

HEALTHCARE DECISION MAKING FOR PARKINSON'S

Most of us realize that we should make plans for our future, especially when it comes to our healthcare wishes. However, many of us avoid having these conversations and/or writing down our wishes, yet this is something every adult should do, ideally when we are healthy, not facing a health crisis or in the hospital.

Parkinson's will progress at a different rate for each person, and it is hard to predict when your health will change. Therefore, it is important to learn about the treatments you may be offered in the future so you and your family have time to think through the risks and benefits, so you can make informed choices. Many people who have done this kind of thinking ahead of time say that it gives them control over how they will cope with the impact of Parkinson's. Having open conversations on how you would like to manage Parkinson's in both the best and worst case scenarios helps your family and friends to know your thoughts and ideas.

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 Plan, Advance Directive and/or a Representation Agreement. Alternatively, you may also decide to not write down your wishes, in which case it is especially important to regularly talk and review your wishes with your doctor(s) and family.

Advance Care Planning

Advance care planning is an ongoing process that includes personal reflection, talking with family members, friends, and substitute decision makers (those who will make decisions on your behalf) about what is important to you, and what gives your life meaning. This process includes talking with your healthcare providers regarding the kind of medical treatment you may be offered in the future because of your illness. You may want to think ahead about intervention decisions in the event that you become unable to communicate. It will be important to share the reasons for your thoughts with your family and doctors so that they can clearly understand where you are coming from. It is very important to involve your doctors in these discussions, so that you may ask questions and understand the risks and benefits of particular treatments ahead of time. Your final advance care plan can be written or verbal, and should also address personal values and goals for living well.

In British Columbia, there are a number of planning options. The BC Ministry of Health and other healthcare authorities and organizations suggest all advance care planning processes include:

- Conversations with family and/or friends, and healthcare providers about your wishes, beliefs, and values.
- Writing down or recording your wishes, beliefs, and values.
- Writing down the contact information for people who qualify to be your temporary substitute decision maker (defined below).

Additional planning options include:

- **An Advance Directive** – a legal plan that allows you to write down and direct what type of healthcare treatments you wish to receive or not receive when you are unable to express your wishes. What we understand is that people who choose this option are often:
 - very clear about a treatment they do not want, such as artificial nutrition and hydration, or
 - people who have received an intervention, and do not want it again (most often, people who choose this are in the later stages of an illness)

- **A Representation Agreement** – a legal plan that allows you to appoint another adult to act on your behalf in making decisions if you are unable to do so. Representation agreements can cover healthcare, personal decisions, and/or routine financial matters.
 - No legal professional is required, though you may choose to involve one.
 - Representation agreements are governed by the *Representation Agreement Act* and Regulation. This law came into effect on February 28, 2000.
 - It is also very important that you discuss with your doctor the type of healthcare and terminology associated with treatments you may be offered in the future. This way, you can learn about different treatments before a health crisis, and talk about what situations you may or may not want. Make your wishes, beliefs, and values known, regardless of which type of document you choose.

Advance care planning is **not**:

- 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 healthcare. Terminology and language in this area differ across Canada.
- No CPR Order – Also known as a Do Not Resuscitate Order (DNR), No CPR orders specify your wish to reject attempts to restart your heartbeat and breathing if they stop.
- MOST – Medical Orders of Scope of Treatment cover restarting your heartbeat and breathing when they stop, as well as medical and critical care interventions. They are most often used in hospital and residential care, but your community doctor may also discuss this order with you.

Why is it important to make healthcare 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. respirators and 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 healthcare decisions is important because:

- Most of us will 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 must make assumptions when they are uncertain of your wishes.
- Loved ones have a significant change 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, and certainly before you are in the hospital. 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, or when our advance care planning conversations will become vital for our family, friends, and doctors. 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 healthcare 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 wishes beliefs, and values.
- Increase appropriate use of health services, along with chances of your wishes being followed.
- Improve communication within families, and encourage discussion about living well and 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 to you.
- Improve communication and shared decision-making with your healthcare team.

What healthcare 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 healthcare treatment?
 - Ex. Do you want to increase your PD medication, even if it results in increased dyskinesia?
- What would you like to see happen? What are your goals?
 - Ex. My goal is to reduce my chances of falling, and then having to be hospitalized, by participating in exercise classes and physiotherapy at least three times a week.
- What are your values and beliefs regarding healthcare treatment? What is important to you?
 - Ex. It is important to me that when I die, my body and organs go towards PD research.

Do you want every health intervention possible, or would you rather let nature take its course? In the case of serious illness or injury, such as pneumonia or falls, 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?

Clearly discuss and write down what these options and interventions mean to you. For example, what does an unsuccessful trial of life support mean to you, and what does it look like? **Remember that this is an ongoing process, and you may change your mind about how you feel about things.**

Substitute Decision Makers and Representatives

Throughout the process of advance care planning, think about who would be good substitute decision makers. Consider who knows you best, could honour your wishes, and be able to communicate effectively in often emotional situations.

You could identify someone specific, such that only that one person would make decisions on your behalf, as your *Representative*. They must honour your wishes and instructions, and it is therefore very important that you have regular and ongoing discussions with them about your wishes.

What happens if I do not write down my wishes?

If there is no legal document in place (i.e. an Advance Directive or Representation Agreement), **AND** at any time, a healthcare provider cannot get informed consent from you for a treatment, **THEN** the healthcare provider chooses 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.

Your assigned TSDM is obligated to follow your wishes unless they are not known, in which case they must act in what they believe to be your best interests. Their view and yours may not be the same. You need to have regular and ongoing discussions about your beliefs and values with your family or close friends while you are capable. For this reason, many prefer to write down their healthcare wishes.

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

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

- How can Parkinson's progress? What signs and 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 medication? Why at this time?
- Parkinson's can affect swallowing – what could happen, and what are my options to treat this?
- If I develop pneumonia, what treatment might be used?
- When would you recommend surgery? 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 (e.g. depression, anxiety, cognitive changes, etc.)? How might this be treated? How could that change how I plan for the future?

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..."

Carepartners and caregivers should be included in advance care planning. Invite your carepartner to speak with your healthcare team so they may ask questions such as: "What should carepartners keep in mind? How can I prepare for what could happen to my loved one with Parkinson's?"

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

I have written an advance directive and/or representation agreement. Now what?

Keep the original. Make copies of the document(s) and distribute them to your doctor or nurse practitioner, the person who is your substitute decision maker, and other significant people in your life. Bring your documents to all medical appointments, and hospital visits and admissions.

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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!

Additional Resources

Healthcare Planning

BC Health Authorities:

Fraser Health | www.fraserhealth.ca/acp | advancecareplanning@fraserhealth.ca | 604-953-4965

Interior Health | bit.ly/2QjOC4p

Northern Health | www.northernhealth.ca

Vancouver Coastal Health | bit.ly/2QlIGaT | advancecareplanning@vch.ca | 604-263-7377

Vancouver Island Health Authority | bit.ly/2QpxWs7 | 1-888-533-2273

Nidus Personal Planning Resource Centre and Registry | www.nidus.ca

Nidus promotes personal planning – the making of legal arrangements for incapacity, end-of-life and the future. They also operate a centralized Registry for planning documents. For more information, contact them at info@nidus.ca, or call 604-408-4714.

Advance Care Planning | HealthLink BC | www.healthlinkbc.ca/health-feature/advance-care-planning

Advance Care Planning Workbook | Speak Up BC | www.speak-upinbc.ca

My Voice Advance Care Planning Guide | Government of BC | bit.ly/2QppSrl

No CPR Form | HealthLink BC | www.healthlinkbc.ca/health-feature/no-cpr-form

No CPR MedicAlert Bracelet | MedicAlert | www.medicalert.ca/nocpr

Medical Orders for Scope of Treatment | Interior Health | bit.ly/2QumSu1

Estate Planning

If you would like to get the rest of your life affairs in order, consult the resources below for information about wills, estate planning, power of attorney, and financial matters.

Legal Services Society (Legal Aid) | www.lss.bc.ca

You may benefit from the professional advice provided by lawyers and notaries public, who can also help you with power of attorney. The Legal Services Society provides legal aid in BC. For more information, call 1-866-577-2525.

Wills & Estate Planning Webinar | Parkinson Society BC | youtu.be/yPLvh7BfvZo

Estate Planning & Trusts Helpsheets | Parkinson Society BC | bit.ly/pdestatesandtrusts

Legacy Commitment Brochure | Parkinson Society BC | bit.ly/psbclegacygiving

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