

## **Advance Care Planning and End of Life Decision-Making: More than Just Documents**

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There is a common misunderstanding that a person must sign an "advance directive" or "living will" in order to have their wishes about end of life care honoured. In fact, many health facilities inappropriately require all patients/residents to complete some form of facility designed health directive on admission, arguing that it is necessary as otherwise staff would not know what to do if the patient/resident experiences a health crisis.

However, this is a dangerous practice as it is based on a misinterpretation of the law. Many of the forms are woefully inadequate for any purpose, are not proper consents, and are not appropriate direction to staff, even in a crisis.

What are the problems with these forms? First, facilities cannot "require" or put undue pressure on patients or their families to complete such forms. It is the patient's choice as to whether they want to complete the facility form, use another form that they have chosen for themselves, or use no form at all to communicate their wishes about future health care. Completion of such a form cannot be made a condition of admission to the facility. Completion of such a form is not a prerequisite to proper care by staff.

Second, the forms are usually not clear as to what they are. Some of the forms purport to be "consents" for future treatment. However it is not possible in Ontario law to have generalized consents to future treatment. Consents must be given voluntarily and must be "informed." That means that the patient must have been provided with information about the risks, benefits and alternatives to the treatment being offered. The patient must be given information on his or her present condition and why the treatment is being offered in order to make an informed decision. A patient may consent to a course of treatment so that consent to each pill in a course of medication is not necessary but changes to that medication would require a new consent. Consents are in effect "time" related, related to treatment offered at a particular time for a present condition and cannot be given for treatment at a future time when that patient's health condition may have changed.

Patients may express "wishes" about future health treatment, particularly about end of life care; however, these are only wishes and not consents to those future treatments or refusals of treatments.

Third, many of the forms require patients to choose between one of three or four "levels of care". This type of form is also not a consent as it is too generalized and does not relate specifically to a particular patient's needs or wishes. The patient may prefer a "combo" of the options but the forms don't permit that option. Or the patient may want other options that are not presented as one of the levels of care. Patients have the right to be offered treatment options that are relevant to his or her particular health condition and not just a choice of "standardized" care from a limited list.

Fourth, many facilities ask the patient's substitute decision-maker (SDM) or family member to sign the form on behalf of the patient if the patient is mentally incapable in respect to treatment. By law, SDMs only can give or refuse consent to treatment on behalf of an incapable person. SDMs cannot sign advance directives. As part of a proper consent, SDMs can consent or refuse consent to treatments that deal with "one or more health problems that the person is likely to have in the future given the persons present health condition" (*Health Care Consent Act*, s.1). Therefore the scope of the consent can deal with end of life care that is anticipated but the consent must be personalized to the patient and be in the context of that patient's present health condition. Most of the forms do not relate to that context.

Fifth, when a patient expresses wishes about future health care, those are directions to that person's SDM and not the health team providing care. The SDM must interpret the wishes as expressed and then give or refuse consent to the health team taking into consideration these wishes. Whatever forms are completed are therefore directions to the SDM not the health providers. Most of the facility forms are wrongly used in practice as directions to the health team and the health team may fail to get proper consents from the SDMs thinking that they can rely on the forms alone. This is inappropriate.

There is one exception to this rule. If the health team is aware of the patients wishes, in an emergency, if the patient is not mentally capable and the SDM is not present and it would not be possible to contact the SDM in light of the fact that it is an emergency, then the health team should follow the wishes of the patient when determining what emergency treatment to deliver. Unfortunately many of the forms are not a good communication of the wishes to be followed in an emergency because of their generality and lack of application to the patient's particular condition.

Sixth, wishes of patients about future care do not need to be written down in a standardized form to be honoured. Wishes may be communicated orally, through other forms (not the facility form), or through other means, such as a Bliss Board. The Facility staff should have some means of charting these wishes expressed in ways other than the facility form in order to be aware of the patient's wishes in an emergency.

In the end, it is not the forms that are important but the communication between the patient and his or her future SDM so that the SDM knows what the patient's wishes are and knows how to interpret them. Communication between the patient, their future SDM and the health care team is also key so that the health team knows what to do in an emergency. The forms may be helpful as a guide in leading that discussion but the health team must be aware that the form is not a consent and that continued communication with the capable patient and his or her SDM if the patient becomes incapable is the best way of ensuring that the patients wishes will be honoured at end of life.