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Advisory

Advance care planning

Advance care planning refers to the process of planning for your future care and focuses on a time when you may not be able to make certain decisions for yourself—either temporarily or permanently. It usually involves documenting your wishes with respect to personal care matters, and discussing those wishes with your substitute decision maker (SDM). Your wishes may be expressed in your power of attorney for personal care or in a letter to your SDM. The document containing your wishes is sometimes referred to as a "living will". You may also express your wishes orally.

When you are no longer capable of making personal care decisions, your wishes guide your SDM in making decisions on your behalf. They may be specific or general, often depending on your circumstances and preferences. If you do not make your wishes known, your SDM must act based on what he or she perceives to be your best interests.

This Advisory outlines the legal frameworks governing personal care decisions. It is helpful to understand these frameworks prior to planning for your future care. By doing so, you will be in a better position to prepare an advance care plan that will address your unique circumstances, needs, beliefs and wishes.

PERSONAL CARE DECISIONS (OTHER THAN HEALTH CARE DECISIONS)

Decisions regarding personal care matters, other than health care, are governed by the *Substitute Decisions Act* (Ontario) (SDA).

Under the SDA, you may plan for personal care matters relating to your nutrition, shelter, clothing, hygiene and safety. There are very few restrictions on the types of wishes you may express. However, you should avoid expressing wishes that may be impractical, such as those that are costly in relation to the size of your estate or difficult to implement.

Your wishes are important because they guide your attorney for personal care when you are no longer capable of making personal care decisions on your own. If your wishes are unknown, your attorney must act in accordance with your best interests under the SDA if you are subject to Ontario law.

Notwithstanding their critical importance, it seems that letters of wishes tend to be underutilized. Where they are used, they are often limited in scope to deal with end-of-life matters only, and not as often with a variety of non-health care matters. These matters are critical to our everyday lives, and should be considered in the formulation of any advance care plan. The following questions provide some guidance as to matters you may wish to consider and include in your unique letter of wishes:

- Do you prefer to remain in your home setting for as long as reasonably possible, as opposed to institutional care? In order to remain in your home, do you want to receive nursing and medical care in your home, such as may be provided by live-in or live-out caregivers?

- Do you have an accustomed lifestyle that you wish to be adhered to as much as possible?

- Under what circumstances would you want to reside in an institutional setting? Do you have a preference as to which ones? Do you have a geographical preference, such as one in your existing residential area or would you prefer to reside in one closer to your family or friends? What special services should be provided?

- Do you require special clothing, footwear or apparel? Do you have special hygiene or personal grooming requirements or preferences, including as to cost and service providers?

- Do you have special transportation requirements or preferences?

- Do you wish to pursue any special activities, including outings?

- Do you have any dietary preferences or restrictions?

If you have preferences with respect to any of the above matters, it is a good idea to express your wishes in a detailed manner, as opposed to relying on general statements.

As discussed in greater detail below, your substitute decision maker is not required to follow your wishes if they are not “applicable in the circumstances”. This may be the case where your circumstances have changed since you expressed your wishes, or where your wishes are vague, unclear, or imprecise.

Take, for example, the following wish expressed by a person while young and healthy: “It is my wish that I remain living in my home until my death”. It is likely this wish would be considered inapplicable if the person were to become totally dependent on others for his or her every need and required medical assistance that could not reasonably be provided in his or her home setting.

Instead of expressing your wishes generally, they can be tailored to your unique personal circumstances and they should contemplate various scenarios. It is important to update them as your circumstances change.

HEALTH CARE

The *Health Care Consent Act* (Ontario) (HCCA) only governs health care decisions (such as consenting to surgery), and does not apply to other personal care matters. Under the HCCA, health care practitioners must obtain your consent before administering or withdrawing treatment, except in emergency situations. If you are unable to consent due to a lack of capacity, your SDM may consent or refuse to consent on your behalf. For example, where a person is suffering from advanced dementia and is no longer capable of swallowing, a health care practitioner must obtain the consent of the person’s SDM before a feeding tube may be inserted.

Your SDM is guided by any prior wishes expressed by you while capable and must follow those wishes if they are applicable in the circumstances. The following describes this framework in greater detail.

Capacity

Your SDM may only act on your behalf if you are incapable. The law presumes a person is capable to make health care decisions. Health care practitioners are entitled to rely on that presumption unless they have reasonable grounds to believe you are incapable of making a decision with respect to the proposed treatment. You will be found incapable if you are unable to understand information relevant to making a decision about the treatment or if you are unable to appreciate the reasonably foreseeable consequences of your decision. Capacity must be determined with respect to each proposed treatment. If you are found incapable with respect to one particular proposed treatment, it does not mean that you are incapable with respect to all future treatments. The following example illustrates some of the above issues.

> *Laura was recently diagnosed with early onset Alzheimer’s disease. She often exhibits various symptoms of Alzheimer’s disease, including confusion and memory loss. One day while gardening, Laura suffered a heart attack and was rushed to a hospital by her husband, George. After being examined on arrival, the emergency room physician recommended that Laura undergo emergency bypass surgery.*

The stress of the situation caused Laura to become more confused than normal. The emergency room physician determined that Laura was incapable of appreciating the reasonably foreseeable consequences of consenting or refusing consent to the surgery. Consequently, George, as Laura's SDM, was asked to provide consent to the surgery on Laura's behalf, which he did.

Laura remained in the hospital for one month after surgery. Prior to leaving the hospital, it was recommended that Laura undergo a second bypass surgery. At the time the treatment was recommended, Laura's physician determined that she was capable to consent or refuse consent to the surgery. After carefully considering the advantages and disadvantages of the surgery, Laura decided not to undergo the surgery.

If a health care practitioner determines you are incapable of making a particular health care decision and you disagree with that finding, you may apply to the Ontario Consent and Capacity Board (CCB), which is an independent body that adjudicates consent and capacity issues, to have the finding reviewed. Pending the outcome of the review, your health care practitioner must not administer or withdraw treatment, except in emergency situations.

Substitute Decision Making

If you are incapable, your SDM may give or refuse consent on your behalf. In making that decision, your SDM must act in accordance with any prior wishes that you expressed while capable, such as those expressed in a letter of wishes to your attorney for personal care or those expressed orally to your SDM or other person. Your wishes speak to your substitute decision maker, and not to your health care practitioners. If your SDM is unaware of any relevant wishes, he or she must act in accordance with your best interests. In determining your best interests, your SDM must consider the following:

- Your values and beliefs while you were capable;
- Any wishes you express while incapable;
- Whether treatment is likely to:
    - improve your condition or well-being,
    - prevent your condition or well-being from deteriorating, or
    - slow the rate that your condition or well-being is likely to deteriorate;

- Whether your condition or well-being is likely to improve, remain the same, or deteriorate without the treatment;

- Whether the expected benefit outweighs the possible harm; and

- Whether a less restrictive or intrusive treatment would be as beneficial as the proposed treatment.

Your Substitute Decision Maker

With respect to health care decisions, your SDM will be the highest ranking person in the following list that is capable of acting, at least 16 years old, available and willing to act as your SDM:

1. Guardian of the person – a person appointed by a court to make personal care decisions on your behalf.

2. Attorney for personal care – a person appointed by you in your power of attorney for personal care.

3. Representative appointed by the CCB – a person appointed by the CCB to make a specific health care decision.

4. Spouse or partner – spouse includes common law spouses and partner includes persons who have lived together for at least one year and have a close personal relationship that is of primary importance in both persons' lives.

5. Child or parent, other than a parent with right of access only.

6. Parent with right of access only.

7. Brother or sister.

8. Any other relative – a relative includes any person related by blood, marriage or adoption.

Despite the above hierarchy, a person described above who is present or has otherwise been contacted may give or refuse consent if he or she believes that no other higher or equally ranked person exists or, if that person exists and is not described in 1 to 3 above, would not object to him or her making the decision.

Equally ranked persons must act together or may appoint one of themselves to act as your SDM. If they are unable to agree on a decision, the Public Guardian and Trustee

will be required to make that decision on your behalf, resulting in unnecessary delay and possibly arguments among family members during an already stressful time. This result can be avoided by appointing an attorney for personal care. If you fail to appoint an attorney, a person who you might not otherwise want to act on your behalf may become your SDM, which may result in decisions being made not in accordance with your values and beliefs. In those circumstances, even though you are incapable, you may apply to the CCB to have an alternative person be your SDM or an alternative person could apply to the CCB to be appointed.

The following example illustrates a situation that could have been avoided if an attorney for personal care had been appointed.

> *Jessica has been in a relationship with Paul for the past eight years. They intend to purchase a home together in the near future. Jessica has one daughter, Sarah, from a prior marriage. Jessica and Sarah have been estranged for over ten years.*
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> *On her drive home from work one rainy day, Jessica lost control of her car and crashed into a telephone pole. Jessica was found unconscious at the scene and was rushed to the hospital where she was treated for non-life threatening injuries. A year after her accident, Jessica has not regained consciousness and it has been determined that she will remain in a permanent vegetative state for the rest of her life.*
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> *Jessica's physician recommended that her life support be removed. Since Paul is not Jessica's guardian of the person, attorney for personal care, spouse, or partner, Sarah would be her mother's SDM, assuming she is willing and capable to act in that capacity. Given the strained relationship between Jessica and Sarah, it is likely that Jessica would have instead wanted Paul to be her SDM. Nevertheless, Sarah would be entrusted to determine whether her mother would be removed from life support or not.*
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> *Paul could apply to the CCB to be appointed as Jessica's SDM or to court to be appointed as her guardian of person (and, effectively, her SDM), but there is no guarantee that the CCB or the court would appoint Paul over Sarah in such circumstances.*

For more information on appointing an attorney for personal care, please see our Advisory titled "Planning for Incapacity Using a Power of Attorney".

The Role of Health Care Consent

Health care practitioners may not administer or withdraw treatment without your consent, except in emergency situations. Consent is valid only if it relates to the

treatment, and it is informed, given voluntarily and is not obtained through misrepresentation or fraud. For consent to be informed, the health care practitioner must disclose information about matters that a reasonable person in the same circumstances would require in order to make a decision, including the nature of the treatment, its expected benefits, material risks, and material side effects, as well as alternative courses of action and the likely consequences of refusing the treatment. If you are incapable, such information must be provided to your SDM so that he or she can make an informed decision.

You may also consent to future treatments that have not yet been proposed if those treatments are part of a plan of treatment. A plan of treatment is developed in consultation with your health care practitioners. It deals with health problems you currently have or are likely to have in the future given your current health condition and it provides for the administration or withdrawal of various treatments or courses of treatment. If you consent to a plan of treatment and later become incapable, your health care practitioner may administer or withdraw treatment in accordance with your plan of treatment. Your SDM, however, may withdraw your previously given consent if appropriate in the circumstances.

In an emergency, health care practitioners may provide treatment without consent if the delay required in obtaining consent or refusal on your behalf would prolong your suffering or would put you at risk of sustaining serious bodily harm. If your health care practitioner is aware of any wishes expressed by you while capable, he or she must act in accordance with those wishes if they are applicable in the circumstances. As well, if your SDM refuses treatment on your behalf in an emergency, your health care practitioner may nonetheless provide treatment if he or she believes your SDM is not acting in accordance with your wishes or best interests.

Health Care Treatment

Your health care practitioners determine which treatments are medically appropriate in your circumstances. An inappropriate treatment does not have to be proposed or administered. If a treatment is proposed, it may not be administered or withdrawn without your consent or your SDM's consent. Treatment is defined as anything done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose. In *Cuthbertson v. Rasouli,* the Supreme Court of Canada held that treatment also includes the removal of life support.

The Importance of Your Wishes in Health Care Treatment

Your wishes guide your SDM when making health care decisions on your behalf. If you do not express any wishes, your SDM must act based on what he or she perceives to be your best interests. Some people prefer that arrangement for various reasons, while

others prefer to set out their wishes in order to ensure that decisions are made in accordance with their preferences, values, and beliefs.

Written Wishes and Oral Wishes

Wishes may be expressed in writing, such as in a power of attorney for personal care or in an accompanying letter of wishes, or orally. Later wishes prevail over earlier wishes, even where later oral wishes conflict with earlier written wishes. It is generally advisable that you set out your wishes in writing as various issues may arise if you express your wishes orally. For instance, health care practitioners are generally reluctant to follow later oral wishes that conflict with earlier written wishes. If the health care practitioner has reason to doubt that later oral wishes are your true wishes, he or she may apply to the CCB for direction. This may result in a delay of treatment and may create a stressful situation for your SDM and family members. Where there is a possibility that family members may challenge decisions made by your SDM, it is helpful if your SDM can refer them to your written wishes when responding to any such challenges. If you express your wishes in writing, it is still important to discuss those wishes with your SDM, especially if you choose to express generally. Those discussions provide your SDM with greater context when making decisions on your behalf.

Prior Wishes Prevail

Your SDM must follow any prior wishes expressed by you while you were capable if it is possible to comply with them and if they are applicable in the circumstances. Wishes are not to be applied mechanically or literally. Your SDM, not your health care practitioners, must interpret your wishes and determine whether they are applicable in the circumstances.

Inapplicable Wishes

Wishes that are vague, unclear and lack precision are most often treated as not applicable in the circumstances. These may include wishes expressing general sentiments in contemplation of an uncertain future. In certain situations, wishes may also not be applicable as a result of changes in condition, prognosis and treatment options.

Wishes tend to be applicable in the circumstances where they arise out of deeply held beliefs, such as a Jehovah's Witness wish not to receive a blood transfusion. These wishes are usually concrete and precise. Wishes dealing with a person's specific medical circumstances, including likely future illnesses and conditions, are usually applicable in the circumstances. These tend to be expressed in medical terms and are useful where the person has knowledge about the likely progression of his or her illness or condition and the types of treatment that may be offered. They are also useful where

a person is scheduled to undergo major and risky surgery. These wishes tend to be applicable in the circumstances because the circumstances to which they apply are specific and the patient also has the benefit of medical advice.

The following are a few examples of court and CCB decisions which dealt with the issue of whether wishes were applicable in the circumstances.

In one case, a patient had told his friend that he wanted all measures to be taken before life support was removed and that he wanted to remain alive if there was any chance he could recover. The CCB ruled that the patient's wishes were not applicable in the circumstances because he likely did not contemplate at the time of expressing his wishes that he would ever be in a persistent vegetative state.

In contrast, a patient had expressed the following wish in his power of attorney for personal care: "I direct that no matter what my condition I be given all applicable medical treatment in accordance with accepted health care standards". The patient's SDM wanted CPR to be administered if necessary. The patient's health care practitioner sought a determination of whether the above wish was applicable in such circumstances. The CCB ruled that the wish was clear and was applicable. In arriving at that decision, the CCB placed a strong emphasis on the words "no matter what my condition".

In another case, the CCB ruled that the following wish was guiding with respect to whether the patient's feeding tube could be removed: "[if] I am suffering from a terminal injury, disease or illness, and that my death will occur whether or not life sustaining procedures are utilized, and where the application of life sustaining procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally and with dignity". The patient was in a persistent vegetative state, but was not suffering from a "terminal injury, disease or illness". The CCB ruled that the above wish technically did not apply for that reason, but that it was nonetheless instructive. As a result, the SDM was able to provide consent to the removal of the feeding tube.

On a slightly different basis than the above cases, a court held that a patient's purported wish that she be allowed to die and not be kept alive by artificial or heroic measures was not valid. In that case, the patient was in a vegetative state with no chance of recovery. The patient's SDM refused to consent to the removal of life support because such would be in contravention of the patient's religious beliefs. Based on evidence regarding the patient's religious beliefs and evidence of the lawyer who drafted the patient's power of attorney for personal care, the court held that the patient did not know and approve of the end of life clause contained in her power of attorney for personal care. Therefore, the end of life clause was not valid and, as such, the patient's SDM was not required to consider that clause when deciding whether to provide or refuse consent to the removal

of life support. In arriving at its decision, the court also noted that the written wishes in a power of attorney for personal care do not automatically prevail. Rather, they create a presumption that those are the wishes of the grantor, which can be rebutted by compelling extrinsic evidence to the contrary.

In a different context, the CCB ruled on two separate occasions that the wishes of two individuals were not applicable where the individuals did not want to be moved from their homes. In one of those cases, the individual had expressed the wish that she never wanted to live in a nursing home. The CCB ruled that the wish was not applicable in the circumstances because at the time it was made the patient never envisioned that she would be totally reliant on others for the care of her every need. In the other case, the individual had expressed the wish that she wanted to remain in her home upon becoming incapable. At the date of the hearing, the person required constant supervision and help with various aspects of daily living. The CCB concluded that the individual's wish was not applicable in the circumstances because it was too vague and because her current circumstances were not likely within her contemplation when she executed her power of attorney for personal care.

If it is unclear whether a prior wish is applicable in the circumstances, your SDM or health care practitioner may apply to the CCB for directions. Your health care practitioner may also apply to the CCB to challenge a decision made by your SDM based on your wishes if your health care practitioner doubts the applicability of those wishes. In most cases, it is typically the health care practitioner who applies to the CCB for guidance.

In addition, your SDM or health care practitioner may apply to the CCB for permission to depart from your prior wishes to refuse treatment. The CCB may grant permission where it is satisfied that you would likely consent, if capable, because of an improvement in the likely result of the treatment since the wish was expressed.

Assisted Dying

Under the *Criminal Code*, assisting a person to die is a criminal offence. In 1993, the Supreme Court of Canada in *Rodriguez v. British Columbia (Attorney General)* was asked to determine whether the law against assisted dying should be struck down on the basis that it infringes certain rights and freedoms under the *Canadian Charter of Rights and Freedoms* and is therefore unconstitutional. In a 5-4 decision, the Court upheld the law against assisted dying.

However, in *Carter v. Canada (Attorney General),* the Supreme of Canada reconsidered its decision in *Rodriguez.* In February 2015, the Court unanimously declared that the law against assisted dying is invalid to the extent that it prohibits physician-assisted death for a competent adult person who (1) clearly consents to the

termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. The Court suspended its declaration of invalidity for 12 months to provide Parliament, the provincial legislatures, and the physicians' colleges with time to develop a new legislative scheme to deal with assisted dying in the above circumstances.

On June 17, 2016, Parliament enacted Bill C-14, amending the Criminal Code to legalize medical assistance in dying ("MAID"). Under the legislation, MAID, which includes both assisted suicide and voluntary euthanasia, is legal if the criteria and procedural safeguards set out in s.242.2 of the Criminal Code are followed by the doctors or nurses involved.

Under S. 241.2(1) of the Criminal Code, a person may receive MAID if he or she:

- Is at least 18 years of age and capable of making decisions with respect to his or her health;
- Has requested MAID voluntarily and not as a result of external pressure or undue influence;
- Has provided informed consent to receive MAID, after having been informed of other options to alleviate suffering, including palliative care;
- Is eligible for publicly funded health care services in Canada; and
- Has a grievous and irremediable medical condition.

Under S. 241.2(2) of the Criminal Code, a person has a "grievous and irremediable medical condition" only if they meet all of the following criteria:

- they have a serious and incurable illness, disease or disability;
- they are in an advanced state of irreversible decline in capability;
- that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

There is continuing controversy on the question of who has access to MAID - the law does not allow consent in advance to MAID and does not allow MAID for minors or the mentally ill. The inability to consent in advance is particularly problematic for individuals with degenerative conditions (e.g. Alzheimer's disease, dementia, ALS, or spinal muscular atrophy) who may not be able to request MAID when they truly need it.

Conclusion

Without proper planning, decisions about your future care may be made without the benefit of knowing your wishes, values and beliefs. By putting a comprehensive personal care plan into place, you increase the likelihood that your wishes – and not someone else's – will be carried out when you are no longer capable of making personal care decisions on your own.

We recommend that you document your wishes in your power of attorney for personal care or in an accompanying letter to your SDM. We also recommend that you discuss your wishes with your SDM as it is important that he or she understands your wishes and how they should be applied in various circumstances.