

What to Expect - Making Decisions and Plans

This section provides information and guidance regarding making personal care choices and final wishes at end of life. Explanations of legal documents and some terminology are provided. Workbooks on advance care planning and a sample Power of Attorney (“living will”) are included for information.

After the Diagnosis

After you have met with your doctor and discussed your diagnosis, there are a number of health related decisions you will need to make. Try to bring a family member with you to all your appointments, as they can be helpful in asking questions and recording the doctor’s answers.

- The doctor will discuss your wishes with you and offer various treatment plans. You may want to take ‘palliative treatment’ which may mean having radiation, surgery, chemotherapy or other procedures. The purpose of these treatments is to improve quality of life, extend it perhaps, but they will not result in a cure. They can be hard on the body initially, and may require more hospital stays.
- On the other hand, you may want to receive palliative care, i.e. discontinuing or stopping treatments and receiving ‘comfort measures’ only. In this case, you can choose to go home as long as there is a plan in place for your care and enough caregiver support.
- Other options for palliative care are to go to a hospice, long-term care facility or hospital. One of these may be a more practical option if being at home would place too much of a burden on your family. Find out about waiting lists as they can be long.
- Some treatments that you may want, may not be a realistic option for you; your doctor will advise you of when this is the case. Other treatments can be out of reach if not covered by NIHB, costs are too high or there is a waiting list for treatment.
- You have the right to a second opinion however, and if this is what you want, have your doctor give you a referral to see another specialist. This will involve travel and more tests and procedures being done (at your expense).
- Whatever you choose, your health care team will try to keep you as comfortable as possible through the use of pain medication and symptom management. These measures will not lengthen your life, but will give you a better quality of life so that you can enjoy your time remaining as comfortably as possible. The decisions are yours to make.

The booklet, 'A Guide to Advance Care Planning' by the Government of Ontario (see copy at the end of this section) answers basic questions about your care choices and prepares you to state your decisions in the Powers of Attorney documents. It covers:

- What is advance care planning
- Making personal care choices
- Choosing your substitute decision-maker (also called 'substitute attorney'- this term means *representative*, not lawyer)
- Communicating your choices
- Why this is important to you

Steps in Advance Care Planning

- Think about your values and what is important to you
- Consult people you trust who can provide guidance
- Decide on and appoint a substitute attorney, and give him/her the power to act on your behalf. Let family members know who you have appointed
- Make your care choices known to others
- Document your choices (directives) on Power of Attorney and/or Living Will forms

Powers of Attorney

The Office of the Public Guardian and Trustee, Ministry of the Attorney General, Government of Ontario has published a booklet, 'Powers of Attorney and Living Wills'. It provides questions and answers on the three types of Powers of Attorney:

- *Continuing Power of Attorney for Property* (CPOA) which documents your financial affairs and allows the person you name to act for you, whether you are mentally capable or not
- *Non-continuing Power of Attorney for Property* which documents your financial affairs but cannot be used if you become mentally incapable. You might use this POA for example if you need someone to look after your banking transactions while you are away from home for an extended period of time; and
- *Power of Attorney for Personal Care* (POAPC) which documents your personal decisions such as housing and health care choices.

In reviewing these booklets and other materials you might notice that some of these legal terms are used interchangeably such as *advance care directive* and *health care directive*, or *substitute attorney* and *substitute decision-maker*.

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Although the term *power of attorney* is often substituted for *living will*, there are some differences as noted in the booklet, 'Powers of Attorney and Living Wills'. Other terms such as *mental capacity* or *incapacity* are also explained, and the booklet provides scenarios and guidance on issues that might arise such as mismanagement of money.

Stating your treatment decisions or wishes (advance care directives) in these documents allows you to let others know what choices you would like them to make, should you become unable to communicate your decisions for yourself.

For questions about Powers of Attorney and Living Wills, more details are available online at: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/livingwillqa.pdf>.

Forms for completing Powers of Attorney are available online at: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>

To obtain these booklets or other information about POA and Living Wills, go to: <https://www.publications.serviceontario.ca/pubont/servlet/ecom/>. They are free of charge and contain forms for the two more common POAs (Personal Care, and Property – continuing, described below). Copies of these forms are included at the end of this section.

The “Speak Up” Advance Care Planning Workbook, Ontario Edition, by the Canadian Hospice Palliative Care Association and the Advance Care Planning Project is another comprehensive source of information to help individuals complete an advance care plan. This workbook is included at the end of this section and is also available online at: <http://www.advancecareplanning.ca/community-organizations/download-the-speak-up-campaign-kit/acp-workbook.aspx>

Uses of the Three POAs

A Power of Attorney for Personal Care is a document that you write *before* you become mentally incapable and its purpose is to put your wishes in writing so that if, for some medical reason you became mentally incapable, your wishes would still be followed, even though you could no longer communicate them to anyone.

By appointing a substitute attorney (decision-maker) or ‘attorney for personal care,’ you are giving someone you trust the authority to speak on your behalf and to follow through with the directives you state in this document. These can include your choices about where and how you want to live, how you will dress, what you will eat, and what kind of medical treatment you want to receive or not receive.

Tools for the Journey Section D

In a medical emergency where life weighs in the balance, doctors will want to know what your wishes are regarding your 'Code Status'. That is, do you want everything possible done to keep you alive - 'Full Code' status – this can include:

- defibrillation (cardiogenic shock treatment)
- CPR (cardio-pulmonary resuscitation), or
- use of artificial life supports such as a respirator, oxygen, blood transfusions, renal dialysis, or intravenous lines

Instead of the *full code* status, you might prefer to have a 'DNR' status (Do Not Resuscitate) where the doctors would allow you to die naturally, 'allow natural death.'

If you have decided one way or the other on these important questions, but have not completed the POA form, tell your trusted family members your wishes. In an emergency situation, if you cannot speak for yourself the doctor will ask the substitute attorney what your wishes are. If they are to 'let you go naturally' the substitute attorney is asked to sign a DNR order, which is consent for doctors to stop treatments. If no one is with you in hospital and you cannot speak for yourself, health care professionals will assume you want everything done and they will continue treatment.

A Continuing Power of Attorney for Property is a document where, *when you are still mentally capable*, you give a trusted family member or friend the authority to act on your behalf as 'substitute attorney' or 'substitute decision-maker' and to handle all your banking and financial matters. This authority continues on if you become mentally incapable, and ends when you pass on (unless your substitute attorney is the same person as the Executor of your will).

A non-continuing Power of Attorney for Property covers your financial affairs *but cannot* be used if you become mentally incapable. This is a temporary POA, which you might use if you are going on a trip for an extended period of time and need someone to look after your banking until you get back.

If you appoint a substitute attorney for the purposes of handling your property *and* finances, take a *signed* copy of this form to the bank; it will allow them to do transactions with your substitute attorney. After you pass on, the substitute attorney can no longer represent you concerning your finances unless this person will also be the Executor of your will.

NOTE: The booklet 'What Every Older Canadian should Know about 'Powers of Attorney (for financial matters and property) and Joint Bank Accounts' is an excellent resource for this purpose and covers topics such as: what to consider when choosing a substitute attorney; what to consider *before* and *after* preparing a Power of Attorney; and the benefits and risks of Joint Bank Accounts. This information can be found online at the Ontario Seniors' Secretariat, which

also provides information on a range of issues relevant to seniors.
<http://www.seniors.gov.on.ca/en/seniorsguide/>.

The Importance of Writing a Will

Regardless of where you live in Canada, it is important to write a will. By doing this you are ensuring, through the legal system, that your wishes for disbursement of your assets (property and money) and other important instructions will be followed according to your wishes. Having a will can prevent certain taxes from being applied to your estate (off-reserve) or from family living situations being disrupted, e.g. child-custody/ guardianship cases, and help settle land claim issues.

If you die 'intestate' (without a will), your family will be subject to provincial laws concerning the settling of a family estate; these laws may be contrary to what you would have wanted.

If you are living on a reserve and are planning to leave your house and/or property to a loved one, you are advised to write this in a will. Not having a will can result in your loved ones not receiving the house or property. Note important rules about this and other issues on the Aboriginal Affairs and Northern Development Canada (AANDC) website: <http://www.aadnc-aandc.gc.ca/eng/1100100025002/1100100025004>. AANDC will administer your estate after you pass on if you lived on-reserve and there is no-one in your family who could do so. The Decedent Estates Program may also help in land claim disputes or family conflict situations that prevent the will from being settled. Refer to your Band Office for information on this program or go to:

<http://www.aadnc-aandc.gc.ca/eng/1100100032519/1100100032520>.

Another good site or information on wills is the Canadian Virtual Hospice:

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Decisions/Wills.aspx

End of Life Process

At the Time of Passing

- Notify out-of-town relatives of the impending death of your loved one, to give them time to travel home. If possible, gather the family at the bedside before your loved one passes, and with your spiritual/traditional elder, clergy or priest, have the final traditional ceremonies

and blessings performed before and after their passing. Allow family to spend as much time with the body as needed.

- Notify the funeral home, health care providers and everyone concerned, of the passing. When death is expected (by health care professionals and family) there is no need for police officers or coroners to be present.
- Follow through with whatever was planned regarding the wake:
 - Will there be a community gathering or feast at the community hall or a small family gathering at your home?
 - Has your loved one requested a religious service to be held at their church, or a sacred fire or other ceremony to be performed?
 - Have they chosen a burial plot and is it arranged with the cemetery?

It is important to follow your loved one's wishes even when they conflict with yours; it is their journey.

Support

At this time it is extremely important that there be support in place for the family. Ask your local health care team for support. Funeral directors are also a good source of information and will gently walk you through the burial process. Option plans and prices vary; your family should not feel pressured into choosing a plan beyond their budget.

Some helpful online resources for support at this time are listed below.

Making Final Arrangements

The Government of Ontario can provide detailed information regarding what to do when someone dies, including contacting a funeral director, the documents you will need to register a death and obtain a death certificate, and other steps. For this information, go to: <http://www.ontario.ca/government/what-do-when-someone-dies>.

What to Bring to the Funeral Home

- Deceased's identification (Birth Certificate, Social Insurance Number card, Indian Status Card, Driver's License or other)
- Photograph of the person
- Clothing
- Burial plot information

After the Funeral

Taking Care of Business

Tools for the Journey Section D

If you or someone else has been named as your loved one's Administrator/Executor (person named to take care of the will) there are several duties to be performed such as:

- Sending out Death Certificates/notices to creditors and government agencies
- Identifying and protecting the estate property and belongings until they are given to the persons named in the will
- Paying the Estate debts, including funeral expenses
- Take care of the Will (if there is one) or the Power of Attorney for Property - distribute everything as stated in these documents to the proper people
- Take care of Insurance claims, closing bank accounts, filing final income tax returns and paying bills on the deceased's home until the new owner takes over
- Provide a report to family members, heirs, beneficiaries on what has been done

If you find you need help or support to complete these tasks, you can enlist the help of a responsible family member. Contact your community health workers to find out how to get access to legal help.
