

Health Care Decision Making and Parkinson's

Where can I find more information on writing an Advance Care Plan?

British Columbia is divided into five different health regions. Each region may have a different approach to advance care planning.

- ▶ If you are in the Fraser Health Region (Burnaby to White Rock to Hope), contact the Advance Care Planning Coordinator at 1-877-825-5034 or www.fraserhealth.ca.
- ▶ Vancouver Island has its own health care planning tools. For more information, 250-370-5687 or email at advance.directives@viha.ca.
- ▶ For other areas, call Service BC (604-660-2421 or 1-800-663-7867), give them your address and then ask them for the number of your local health unit.
- ▶ People throughout BC may also call Fraser Health at the number above, and they can send you ACP tools.

There is generally no cost to writing an Advance Care Plan.

Can you tell me more about Representation Agreements?

A Representation Agreement covers authority and wishes for many more situations than end of life, such as:

- ▶ Arranging rehabilitation after a stroke or consent for surgery as a result of a traffic accident.
- ▶ Arranging for support services and personal care, including where you live.
- ▶ Quality of life concerns such as personal grooming, diet and exercise, and more.

A Representation Agreement can be created through a self-help legal kit or it may be necessary to attend a legal clinic to consult with a lawyer (there is a cost of at least \$50 for either option). For more information, contact Nidus Personal Planning and Resource Centre and Registry, 604-408-7414 or www.nidus.ca.

Partial funding of this helpsheet provided by HaloMetrics.

This information is current as of June 2009. Please note that the area of health care planning and resources can change. For the most current information possible, please talk to your doctor or contact your local health authority.

I have written an Advance Care Directive and/or Representation Agreement. Now what?

Make copies of the document(s) and distribute them to your doctor, the person who is your substitute decision maker, and other significant persons in your life.

I would also like to get the rest of my affairs in order. How do I write a will, and how do I designate a power of attorney for financial matters?

For more information, visit Law Link BC at www.lawlink.bc.ca or call their Vancouver office at 604-601-6206 (offices found throughout BC).

While self-help will kits are available, you may benefit from the professional advice provided by lawyers and notaries public, who can also help you with Power of Attorney.

Wrapping it up

Planning in advance for health care decisions will not solve all the problems you will face with Parkinson's. However, by discussing your wishes for future care, you can decrease the stress faced by yourself as well as that of your family/significant others, who will be better prepared to make decisions on your behalf if necessary. You will have the opportunity to gain further control and input into your care and treatment – this is one way of taking charge and living well with Parkinson's!



Parkinson Society British Columbia
Société Parkinson Colombie-Britannique

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PLANNING SERIES

PLANNING IN ADVANCE

Health Care Decision Making and Parkinson's¹

Most of us realize that we should make plans for our future, especially when it comes to our health care wishes. However, many of us avoid having these conversations and/or writing down our wishes, yet this is *something every adult should do*, regardless of age or state of health.

To assist you in this process, Parkinson Society British Columbia has prepared this document to help you, a person with Parkinson's or carepartner/family member/friend, to become more informed about health care planning as it relates to Parkinson's. Included are suggestions to guide you along the way. Please call us if you have any questions on this topic – we are here to help! There is no way of knowing how Parkinson's will progress. No doctor can tell you this. However, it is important to take control of how you and your family will cope with the impact of Parkinson's. One way to do this is by having open conversations on how you would like to manage Parkinson's in the best and worst case scenarios.

To plan or not to plan?

It is your choice. In British Columbia, you may choose to create a formal document to write down your health

care wishes, such as an Advance Care Directive and/or a Representation Agreement (these will be discussed in more detail throughout the document).

Alternatively, you may also decide to not write down your wishes, in which case it is especially important to discuss your wishes with your doctor(s) and family.

Advance health care planning IS:

- ▶ An ongoing process that includes talking with family members, substitute decision makers (those who will make decisions on your behalf), and health care providers regarding the kind of medical treatment you would or would not want to receive in the future if you were unable to communicate.
- ▶ A process that addresses personal values and goals for living well.
- ▶ A verbal or written plan.

In British Columbia, you have two options (you can choose to do one or both) to write down your wishes:

- ▶ An **Advance Directive**² allows you to write down and direct what type of health care you wish to receive when you are unable to express your wishes.
- ▶ A **Representation Agreement** is a legal plan that allows you to appoint another adult to act on your behalf in making decisions (health care, personal decisions, financial and legal matters) if you are unable to do so.
 - In this case, you appoint a person (called a "proxy") to speak for you based on your beliefs and values. For this reason, it is important that you make those beliefs and values known.

It is also very important that you discuss with your doctor the type of health care and the terminology associated with end of life medical treatment. In that way, you can make your wishes, beliefs and values known regardless of which type of document you choose.



¹PSBC gratefully acknowledges Fraser Health Authority and Cari Hoffman, FHA Advance Care Planning Project Coordinator, for their assistance with this project. Fraser Health does not warrant the accuracy or completeness of the information contained in this helpsheet.

²As of March, 2009 an advance directive is a part of a package of new BC legislation that has been proclaimed but not yet brought into force.

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Advance health care planning IS NOT:

- ▶ **An Advance Care Plan is NOT a power of attorney.** In BC, if you give someone “power of attorney” they can only make decisions on your behalf regarding legal or financial matters but not health care.
- ▶ **An Advance Care Plan is NOT the same thing as a No CPR Order** (known more commonly as a Do Not Resuscitate Order or DNR).
 - An Advance Care Plan can express your wishes with respect to resuscitation, but the No CPR Order must be written by your physician when you are receiving care in hospital or a residential care facility.
 - If you are at home, your doctor must sign a provincially recognized “No CPR” form for guiding ambulance attendants and others. Consider ordering a free “No CPR” MedicAlert bracelet with this information.

Why is it important to make health care decisions in advance?

Advances in medical technology allow patients with no reasonable hope of recovery to be kept alive using artificial life supports e.g. respirator, artificial nutrition and hydration. In these circumstances, some people prefer a treatment plan that allows nature to take its course.

Generally speaking, taking the time to plan for future health care decisions is important because:

- ▶ Most of us will most likely die under the care of health professionals.
- ▶ 80% of us will die of a chronic disease.
- ▶ Up to 50% of us cannot make our own decisions when we are near death.
- ▶ Health professionals typically treat when they are uncertain of your wishes.
- ▶ Loved ones have a significant chance of not knowing what kind of care you would want unless you have discussed it thoroughly together.

When should I start thinking about future health care decisions?

Now! The best time to think about these issues is before a crisis. Each one of us hopes that we will always be able to speak for ourselves, but we can never predict when we might need an Advance Care Plan. This is why we encourage every adult to make such a plan, whether they are people with Parkinson's, carepartners or their family and friends.

How could I benefit from planning in advance?

Planning in advance for health care decision making is important because it can:

- ▶ Improve your quality of life by increasing your sense of control if, for whatever reason, you are not able to speak for yourself.
- ▶ Ensure that you have all the medical information needed to make choices for yourself that align with your values and beliefs.
- ▶ Increase appropriate use of health services and increase chances of your wishes being followed.
- ▶ Improve communication within families and encourage discussion about end of life wishes. This can prevent some conflicts and the burden a family may feel when having to make decisions without being able to talk with you.³
- ▶ Improve communication and shared decision making with your health care team such as physician, specialist, etc.

What health care decisions should I consider in my planning?

Pre-planning can be done by thinking about, discussing and recording the following:

- ▶ What are your **wishes** regarding health care treatment? What would you like to see happen? What are your goals?
- ▶ What are your **values and beliefs** regarding health care treatment? What is important to you?

Do you want every health intervention possible, or would you rather “let nature take its course”? In the case of serious illness or injury, would you want to:

- ▶ Have full life support with medical interventions?
- ▶ Have a trial period of life support with medical interventions and, if unsuccessful, allow natural death to occur?
- ▶ Limit the use of life support with medical interventions and allow natural death to occur?
- ▶ Identify someone specific, where only that person would make decisions on your behalf (called a substitute decision maker)?

Clearly discuss and write down what these options/interventions mean to you.

What happens if I do not write down my wishes?

If there is no formal document (an Advance Directive or Representation Agreement) in place, AND

- ▶ If at any time a health care provider cannot get informed consent from you for treatment, THEN
 - The health care provider must choose someone from a list of relationships (spouse, children, etc.) as defined in section 16 of the Health Care Consent Act to make decisions for you. This person is known as a temporary substitute decision maker or TSDM.
- ▶ A TSDM appointment applies only to specific health care issues and is not an ongoing relationship.
- ▶ As well, he/she is obligated to follow your beliefs and values unless they are not known. If your wishes are not known, a TSDM must act in what they believe to be your best interests.
- ▶ Their view and yours might not be the same – thus you need to have the discussion while you are capable. For this reason, many prefer to write down their health care wishes.

What Parkinson's issues should I consider in my planning?

You might like to discuss certain questions or issues with your family and health care team. Talking with your doctor(s) can help them better understand your wishes. Here are some questions to discuss with your Parkinson's health care team:

- ▶ How can Parkinson's **progress**? What signs/symptoms should I be aware of?
- ▶ I know that Parkinson's **medications** can help my symptoms, but what are their risks?
- ▶ Could a time come when you would recommend that I reduce my Parkinson's medication? Why at this time? Here are my thoughts...
- ▶ I have heard that Parkinson's can affect **swallowing**. What could happen and what are my options to treat this?
- ▶ I have heard that **pneumonia** is a risk with Parkinson's. What treatment might be used? If that happens, here's what I think...
- ▶ Sometimes, **surgery** is an option. When would you recommend this? When would you not?
- ▶ If I go in for surgery for a non-Parkinson's related condition, how could Parkinson's affect my surgery and the care I receive in the hospital? How can I prepare for this?
- ▶ What impact could Parkinson's have on my **thinking, memory and mood** (depression, anxiety, etc)? How might this be treated? How could that change how I plan for the future?
- ▶ If you are the **caregiver**, ask: What should caregivers keep in mind? How can I prepare for what could happen with Parkinson's?

In sharing this information with your family, you can say:

“I know that Parkinson's may affect my ability to _____. If that happens and I cannot speak for myself, this is what I would like you to do _____.”

³Palliative care input and advance decision making in patients with long-term neurological conditions. National Library for Palliative and Supportive Care, Creator: Joy Waldoock © Crown Copyright 2005.