Advance Care Plan: A Guide for Caregivers of Adults with Intellectual and Developmental Disabilities

Introduction

This tool guides care providers of adults with intellectual and developmental disabilities (IDD) through the process of advance care planning regarding possible medical treatments for serious conditions. Advance care planning is a process that promotes person-centred care, by clarifying the individual's present goals and values along with his or her preferences regarding future health care. For adults with IDD, this process involves the adult's substitute decision-maker, a healthcare provider (ideally the family physician), and others who know the adult well, whom the adult trusts, and who are willing to support this process. Adults with IDD should be engaged, with supports as needed, to participate as much as they can and wish to. They do not need to pass a legal capacity test to contribute to this process.

How to use this tool

What is an Advance Care Plan?

- An Advance Care Plan is a document that outlines the outcome of discussions in the advance care planning process.
- By completing an Advance Care Plan, the adult with IDD is *not giving consent or refusal* to future medical treatments but is providing guidance directly to the authorized substitute decision-maker, and indirectly to (health)care providers.
- Refer to an Advance Care Plan *when an adult with IDD becomes incapable of contributing* to discussions or decisions regarding level of care or specific treatments.

Why is it important to develop or review an Advance Care Plan?

- An adult with IDD's prior Advance Care Plan, which typically is developed for end-of-life care, might not *address the current context*.
- The Advance Care Plan can be used to *identify needed additional supports* for the adult with IDD (e.g., home care might not be an option or isolation in hospital).
- Knowledge of the adult with IDD's preferences for future care can help *inform triage and treatment* decisions in hospital, especially when they are invasive or intensive-care resources are limited.

Developing a Advance Care Plan

Use the **Advance Care Plan: Guidance for Discussion** and the **Advance Care Plan: Information for Substitute Decision-Makers and Healthcare Providers** to complete the **Advance Care Plan: Form** together with the adult with IDD, substitute decision-maker(s), and other relevant persons. Steps to completing the advance care plan are:

A. Identify who would be the adult with IDD's highest and next-highest ranked *substitute decision-maker(s)*
B. Discuss the adult with IDD's *present goals and values*
C. Discuss the adult with IDD's *preferences for future health care* in context of any risk of a specific serious condition.
D. Share the plan with the adult with IDD, future substitute decision-maker(s), and other relevant persons

Advance Care Plan: Form

Surrey Place Developmental
Disabilities Primary Care Program

1. Use the Advance Care Plan: Guidance for discussion (Guidance A1 to C7; pages VI-VIII) to fill in this form.
2. Attach a paper copy of this plan or an electronic attachment to the family physician's Cumulative Patient Profile (CPP) record.
3. Give a copy of this form to the person's substitute decision-maker(s) to retain and refer to.
4. With the consent of the adult with IDD (if capable) or their substitute decision-maker, inform everyone in the person's regular circle of care about this Advance Care Plan, how to contact the substitute decision-maker(s), and specific directives in C7.

This Advance Care Plan has been completed by: **Date:**

	First Name	Last Name	Relationship
☐ Adult with IDD:			
☐ Substitute decision-maker (highest ranked):			
☐ Substitute decision-maker (next highest ranked):			
☐ Family physician or other healthcare provider:			
☐ Other (family, other caregiver or people who know the adult with IDD well):			

A - SUBSTITUTE DECISION-MAKER

Substitute Decision-Maker (SDM): **(see pages VI-VIII) A1 | A2 | A3**

First Name: **Last Name:** **Relationship:**

Phone (mobile # preferred): **E-mail:**

Address:

Next highest ranked Substitute Decision-Maker (if the above SDM is unavailable): **A1 | A2 | A3**

First Name **Last Name:** **Relationship:**

Phone (mobile # preferred): **E-mail:**

Address:

Name of Family Physician (important if the Office of the Public Guardian and Trustee is the SDM of last resort): **A4**

First Name: **Last Name:** **Relationship:**

Phone (mobile # preferred): **E-mail:**

Address:

Family, other caregivers or other people who know the adults with IDD well: (important especially for the Office of the Public Guardian and Trustee if they are the SDM of last resort)	**A4**

First Name: **Last Name:** **Relationship:**

Phone (mobile # preferred): **E-mail:**

Address:

Contact the Ontario Treatment Decisions Unit, Office of the Public Guardian and Trustee* at
595 Bay Street, Suite 800, Toronto, ON, M5G 2M6

Toll-free: 1-800-387-2127
Tel.: (416) 314-2788
Fax: (416) 314-2637

*For other jurisdictions, find a similar office.

B - PRESENT GOALS AND VALUES OF THE ADULT WITH IDD

Summary of Present Goals and Values:	**B1**

Goals and values:

Audio/video recording available at:

Input from others who know the person well:	**B2**

First Name: **Last Name:** **Relationship:**

First Name: **Last Name:** **Relationship:**

Attached photos of the adult with IDD engaging in activities with people they enjoy (list others than above):	**B3**

First Name: **Last Name:** **Relationship:**

First Name: **Last Name:** **Relationship:**

C - PREFERENCES OF THE ADULT WITH IDD FOR FUTURE HEALTH CARE

Before completing this section, brief the substitute decision-maker(s) (See section A) on the Advance Care Plan: Information for Substitute Decision-makers and Health Care Providers (pages IX-XI).

Summary of Preferences for Future Health Care:

Confirm that the adult with IDD has a basic understanding of their condition (e.g., If the coronavirus gets into your lungs, this can make it hard for you to breathe). If they do not, despite accommodating needs, proceed to C6 and C7. **C1**

☐ The adult with IDD would like to talk about preferences for future care. Proceed to C3.

☐ The adult with IDD does not wish to talk further about future treatment decisions with the SDM and health care provider. Proceed to C6. **C2**

Preferences for Hospital Care: **C3**

Preferences for Active Care in hospital or, when possible, at home: **C4**

Summary of Preferences for Future Health Care (Cont.):

Preferences for Intensive Care: **C5**

Preferences if goals of medical treatment are not achieved following an adequate trial: **C6**

Does the adult with IDD have a Do Not Resuscitate (DNR) confirmation form or order in their health record? **C7**

☐ YES ☐ NO If yes, specify the date of the most recent version:

Advance Care Plan: Guidance for Discussion

Use this guidance for discussion to complete the **Advance Care Plan Form**. The item numbers correspond to sections in the form.

A. IDENTIFY SUBSTITUTE DECISION-MAKER(S)

A1 Everyone in Ontario has a substitute decision-maker according to the hierarchy outlined in the Ontario Health Care Consent Act. Review this substitute decision-maker hierarchy. For other jurisdictions, seek similar information. See links in the Supplemental Materials, page XIII[i]. Then, determine whether the adult with IDD has a court appointed guardian, an attorney for personal care, a representative named by the Consent and Capacity Board or someone in the list of family members specified in the hierarchy.

A2 Explain to the adult with IDD that the SDM(s) will act in future, if the adult with IDD is found incapable to consent to treatment. The SDM(s) will act based on their knowledge of the adult with IDD's prior capable wishes, or if there are none, values and beliefs.

If the highest-ranking SDM(s) would be family members, check with the adult with IDD whether they agree.

ASK: "If you become very sick, sometimes you could be too sick to tell others or decide what treatment you want or don't want. The person(s) who would decide for you would be _____ (i.e., name top ranked family member(s)). Is that okay?"

If the adult with IDD agrees to the automatic family member SDM(s), contact that person to confirm that they are at least 16 years old, willing to act as the SDM, and available in person, by phone or via electronic communication. Then, enter their contact information on the form.

If the adult with IDD does not agree to the automatic family member SDM(s), go to A3.

A3 If the adult with IDD has no available family member(s), prefers a lower ranking family member SDM over a higher ranking one, prefers one equally ranked family member as the main SDM and the other as the back up, or wants a non-family member to act in the role of SDM, then:

- Explore whether the adult with IDD wants to appoint one or more Attorney(s) for Personal Care (usually preferred option). For details, see the Power of Attorney Kit at the Ontario Ministry of the Attorney General[ii] and Appendix 1 (or similar documents for jurisdictions outside Ontario).
- If the adult with IDD wants to appoint one or more attorneys for health care (jointly or, to avoid conflicts, naming a second person as the backup SDM), enter their contact information once a Power of Attorney (POA) for Personal Care form or letter is completed, signed, dated, and witnessed by two people (no special form, doctors or lawyers required; witnesses should not be staff). The named Attorney(s) for Personal Care will need copies of this POA form or letter to confirm their POA status when asked by a physician to consent to a proposed treatment. Make sure they have an electronic copy of the signed POA form so they can send it via email if they are unable to accompany the adult with IDD. A healthcare organization may ask for a copy of the document, but will also get the treatment decision directly from the SDM(s).
- Enter contact information for the appointed attorney(s) for personal care.

A4 If none of the above three options are possible, the physician proposing treatments will need to contact the Treatment Decisions Unit, Office of the Public Guardian and Trustee (OPGT), who will become the SDM of last resort for consent to a proposed treatment of the adult with IDD. With planning, this option can be avoided.

B. DISCUSS PRESENT GOALS AND VALUES

B1

Discuss the adult with IDD's present goals and values. Use accommodations and supports as needed (e.g., communication aids). Consider audio- or video recording this discussion so that clips of the person's own statements can be available with the written summary.

ASK: "What do you want your SDM to know about you and what matters to you?" Explore further:

- What does life now look like for this person?
- What does the person enjoy most in or about his/her life (e.g., being part of a loving family, having friends, being outdoors, making people happy, making things, listening to music)?
- Who/what is the person committed to (e.g., family, friends, culture, religion)?
- What does the person hope for (e.g., to be treated with respect, appreciated for who he/she is, to be or become..., to always...)?
- How does this person cope with discomfort or loss? What supports does he or she draw on?

Document a summary of this discussion, including available audio or video recordings.

B2

Engage with others who know the adult with IDD well for their input to the above.

B3

With permission of the adult with IDD, obtain one or two photos of them engaging in activities or with people they enjoy. Attach the photos to the Advance Care Plan.

C. DISCUSS PREFERENCES FOR FUTURE CARE

C0

Talk with the substitute decision-maker of the adult with IDD about the information in **Advance Care Plan: Information for Substitute Decision-makers and Healthcare Providers** (pages IX-XI).

C1

Explore the adult with IDD's understanding of any significant diagnoses they have and educate as needed. See the section Supporting Materials for examples of plain language resources and accessible information about COVID-19.

Some important points to communicate:

- *Whether most people recover or not from the condition*
- *Whether people can die from the condition or not*
- *Whether a hospital stay might be considered in the future and how long hospital stay might be (if known) and if the person has a better chance of getting better at hospital than at home*
- *If there are any visitor restrictions in place for hospitals*
- *What side effects the person might experience from treatments proposed, and how long these might last. For example: hair loss from chemotherapy, or long-term changes to senses/mobility/ability to participate in activities that might occur from either the serious condition or proposed treatments.*

C2

Ask the adult with IDD for permission to talk about preferences for future care, which need not include end-of-life care, now or at some other time. In future, when a decision will be made, the SDM's consent to proposed treatments should be informed by statements in section B.

EXAMPLE: "We hope that none of this will happen to you. But it is good to be ready by thinking about what you would want if you become very sick with [insert diagnosis] and cannot tell others what you want or make decisions. Is it okay to talk about that?"

If the person answers YES, proceed to C3. If the person answers NO, proceed to C6.

C3

Discuss hospital care. Use accessible resources, see the section Supporting Materials.[iv-vi] Engage with caregivers and others who know the person well to add their input.

EXAMPLE: "Let's talk about what it will be like if you need to stay in the hospital. Doctors and nurses can look after you in the hospital until you get well. They will try to keep you as comfortable as possible. But your family and friends will probably not be allowed to visit you in the hospital because of the pandemic. You may instead be able to talk to them by phone. What do you think?"

If you stay in the hospital...

- Who would you want to talk to on your phone (choose a couple of people)? Let's write down their names, phone numbers, and the best times to call them, so the nurses will have it. They can help you.
- If you could only take one thing with you to the hospital, what would it be? What else would you want to take with you if you could?
- What can the nurses do to cheer you up, help you stay calm, and to help you when you're afraid or upset?
- Some hospitals might allow a visitor. If the hospital lets you have one visitor, who would you want it to be? Let's write their name and phone numbers down.

C4

Discuss active care in the hospital or, when possible, at home.

EXAMPLE: "Doctors and nurses might do things to help you feel better, for example, give you a needle for medication or have you put on a mask to help you breathe better. Doing these things will also give your body time to get well. But it might take you some time also to get used to these things and to feel comfortable with them. Is it okay if they want to help you to get well in this way?"

Engage caregivers and others who know the person well to add their input, especially on accommodations to make active care procedures tolerable. Then proceed to C6.

If the person expressed being able to tolerate staying in hospital (see C3 above), proceed to C5.

C5

Discuss intensive care. Use pictures and Easy Read materials to explain care [iv]. For example for COVID-19 care:

EXAMPLE: "Some people with the coronavirus have a hard time breathing. If this happens to you, the doctors and nurses could give you air to help you breathe, sometimes for about a week. You might need a breathing mask or something like a snorkel that goes into your mouth. If the doctors think you need it to get better, would you be okay with wearing a mask over your face or a snorkel in your mouth?"

EXAMPLE: "A few people with the coronavirus who get these treatments never get well enough to enjoy some things they could do before they got sick, even after they get over coronavirus. They might need much more help in their lives from other people. They might have to stay in the hospital or another home to get this help. We hope none of these things happens to you. But, would you want doctors to give you these treatments to help you live longer even though you might not be strong enough to do things you could before, like running or taking long walks?"

C6

Discuss preparing for death.

EXAMPLE: "Some people who are very sick from the coronavirus die. We hope that will not happen to you. Are there things important to you that you might want or want to do before you get too sick" (for example, spiritual care, leaving something for others to remember me by, spending more time with....)?

EXAMPLE: "If you are very sick, what are the things you would like around you (for example, your favourite music, pictures of families, friends, pets)? What else can we do to help you live the way you want?"

C7

Indicate if the adult with IDD has a Do Not Resuscitate (DNR) Confirmation Form. If the person is receiving palliative care and has specific care directives signed by a doctor or nurse (e.g., Do Not Resuscitate or DNR Confirmation Form or DNR in a treatment plan). Have this document accessible to first responders, and attach a paper copy to any documentation that would go with the patient to hospital. This form should be carried by the adult with IDD if they are taken to the hospital. If it should be revised, an updated form, signed by a doctor or nurse, should be obtained and documented here.

ADVANCE CARE PLAN:
Information for Substitute Decision-Makers and Healthcare Providers of Adults with Intellectual and Developmental Disabilities

Review this information with the highest-ranked substitute decision-maker(s) of the adult with intellectual and developmental disabilities (IDD), who may be called upon in future, if the adult with IDD is incapable. A healthcare provider (e.g., the adult's family physician) might be needed to explain proposed treatment.

What is the substitute decision-maker's role?

As a substitute decision-maker (SDM), your role ultimately is to provide *informed* consent or refusal to proposed treatments on behalf of the adult with IDD whom you are representing. This begins when they cannot pass the test for legal decision-making capacity even with needed supports.

When you are asked to make a treatment decision, your decision on behalf of the adult with IDD whom you represent must be based on:

A. information provided by the healthcare provider sufficient for informed consent or refusal. This includes relevant information about the adult with IDD's: health condition; the benefits, burdens, and risks of proposed and other treatment option; and what could happen without treatment options;
B. preferences for future care previously expressed by the adult with IDD (e.g., Section C of the COVID-19 Advance Care Plan Form). Healthcare providers are not obliged to propose treatments that, in their judgment, would be of no or little clinical benefit to their patients;
C. if preferences are unknown or irrelevant to the clinical situation, deliberating on the adult with IDD's best interest in the present circumstances, considering their prior capable wishes and if none, their values and beliefs (e.g., Section B of the COVID-19 Advance Care Plan Form); and
D. ethical reasoning and human rights considerations (see below).

In detemining the person's best interest, SDMs should consult, as needed, with supportive family members, friends, and personal support professionals in the adult with IDD's regular circle of care who know them well.

Some other people who could support SDMs in deliberating might include: a member of the adult with IDD's cultural or religious community, a spiritual care provider or a clinical ethicist at the hospital.

What is the most responsible healthcare provider's role in treatment decisions?

Healthcare providers draw up, propose, and implement agreed to treatment plans for the adult with IDD. They should:

A. provide and offer to discuss with the adult with IDD, their SDM if any, information sufficient for informed consent or refusal. This should include relevant information about: the adult with IDD's health condition; the benefits, burdens, and risks of proposed and other treatment options; and what could happen without treatment;
B. recommend a level of care and treatment options based on their clinical judgment, available resources, and ethical reasoning and human rights considerations (see below); and
C. offer available decision-making and psycho-social supports that the adult with IDD needs.

Health and health system considerations specific to COVID-19

This information is provided so that SDMs can be as prepared as possible for future discussions relating to the level of care or treatment options for the adult with IDD whom they represent. In a rapidly changing pandemic context, this information might change and should be reviewed with the healthcare provider proposing treatments.

Hospital stay and possible treatment

- Most adults with IDD who develop mild COVID-19 symptoms will fully recover within two weeks from symptom onset.
- Some adults with IDD who are infected by COVID-19 develop moderate to severe breathing difficulty, usually due to pneumonia that affects the lungs. Also, co-existing health conditions might get worse. These adults with IDD might need emergency, active care in a hospital setting that is only for patients who also have COVID-19 (e.g., to provide medications, fluids, oxygen support). This might involve having needles to give fluids and wearing restrictive masks that might be unfamiliar and distressing to adults with IDD. Doctors and nurses should make reasonable adjustments to usual care to accommodate and support the medical and developmental needs of adults with IDD and keep them comfortable.

- Hospital visits to an adult with IDD who is in a COVID-19 restricted setting will usually not be allowed. This rule could be distressing for many people with IDD. Some accommodations can lessen this distress (e.g., phone calls, familiar items). If in-person support is essential for their care, an exception to the rule should be requested.
- Some patients with COVID-19 whose breathing difficulty continues to get worse will need in-hospital intensive care and ventilator support. When a ventilator is started, it can usually be safely withdrawn in 1 to 2 weeks. At this point intensive care is no longer needed and the patient is usually no longer transmitting the virus. Ventilators do not cure pneumonia. They can help the adult with IDD to stay alive while their lungs and body fights to overcome the coronavirus.
- While on a ventilator, the adult with IDD will be unable to talk, eat or drink by mouth. The adult with IDD will also need medications to make him or her feel comfortable (e.g., sedatives). Consequently, they might have little memory of the time they spent in intensive care.
- There could be a limited supply of ventilators and intensive care beds during peak times of the COVID-19 pandemic. So far this has not happened. However, if it does, hospitals will need to have fair guidelines for selecting who will be eligible for these limited resources. It is important that those decisions be made using an ethical framework that does not discriminate against people with IDD solely because they have a disability (see page XI).

Survival and long-term effects of ventilator support and other intensive-care treatments

- Patients on ventilators who have certain co-existing health conditions, such as chronic obstructive pulmonary disease, congestive heart failure, or diabetes, generally have a low survival rate on ventilators (estimated to be less than one third). On the plus side, many adults with IDD who were generally healthy before becoming sick with COVID-19 and who need and can tolerate ventilator support and other intensive-care treatments will survive this infection.
- It is too early for researchers to have firm evidence of anticipated long-term effects on adults with IDD after receiving ventilator support, sedating medications, and other intensive-care treatments.
- The level of fitness or conditioning of an adult with IDD who requires intensive-care treatments will decline from their level prior to the illness. Generally, for every day that a patient spends in intensive care, they will need seven days of rehabilitation therapy to regain their prior level of fitness and conditioning. Such rehabilitation could be limited during a pandemic, which will lead to even poorer fitness and functional outcomes following discharge from intensive care. These outcomes for adults with IDD could be further compromised by new illnesses that occur during hospitalization, such as delirium or worsening of co-existing health conditions. Some adults with IDD could also develop new or worsening mental health conditions, such as post-delirium psychosis, nightmares, and other symptoms related to the stress and trauma of this experience. They could also develop new or worsened behaviours of concern.

Palliative care

A palliative approach to care, which addresses discomfort, is appropriate for all levels of care. Whether palliative care can be provided in the patient's home will depend on available resources (e.g., drugs), capacities of caregivers, and other supports for the adult with IDD.

Discussing proposed treatments

If a patient is or becomes incapable of making treatment decisions, the SDM and healthcare providers will need to discuss options for the adult with IDD and treatment options within these levels. These will need to be adjusted as the adult with IDD's health condition changes. The following section relates these options to three broad goals of care.

GOALS OF CARE	TREATMENT OPTIONS
Being comfortable only	**Palliative and end-of-life care only** - Adults with IDD stay, if possible, at home or are transferred to a hospice or hospital. - Focus on providing comfort for the adult with IDD and addressing symptoms. - Do Not Resuscitate or no CPR status, which includes no intubation, is consistent with this goal of care (i.e., allow a natural death to occur if the adult with IDD's heart or breathing stops). - Support adults with IDD and their loved ones to live as well as possible during what might be the adult with IDD's final phase of life.

GOALS OF CARE	TREATMENT OPTIONS
Returning to prior health and functioning	**Active treatments level A** *(without intensive-care level treatments)* ▸ Focus on recovery and rehabilitation while providing comfort and symptom management. ▸ Attempt first low-intensity treatments (e.g., antibiotic medications, intravenous fluids, oxygen support). ▸ Manage co-existing health conditions. ▸ Withdraw treatments that no longer work or have become intolerable to the adult with IDD despite attempts to accommodate needs and provide supports. ▸ If hospital healthcare professionals are unfamiliar with such accommodations and supports, seek advice from people who know the patient well (e.g., personal support professionals), and from the adult with IDD's family physician, psychiatrist, pharmacist, and other colleagues with expertise in the care of adults with IDD.
	Active treatments level B *(as above but, when symptoms worsen, could include intensive-care treatments).* ▸ Withdraw intensive-care treatments when health is not improving after an adequate trial period (e.g., 2 weeks) or when it becomes intolerable to the adult with IDD even with needed adjustments and supports (as outlined for level A).
Living longer even at the risk of poorer long-term functional and mental health outcomes	**Intensive-care treatments** ▸ Stay in hospital and the intensive-care unit. ▸ Focus mainly on patient's survival (with or without resuscitation). ▸ Provide intensive-care treatments as long as the adult with IDD lives and resources permit.

Ethical reasoning and human rights considerations related to treatment decisions

- Non-discrimination based on disability alone. The common good includes respecting the right to life, to accommodations for decision making, and to health care of people with IDD on an equal basis to others.
- These and related legal norms are specified in the United Nations Convention on the Rights of Persons with Disabilities (see Arts. 1 on equal right to life; 5 on equality and non-discrimination; 11 on state obligations to ensure safety; 12 on legal capacity; and 25 on attaining the highest standard of care).
- Four norms of ethical therapy should always be applied, even during a pandemic.
  - discretion (respecting the limits of medicine)
  - totality (promoting overall health and well-being, not just survival or integrity of part of the body)
  - parsimony (use only as much treatment as is necessary for goal of care)
  - proportionality (medical means must be proportionate to goal of care; benefits for patient must also be proportionate to risks and burdens for patient and caregivers—see below).
- A helpful guide to deliberating on the proportionality of treatments for a patient is the ordinary/extraordinary treatment distinction.
  - Ordinary treatment
    - offers a **reasonable hope of benefit to the patient**
    - uses **common means** (e.g., is available and is normally the standard of care)
    - is **possible or tolerable for the patient** (not excessively demanding or burdensome).
  - Treatment can be considered extraordinary or excessively demanding and burdensome, and hence, *ethically optional*, if it involves factors such as:
    - severe pain, discomfort, dread or other distress that cannot be addressed adequately by any means.
    - great effort on the part of the patient that cannot be alleviated by any means.

Appendix 1:

LETTER APPOINTING A POWER OF ATTORNEY FOR PERSONAL CARE IN ONTARIO

under the Substitute Decisions Act, 1992

Please read with or to the adult with the IDD.

I, ______________________ (name) trust[1a] ______________________ (name) and want him/her to be my Attorney for Personal Care.[2,3]

I understand[1b] and agree that my Attorney can do anything I can do to make a treatment decision for me when I cannot make this decision.[4]

If my above named Attorney cannot make this decision, I want ______________________ (name) to be the Substitute (back up) Attorney to do anything I can do to make this decision for me.

Attorney Mobile # ______________________

Substitute Attorney Mobile # ______________________

This letter replaces any past Power of Attorney for Personal Care I made.

Name of Appointing Adult	**Signature or Signed Mark**[5]	**Date**

Address: ______________________

Witnesses[6]

Name of First Witness	**Signature**	**Date**

Address: ______________________

Name of Second Witness	**Signature**	**Date**

Address: ______________________

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1. To be capable of completing this Letter, the adult with IDD who is appointing should be capable of (a) indicating trust in the named Attorney and the Substitute Attorney and (b) understand what an Attorney for Personal Care may do.
2. An Attorney must be over 16 years old and may not be a paid provider of health care, residential, social, training, or support services to the person who is appointing (e.g., current landlord, group home staff member, social worker, counsellor, teacher, Personal Support Professional).
3. A Power of Attorney for Personal Care covers all areas of personal care, including health care (treatment and admission to a care facility under the Health Care Consent Act) and other decisions including hygiene, housing, nutrition, clothing and safety under the Substitute Decisions Act. The adult with IDD may add a note to this letter limiting the Attorney's responsibilities to healthcare decisions only if they so desire.
4. "Treatment" and "capacity for decision-making" are both defined in the Health Care Consent Act, 1996.
5. The adult with IDD who is appointing must provide a signature or signed mark in the presence of two witnesses who can attest to the validity of this letter.
6. The following people cannot be witnesses: the attorney or his or her spouse or partner; the spouse, partner, or child of the person making the document, or someone that the person treats as his or her child; a person whose property is under guardianship or who has a guardian of the person; a person under the age of 18.

Supporting Materials

Decision making

i. **The substitute decision-maker hierarchy, Speak Up Ontario, HPCO, Ontario**
https://www.speakupontario.ca/resource/the-substitute-decision-maker-hirearchy/

ii. **Power of Attorney Kit, the Ministry of the Attorney General, Ontario**
https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php

iii. **What is advance care planning?, Speak Up Canada, CHPCA, Canada**
https://www.advancecareplanning.ca/what-is-advance-care-planning/

Social stories (examples)

iv. **Jack plans ahead for coronavisus: A guide for family and carers,**
Books Beyond Words, Beyond Words, United Kingdom, 2020
https://booksbeyondwords.co.uk/coping-with-coronavirus

v. **Going to the hospital with COVID-19, Surrey Place, Toronto, 2020**
ddprimarycare.surreyplace.ca

vi. **When I am in the hospital with COVID-19, Surrey Place, Toronto, 2020**
ddprimarycare.surreyplace.ca

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