

BC Association for Community Living Advanced Health Care Directives Policy

Policy Issue

In BC's health care law, all people are considered capable of making a health care decision unless they are found incapable. Advanced health care directives are being promoted by some health authorities as a way for people to ensure their wishes about health care are followed in situations where they are not capable of making their own health care decisions.

Advanced health care directives provide a written set of instructions and guidelines for a person's family members and health care providers about the level and type of medical treatment they want if they are injured or ill and are unable to express their wishes. While intended to ensure that a person's wishes are followed, advanced health care directives pose some fundamental problems.

Advanced health care directives are often written long before a health care situation occurs. They can only reflect a person's intentions at a specific time, they are rarely updated, and they cannot anticipate people changing their minds. These documents are usually written down and then entrusted to family members, physicians and lawyers for safekeeping until they are needed. As time passes, people's circumstances change and new technology and treatment options become available, with the result that the advance directives may no longer apply to the person's wishes or circumstances.

Advanced directives are being promoted as a tool for "self-determination." However, because they are usually general in nature, they are vulnerable to different interpretations. This is less of a problem if the physician knows the adult well, but in today's health care system, people are often treated by a hospital-based physician who does not know them. Adults with developmental disabilities are especially vulnerable in this situation, as they are frequently judged as having a "poor quality of life" or a life not worth living.

There is widespread misunderstanding about advanced health care directives and who can make them. The legal authority to make an advanced health care directive belongs to the individual. While a legally appointed substitute decision-maker can make a health care decision on behalf of an individual, they do not have the authority to make decisions about what type of health care will be provided sometime in the future.

In various care facilities across British Columbia, the current practice is to require an individual *or a substitute decision-maker* to make an advanced health care directive by signing a Levels of Intervention form upon admission. By signing this form, an individual or substitute decision-maker is agreeing to treatment that will (or will not) be provided sometime in the future, without full knowledge of the specific health care issue and treatment options that will be available. The Levels of Intervention form becomes the basis for future health care decisions and may or may not reflect the adult's wishes, values or beliefs at the time a health care decision is required.

In British Columbia, the *Representation Agreement Act (RAA)* and the *Health Care (Consent) and Care Facility (Admission) Act (HCCFAA)* include provisions for individuals to communicate their values, beliefs and wishes, which become the basis for making health care decisions on their behalf. BC does not have specific legislation on advance health care directives. However, the existing legislation provides a framework that ensures substitute decision-makers are ethically making health care decisions that reflect the values, beliefs and wishes of the individual for whom the decision is being made.

The issue of advanced health care directives should ring alarm bells for all British Columbians, but is of particular concern to people with developmental disabilities. The legislation described above does a much better job than advanced health care directives of providing the safeguards to ensure that adults with developmental disabilities receive equal access to health care and are not denied treatment based on their disability or others' assumptions about their quality of life.

An effective way of increasing safeguards for adults with developmental disabilities is through individualized anticipatory health care planning. This is a process focused on guiding and supporting specific decisions and reducing the vulnerability of the adult when faced with decisions about life-supporting care and treatment. In an anticipatory planning model, health care decisions are based on values, beliefs and wishes and involve the individual in the decision-making process. Anticipatory planning is not a static or single event; it is continuous throughout the lifetime of the adult and becomes more focused when critical health care decisions are required. These decisions may include end-of-life planning and palliative care.

Purpose

To ensure that advanced health care directives are not used as a health planning tool for adults with developmental disabilities.

Guiding Principles

- Substitute health care decisions are best made by people who are personally committed and bonded to the adult and are aware of their values, beliefs and quality of life.
- Health planning needs to be flexible enough to accommodate changes in an individual's perspective and circumstances over time, and changes in their health and the health care treatments available.
- Bureaucratic and administrative policy should not increase the vulnerability of someone with a developmental disability or diminish the value of their life.

Background

The provincial legislature has in recent years proposed legislation to enshrine advanced health care directives in law. Some health authorities have already initiated projects to educate and encourage people to document their choices for the type of medical care they want in the form of advance health care directives, so these can be used by health care providers and substitute decision-makers as the basis for health care decisions. The promotion of advance health care directives is of great concern.

The greatest health care costs for a person typically occur in the last six months of their life. This has led many health care providers to assume that people are getting treatment they do not want during the last six months of life. Their belief is that if people could give instructions in advance, they would more often choose to refuse intervention, and health care dollars could be saved.

It is doubtful whether advanced health care directives are successful in ensuring that health care decisions are consistent with the adult's values, wishes and beliefs¹.

Many community organizations supporting adults with disabilities, as well as the BC Medical Association, support the use of Representation Agreements to ensure that substitute decision-makers are legally bound by a person's wishes, values and beliefs regarding health care decisions.

¹ Summarized from: An Update on Advance Care Directives in BC and in Relation to Representation Agreements, by Joanne Taylor

Policy Statements

1. Advanced health care directives are not an appropriate health care planning tool for adults with developmental disabilities.
2. BCACL supports the use of Representation Agreements as the legal mechanism for delegating the responsibility to make health care decisions.
3. Signing a Levels of Intervention form should not be a requirement for admission to a health care facility.
4. BCACL supports anticipatory planning as the process for guiding health care decisions throughout the lifetime of an adult.
5. Substitute health care decisions are made in collaboration with the adult, and with an understanding of the adult's values, beliefs and wishes.
6. All health care decisions require consent by the adult or a legally appointed substitute decision-maker² and should not be controlled by care facility policy.

Definitions

Advanced health care directives are most often defined as a written document made by a capable adult, which includes general and/or specific instructions or directions about preferences for health care or treatment and is given in anticipation of an event when such care or treatment may be offered³.

Advanced directives include living wills, pre-signed levels of intervention, instructions in a health care representation agreement, notes in family doctor files, and instructional directives.

Anticipatory Health Care Planning is an ongoing planning process focused on guiding and supporting specific health care decisions and reducing the vulnerability of the adult when faced with decisions about life-supporting care and treatment.

² Includes a representative under the *Representation Agreement Act*

³ An Update on Advance Care Directives in BC and in Relations to Representation Agreements

Degrees of Intervention⁴ is a system used by hospitals or care facilities to indicate the level of care to be provided to an adult sometime in the future. A Degrees of Intervention document may be related to health issues present at the time of admission or may be based on the presumption of future health issues. *Degrees of Intervention* documents are created by the health care provider after discussion with a capable adult or his/her legally appointed substitute decision-maker and are based on the current or previously expressed values and beliefs of the individual. As *Degrees of Intervention* are intended to guide decisions on the level of care to be provided to an adult in the future, they are considered an advanced health care directive.

Instructional directives traditionally focus on end-of-life issues i.e., refusal or withdrawal of life support measures and consent to pain control and comfort measures⁵.

Health Care is anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other purpose related to health and includes:

- a series or sequence of similar treatments or care administered to an adult over a period of time for a particular health problem
- a plan for minor health care
- participation in a medical research program approved by an ethics committee designated by regulation

Major health care means:

- major surgery
- any treatment involving a general anesthetic
- major diagnostic or investigative procedures
- any health care designated by regulation as major health care

Minor health care mean and health care that is not major health care and includes:

- routine tests
- routine dental treatment that prevents or treats a condition or injury caused by disease or trauma

Palliative care is defined as care directed towards maintaining the comfort and emotional well-being of the patient, rather than on active curative treatment. It includes the administration of medication or other treatment to a patient with the intention of relieving pain or suffering and improving quality of life until death.

⁴ Degrees of Intervention are also referred to as Levels of Care

⁵ An Update on Advance Care Directives in BC and in Relations to Representation Agreements

Representation Agreements are a proxy-type of directive. A representation agreement names a substitute decision-maker and may also include general and/or specific instructions about medical interventions.⁶

End of life planning is a collaborative planning process where the pre-expressed values and beliefs and quality of life of an individual are discussed in the context of a current health issue. This process includes the capable adult, his/her family or legal substitute decision-maker, knowledgeable support workers, and appropriate health care professionals. End of life planning typically includes palliative care decisions to ensure the comfort and emotional well-being of the individual. End of life planning may result in the decision by the physician to write a “do not resuscitate” order or complete a “levels of intervention” document. In this case, as the decision is made within the context of a current health issue, the “levels of intervention” is not considered an advanced health care directive.

⁶ An Update on Advance Care Directives in BC and in Relation to Representation Agreements