, and that they appreciate the power to advocate for your specific wishes regarding personal care decisions.<sup>23</sup>

## Types of Health Care Decisions to Consider

The [Advance Care Planning Ontario](#) website contains helpful resources that can be used to help you reflect on the various types of decisions that may need to be made, as well as the values that you wish to guide your treatment plan in the future. The following steps are highlighted by this website, and you may find them useful as you begin the process of creating an Advance Care Directive:

- 1. Identify someone that you wish to make your decisions for you once you are no longer capable.**

<sup>15</sup> *Powers of Attorney Act*, RSO 1990, c P.20.

<sup>16</sup> *Substitute Decisions Act, 1992*, SO 1992, c 30.

<sup>17</sup> *Health Care Consent Act, 1996*, SO 1996, c 2, Schedule A.

<sup>18</sup> “Make a power of attorney” (footnote 1).

<sup>19</sup> “Make a power of attorney” (footnote 1).

<sup>20</sup> “Make a power of attorney” (footnote 1).

<sup>21</sup> *Substitute Decisions Act, 1992*, SO 1992, c 30, s 46(4).

<sup>22</sup> *Substitute Decisions Act, 1992*, SO 1992, c 30, s 46(2).

<sup>23</sup> “Make a power of attorney” (footnote 1).

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- 2. Take the time to learn more about Parkinson's, its complications, and how the disease may progress for you.**
- 3. Reflect on your personal values (e.g., independence, dignity, happiness, socializing).**
  - As you let your values guide your wishes with respect to certain medical treatments, it is also important to consider desired outcomes.
  - For example, you might wish to undergo certain treatments only in specific circumstances where the health issue involved can be resolved.
- 4. Communicate these values to your Substitute Decision Maker as they evolve. Beginning a conversation regarding future wishes can feel uncomfortable.**
  - While being straightforward in opening this dialogue can be effective, you may wish to use examples from family members, friends, or the news as a conversation starter.

Your Substitute Decision Maker will be consenting on your behalf to proposed medical treatments. They will need to understand what your wishes were at the time when you were capable of making decisions related to health care.

## GUIDANCE IN SELECTING A LONG-TERM CARE HOME

Choosing a long-term care home is a significant decision that requires careful consideration of personal needs, medical requirements, and lifestyle preferences. It is a place for you to live comfortably and safely once living independently becomes too difficult. Individuals may conduct their own research or seek assistance from an [Ontario Health at Home](#) placement coordinator. These coordinators are knowledgeable about facilities in your area and can guide applicants through the placement process. Applicants are permitted to apply to a maximum of five long-term care homes at one time.

### Making an Informed Long-Term Care Decision

If you are doing your own research, the following three steps can help you make an informed choice to find a home that will be right for you.<sup>24</sup>

#### **Step 1: Identify your Wants and Needs**

The first step in selecting a home is to identify your personal needs and wants. This can be done by making a list of all the things that matter to you in choosing a home. Your list can include things such as

<sup>24</sup> Ontario, Ministry of Long-Term Care, "Choosing a long-term care home", online: <<https://www.ontario.ca/page/choosing-long-term-care-home>>.

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medical and daily living requirements, cultural or religious preferences, language considerations, costs and subsidies, services needed, recreational opportunities, and proximity to family and friends.

Individuals should also consider the type of accommodation they prefer, such as private or semi-private rooms, and the surrounding environment of the facility, considering elements such as what shops and parks are nearby. Future care needs should also be taken into account, including possible requirements for rehabilitation, assistance with daily activities, hospice care, or specialized memory care services.<sup>25</sup>

## **Step 2: Gather Information**

After you identify your priorities, the next step is to gather information about potential facilities and build a list of homes that may be right for you. Ontario provides an [online search tool](#) that allows individuals to review long-term care homes across the province. Home websites are also helpful tools for gathering information. They typically offer information on the home as well as virtual tours of the facility.<sup>26</sup>

It is also a good idea to speak with people that you know who can provide insight on their experiences with particular facilities. For example, you can ask what they liked and disliked about the home, whether they were happy with their care, and ask about any particular offerings that are important to you.

Other sources such as health care providers, social workers, and support groups may also be able to provide insight and suggest homes. After identifying some potential homes, it can be a good idea to contact them directly to ask questions about the capacity, costs, special needs that may need to be met, and availability.<sup>27</sup>

## **Step 3: Visit in person**

After building your list of potential homes, it is a good idea to start visiting facilities in person as this is the best way to get a feel for a home. To do this, you should call the home to book a tour in advance. If possible, you should make plans to meet with key staff members such as the nursing director.

It may be a good idea to schedule your visit during meal time or take part in an activity at the home to experience the home's offerings. During your visit, do not be afraid to ask questions about anything that is important to you or that you find concerning. You can also find out about any additional services

<sup>25</sup> “Choosing a long-term care home” (footnote 24); National Institute of Aging, “How to Choose a Nursing Home or Other Long-Term Care Facility”, online: <<https://www.nia.nih.gov/health/assisted-living-and-nursing-homes/how-choose-nursing-home-or-other-long-term-care-facility>>.

<sup>26</sup> “Choosing a long-term care home” (footnote 24).

<sup>27</sup> “How to Choose a Nursing Home or Other Long-Term Care Facility” (footnote 25).

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that the facility offers such as rehabilitation or dental and about the policies that might impact you such as visitors, including pets, as well as day and overnight trips.

It may be helpful to use the [Medicare Nursing Home Checklist](#) to help with facility assessments of the various homes that you visit. It can also be helpful to make a second, unscheduled trip, at a different time or day so that you can get to experience different activities and meet other staff members.

Before making a final decision, individuals should carefully review the cost structure and contract terms. Each facility may include different services in its base fees, and optional services may incur additional costs. Financial offices within facilities may assist in determining eligibility for government programs or insurance coverage. Contracts should be read thoroughly, and clarification should be sought for any provisions that are unclear prior to signing.<sup>28</sup>

**For additional resources to help with your long-term care research, you can use the following:**

- Search the [Eldercare Locator](#) or call 800-677-1116 for help finding care in your area.
- Visit [LongTermCare.gov](#) for information about housing options for older adults and finding local services.
- Call your local Area Agency on Aging or department of human services from your state or local government.
- Use [Medicare's Care Compare tool](#) to find and compare nursing homes and other health care facilities in your state or territory.
- Check the quality of nursing homes and other health care facilities with the [Joint Commission's Quality Check](#).

<sup>28</sup> “Choosing a long-term care home” (footnote 21); “How to Choose a Nursing Home or Other Long-Term Care Facility” (footnote 22); Ontario Health at Home, “Guide To Placement in Long-Term Care Homes”, online: <<https://ontariohealthathome.ca/wp-content/uploads/2022/10/OHaH-Long-Term-Care-Placement-Guide-EN.pdf>>.

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## KEY CONSIDERATIONS AROUND WILLS AND ESTATES

### What Are Wills and Estates?

When a person dies, the possessions and finances they leave behind are referred to as an estate.<sup>29</sup> A will is a legal document that identifies how that estate is to be distributed.<sup>30</sup> A will achieves this by identifying how and to whom a person wanted their possessions dispersed.<sup>31</sup> Some notable items typically included in wills are:

- Land
- Money or other financial assets
- Physical valuables (vehicles, watches, jewelry, antiques, collectibles, etc.)<sup>32</sup>

Property listed as inheritance can include an item even if it lacks substantial financial value. Wills allow for a particular item to be given to a particular person, and can ensure family heirlooms, sentimental items, and pets are received by their intended recipient.<sup>33</sup>

### Why Create a Will?

A will is created prior to death, and seeks to ensure that a deceased's estate is distributed in accordance with their wishes while they were living.<sup>34</sup> If a person does not have a will, their personal wishes will not be taken into account in the eventual distribution of their estate after they die.<sup>35</sup> In essence, a will provides a structure for the distribution of an estate and provides security for the person creating the will, as well as the people in their life, that their possessions will be distributed in accordance with their wishes after their death.<sup>36</sup>

### The Structure of a Will

In a will, its creator can name an executor(s) and beneficiaries. An executor is the person made responsible for the accurate distribution of the estate, in accordance with the instructions contained in

<sup>29</sup> Scotia Bank Advice+ Team, "Understanding will and estate planning terms", online: <<https://www.scotiabank.com/ca/en/personal/advice-plus/features/posts.understanding-will-and-estate-planning-terms.html>>.

<sup>30</sup> King's Printer for Ontario, "Estate planning and wills", online: <<https://www.ontario.ca/page/estate-planning-and-wills>>.

<sup>31</sup> King's Printer for Ontario, "What to do when someone dies", online: <<https://www.ontario.ca/page/what-do-when-someone-dies>>.

<sup>32</sup> Community Legal Education Ontario, "What do I need to think about when making a will?", online: <<https://stepstojustice.ca/questions/wills-and-powers-of-attorney/what-do-i-need-think-about-when-making-will/>>.

<sup>33</sup> "What do I need to think about when making a will?" (footnote 32).

<sup>34</sup> Government of Canada, "What every older Canadian should know about: Having a will and making funeral plans", online: <<https://www.canada.ca/en/employment-social-development/corporate/seniors-forum-federal-provincial-territorial/will-funeral-plan.html>>.

<sup>35</sup> "What every older Canadian should know about: Having a will and making funeral plans" (footnote 34).

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the will.<sup>37</sup> Beneficiaries are the people who will receive items from the will.<sup>38</sup> The executor is responsible for the estate's payment of any debts, before the distribution of the estate to its beneficiaries.<sup>39</sup> Importantly, the executor is not personally responsible for any debts the deceased had, but when an individual dies, their debts are included as a part of their estate.<sup>40</sup> The executor uses the assets contained in the estate to pay the estates debts prior to distributing assets to those named in the will.<sup>41</sup> If the debts of the estate exceed the assets, the debts are not passed on to the executor or the family of the deceased, but this can impact what the beneficiaries receive from the estate.<sup>42</sup> A beneficiary can be a family member, a friend, a charitable organization, etc.<sup>43</sup> The creator of the will decides what a beneficiary will receive from the estate and can impose conditions upon that inheritance.<sup>44</sup> For example, a will could indicate that:

- A beneficiary is to receive a home, but only for the remainder of their life, at which point it will be received by another beneficiary permanently.

Even if the estate is small, or there are few potential beneficiaries, a will is still helpful. As stated above, a will allows for the naming of an executor. An executor is the person responsible for making many decisions on the creator of the will's behalf after their death where applicable. Naming an executor in a will enables a trusted person to oversee the affairs of the deceased.<sup>45</sup>

#### How to Create a Will

A will can be created directly by the individual, or through hiring an attorney. For more information on how to create a will, and the reasons for or against the methods of creation listed above, please visit: <https://www.ontario.ca/page/estate-planning-and-wills>

## Probate

Many estates will require a legal process known as probate to occur.<sup>46</sup> Probate is the process through which an individual is granted authority over the estate and its assets.<sup>47</sup> The Government of Ontario

<sup>37</sup> "What every older Canadian should know about: Having a will and making funeral plans" (footnote 34).

<sup>38</sup> "Understanding will and estate planning terms" (footnote 29).

<sup>39</sup> "Understanding will and estate planning terms" (footnote 29).

<sup>40</sup> Canadian Legal Wills, "What happens to your debt when you die?", online: <<https://www.legalwills.ca/blog/debt-when-you-die/>>.

<sup>41</sup> "What happens to your debt when you die?" (footnote 40).

<sup>42</sup> "What happens to your debt when you die?" (footnote 40).

<sup>43</sup> "Understanding will and estate planning terms" (footnote 29).

<sup>44</sup> Mann Lawyers, "The Limits on Conditional Gifts in Wills", online: <<https://www.mannlawyers.com/resources/the-limits-on-conditional-gifts-in-wills/>>.

<sup>45</sup> "Estate planning and wills" (footnote 30).

<sup>46</sup> King's Printer for Ontario, "Administering estates", online: <<https://www.ontario.ca/page/administering-estates>>.

<sup>47</sup> "Administering estates" (footnote 46).

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has created a guide to better understand probate, when it is necessary, and what is required. Please visit: <https://www.ontario.ca/page/apply-probate-estate> for more information.

## **In the Absence of a Will**

When a person dies, probate is the legal process for determining how an individual's estate is distributed. If a will exists, it will determine how some or all of the estate is distributed. In Ontario, if a person dies without a will, the estate is distributed in accordance with the [Succession Law Reform Act](#).<sup>48</sup> This process can complicate the distribution of the estate, delay the distribution, and lead to a distribution that does not match the wishes of the deceased while they were living.<sup>49</sup> There are legal mechanisms in place to facilitate the distribution of an estate in absence of a will, but a will helps to protect its creator's interests and the interests of those they care about.<sup>50</sup>

# EMPOWERING FAMILIES AND CARE PARTNERS

## **Overview**

For those assisting a family member or care partner, there are tangible steps you can take to help. Generally, these steps will be helpful for individuals as well but can be delegated to someone assisting.

## **Preparing for Medical Appointments and Assisting in Care**

There are a variety of steps that can be taken to maximize the benefit of a medical appointment. In the time leading up to an appointment, you may want to make note of any questions you have so that you can be sure to remember them during the appointment.<sup>51</sup> You may have symptoms you wish to ask questions about.

Visit *Parkinson Canada* at the link below for more information on tracking symptoms for your appointments: <https://www.parkinson.ca/wp-content/uploads/Preparing-for-a-Medical-Appointment.pdf>.

<sup>48</sup> "Administering estates" (footnote 46).

<sup>49</sup> "What to do when someone dies" (footnote 31).

<sup>50</sup> "What to do when someone dies" (footnote 31).

<sup>51</sup> Katrina Lingrell, "Six ways to get more from your medical appointment", online: <https://covenanthealth.ca/news-and-events/news/six-ways-to-get-more-from-your-medical-appointment>.

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Additionally, you may want to take notes during the appointment itself to ensure you remember the correct information.<sup>52</sup> A family member or care partner can likely attend appointments with the patient if the patient gives permission, and if they do, they can assist in note taking to help the patient manage their care.<sup>53</sup>

## **Additional Supports**

Family members or care partners may find themselves providing substantial amounts of care to the patient. If these demands necessitate taking time off work, there are programs available to help. The Canadian government's employment insurance program offers insurance benefits to people caring for family members that are critically ill, critically injured, or in need of end-of-life care.<sup>54</sup> For information on how to apply, visit: <https://www.canada.ca/en/services/benefits/ei.html>.

Alternatively, the support required may extend beyond what a family member or care partner is capable of providing. In that case the patient may wish to seek in-home healthcare support. For more information, visit: <https://ontariohealthathome.ca/>.

For general caregiving resources please visit: <https://www.ontariocaregivercoalition.ca/>.

Those caring for others may also find themselves in need of their own support. If you are a family member or care partner in need of support regarding the care you give, please visit: <https://www.parkinson.org/resources-support/carepartners/caring-for-self>.

If you are seeking general information for the family of a patient, please visit: <https://www.parkinson.ca/celebrating-connections-navigating-parkinsons-as-a-family/>.

# HOSPICE CARE OPTIONS IN ONTARIO

## **What is Hospice Care?**

Hospice care, also known as end-of-life care, is offered to patients and families facing serious, life-limiting illnesses. The focus of hospice care is on comfort, quality of life, and support for both the patient and family. It can include pain and symptom management, emotional support, and planning

<sup>52</sup> "Six ways to get more from your medical appointment" (footnote 51).

<sup>53</sup> Dying With Dignity Canada, "How to be a Patient Advocate", online: <[https://www.dyingwithdignity.ca/wp-content/uploads/2023/05/How-to-be-a-patient-advocate\\_EN.pdf](https://www.dyingwithdignity.ca/wp-content/uploads/2023/05/How-to-be-a-patient-advocate_EN.pdf)>.

<sup>54</sup> Government of Canada, "EI caregiving benefits", online: <<https://www.canada.ca/en/services/benefits/ei/caregiving.html>>.

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for future care decisions. In Ontario, this care can be delivered in different settings, including at the hospital, in a long-term care home, at a specialized hospice residence, or in the patient's home.<sup>55</sup>

## What are My Options for Hospice Care?

Depending on your circumstances, needs, and location, you may be able to receive care through:

- In-home hospice services (comfort-focused care in your own home).
- Hospice residence care (comfort care for those who need continuous end-of-life support).
- In-hospital palliative care.
- Long-term care palliative support (if you already live in a long-term care facility or need placement there).<sup>56</sup>

## How do I Access Hospice Care?

According to Ontario Health, your planning for palliative and hospice care should start as soon as possible after your diagnosis. You do not need to wait until a crisis to ask about or obtain hospice supports. You can obtain more information and access hospice care through a referral from:

- Your family doctor
- Your treating neurologist
- Your hospital treatment team
- Your long-term care home
- Through Ontario Health atHome
- In Ontario, anyone can make a referral through the Ontario Health atHome service with the patient's consent.
- Patients or authorized family members/friends can visit <https://ontariohealthathome.ca/> or dial 310-2222 (no area code) to access Ontario Health atHome services<sup>57</sup>

Any of these sources are able to work with you and your family to ensure you receive the type and level of hospice care that is best for you, your family, and your circumstances.<sup>58</sup>

<sup>55</sup> Ontario Ministry of Health, "Palliative and End-of-life Care", <<https://www.ontario.ca/page/palliative-and-end-life-care>>.

<sup>56</sup> "Palliative and End-of-life Care" (footnote 55).

<sup>57</sup> "Palliative and End-of-life Care" (footnote 55).

<sup>58</sup> "Palliative and End-of-life Care" (footnote 55).

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## Your Legal Rights When Making Hospice Care Decisions

If you are capable of making decisions for yourself, you decide your treatment. You have legal rights regarding your medical and hospice treatment, like the right to informed consent, refusal, and complaints. Informed consent refers to your right to receive enough information to fully understand and make treatment decisions. If you become incapable of making treatment decisions, a substitute decision-maker can make these decisions on your behalf.<sup>59</sup>

Like all other forms of health care, you also have the right to refuse all or some aspects of hospice care. You do not need to explain why. You can always withdraw your consent at any time, even if you said yes at first.

If you have a concern about your hospice care treatment and want to make a complaint, your first step is to raise this concern with the organization and attempt to resolve it through their internal process. If your concerns cannot be resolved through this process, or you are unable to or unsure of how to begin this process, you can reach out to the Ontario Patient Ombudsman. This free service can review complaints involving public hospitals, long-term care homes, and home and community care organizations, and help find a resolution. If they are unable to help you, they may be able to direct you to another service that can.

You can access the Ontario Patient Ombudsman through <https://patientombudsman.ca> or by dialing 416-597-0339.<sup>60</sup>

## PARTICIPATING IN CARE—TEACHING HOSPITALS

### What is a Teaching Hospital?

Teaching hospitals are affiliated with medical schools at universities, like the Schulich School of Medicine & Dentistry at Western University in London. These hospitals make agreements with universities to provide high-quality health care to patients while training and educating the next generation of doctors, nurses, and other health care professionals. These students are guided and supervised by experienced doctors and

<sup>59</sup> See page 5 for information about substitute decision makers.

<sup>60</sup> College of Physicians and Surgeons of Ontario, “Complaints and Concerns”, online: <<https://www.cpso.on.ca/public/services/complaints-and-concerns>>.

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nurses, who lead patient care. Due to their affiliation with universities, teaching hospitals are often able to conduct innovative research and trials.<sup>61</sup>

Major teaching hospitals in Southwestern Ontario include the London Health Sciences Centre (London), St Joseph's Health Care London, and McMaster University Medical Centre (Hamilton).

## What Should I Know About Care at a Teaching Hospital?

Many of Ontario's largest and most advanced hospitals are teaching hospitals. Some teaching hospitals in Ontario are ranked among the leading health care centres in Canada. Given their size and research connections, they can offer specialized care, access to cutting-edge trials and research, and are often equipped with the latest technology.<sup>62</sup>

### **1. Making Decisions About Treatment**

You can always ask questions, request additional explanation if there is something you do not understand, and take part in choosing your care plan. You always have the right to make informed decisions about your health care.

### **2. Understanding Who is on Your Care Team**

At a teaching hospital, your care team may include staff physicians, residents (licensed, graduated doctors who are undergoing training to specialize in a specific area of medicine, like neurology), and medical students (who are still in medical school). You have the right to be informed about the roles and status of the health care professionals on your team. You can typically decline to have students present if you wish.<sup>63</sup>

### **3. Joining Research or Clinical Trials (optional)**

Research or clinical trials involve testing the safety and effectiveness of new and/or experimental treatments, drugs, or medical technologies. Participation in research is always voluntary and optional. Before you consent to participating in a trial, you should receive information about its purpose, risks, potential benefits, alternatives, and your privacy. If you decide to participate but later change your mind, you can stop at any

<sup>61</sup> Ontario Hospital Association, "Ontario's Hospitals", online: <<https://www.oha.com/about-oha/Ontario-Hospitals>>.

<sup>62</sup> "Ontario's Hospitals" (footnote 61).

<sup>63</sup> "Ontario's Hospitals" (footnote 61).

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time, even though you said yes at the beginning. You do not need to provide a reason why you want to stop. Withdrawing from a trial will not affect your access to regular health care.<sup>64</sup>

If you want to find out about available trials, you can ask: “Are there Parkinson’s studies or trials I may be eligible for?” If you want to find out more information about a trial your doctor has suggested, try asking “If I am offered a research study, what are the risks, benefits, and alternatives?”

#### **4. Looking for Research or Clinical Trials by Yourself**

If you choose, you can also search for clinical trials by yourself and suggest them to your care team. Clinical Trials Ontario offers a tool that can help you search for trials, but discussing this with your doctor first is always important. You can find out more at [trialfinder.ctontario.ca](http://trialfinder.ctontario.ca).

### **Your Legal Rights Related to Teaching Hospitals**

You have the right to decide who is involved in your care. This includes the right to decline student observation or participation in your care. However, an experienced, licensed, and fully trained doctor will always be leading your treatment. You should always be informed about the roles of the staff on your care team, and how student or trainee doctors are involved.<sup>65</sup>

It is always okay to ask questions like “Is this a teaching hospital, and who is responsible for my care today?” or “Can you explain each team member’s role before we begin?”

## **MEDICAL ASSISTANCE IN DYING**

### **What is it?**

Medical assistance in dying (MAID) is a process that enables eligible individuals to receive assistance from a medical professional to help them end their life. This process is highly regulated and can only be administered under certain circumstances, where all of the eligibility criteria are met, and all of the

<sup>64</sup> UHN, “About Clinical Trials”, online:

<[https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Patient\\_Family\\_Library/About\\_Clinical\\_Trials/Pages/what\\_are\\_clinical\\_trials.aspx](https://www.uhn.ca/PrincessMargaret/PatientsFamilies/Patient_Family_Library/About_Clinical_Trials/Pages/what_are_clinical_trials.aspx)>.

<sup>65</sup> London Health Sciences Centre, “Patient Rights and Responsibilities”, <<https://www.lhsc.on.ca/patients-visitors/patient-rights-and-responsibilities>>.

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required safeguards are satisfied. This service can only be assessed and administered by medical professionals such as nurse practitioners and physicians, in provinces and territories that permit it.

In Canada, there are two different ways in which MAID can be provided:

1. **Clinician-Administered MAID:** a substance that causes death, such as the injection of a drug is administered by either a physician or a nurse practitioner.
2. **Self-Administered MAID:** A drug is prescribed by a nurse practitioner or a physician to the eligible person. The eligible person will then take the drug themselves, in order to bring about their own death.<sup>66</sup>

## Eligibility

**To be eligible for MAID, you must meet all of the following criteria:**

1. You must be eligible for health services funded by a province or territory, or the federal government
  - You may also be eligible if you meet your province or territory's minimum period of residence or waiting period.
2. You must be at least 18 years old and mentally competent such that you are able to make health care decisions for yourself
3. You must have a grievous and irremediable medical condition
4. You must make a voluntary request for medical assistance in dying, free from third party pressure or influence
5. You must give informed consent to receive medical assistance in dying

The third criterion of having a grievous and irremediable medical condition is defined by several elements. The individual must have a serious illness, disease, or disability that is in an advanced and irreversible state of decline. Your disease, illness, or disability must cause unbearable mental or physical suffering that cannot be relieved under conditions that you consider acceptable. However, the condition does not have to be fatal or terminal. If your condition is a mental illness, you will not be eligible for MAID until March 17, 2027.

The last criterion regarding informed consent requires you to have all of the information that you need to make your decision. Prior to giving consent, you must be informed of your medical diagnosis, the forms of treatment that are available, and available options to relieve your suffering, such as palliative

<sup>66</sup> Government of Canada, "Medical Assistance in Dying: Overview", online: <<https://www.canada.ca/en/health-canada/services/health-services-benefits/medical-assistance-dying.html>>.

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care. Consent can be given both at the time of the initial request as well as immediately before receiving MAID; however, it can be withdrawn at any time.<sup>67</sup>

## **Procedural Safeguards**

After eligibility is confirmed, where death is naturally foreseeable, the medical practitioner must satisfy the required safeguards before continuing with the procedure.

### **They must ensure that you:**

1. Have two independent medical assessments
2. Make a written request signed by an independent witness
3. Know that you can withdraw your request at any time
4. Provide final consent before receiving MAID
5. Give advance consent, if applicable

If, however, death is not naturally foreseeable, the following additional safeguards must also be met before administration of MAID:

1. One of the two medical assessments must be made by a practitioner with expertise in the medical condition that is causing the unbearable suffering. If neither of them have expertise, an additional practitioner with expertise must be consulted
2. You must be informed of the means by which you can relieve your suffering and be offered consultations with professionals who provide services.
3. All reasonable and available means to relieve your suffering must be discussed with your practitioners. All parties must agree that those alternatives have been seriously considered
4. The assessment of eligibility must take a minimum of 90 days to complete. The exception to this is if there is a risk of losing capacity prior to the end of the 90-day period.

Immediately before receiving MAID, the practitioner must give you an opportunity to withdraw your request and ensure that you are giving express consent to receive the procedure.<sup>68</sup>

## **Getting Started with MAID**

If you are considering MAID, the Provincial Health Services Authority first recommends discussing it with others. You should start by discussing your medical condition and possible treatments with your own doctor, nurse or another qualified health care professional. Once treatment options are discussed, you are under no obligation to accept or pursue any of them, however, it is important to ensure that you

<sup>67</sup> “Medical Assistance in Dying: Overview” (footnote 66).

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are informed about them as you consider MAID. While not all medical professionals can assist you with MAID, they should connect you with other providers who can.

You should additionally consider who else that you want to involve in the process and discussions of MAID. This may include your family, friends, or others. Once decided, you should inform your doctor of how you would like the others to be involved. The PHSA encourages anyone that is considering MAID to talk about it with anyone who can support them through the process

If you want to pursue MAID, you must submit the Request for Medical Assistance in Dying form. Once the form is complete, you will be connected with your local health authority to assess your eligibility. You may submit the form, receive your assessment and eligibility status before deciding whether or not you want to proceed with MAID. You may take as long as you need with the process, and it can be paused at any time.<sup>69</sup>

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<sup>69</sup> Provincial Health Services Authority, “Medical Assistance in Dying”, online:<<https://www.phsa.ca/health-info/medical-assistance-in-dying>>.