

HEALTH CARE CONSENT AND ADVANCE CARE PLANNING (ACP) GUIDELINES TEMPLATE

MATTERS TO CONSIDER IN REVIEWING FACILITY GUIDELINES/POLICIES ON INFORMED CONSENT AND ACP OR CREATING NEW GUIDELINES/POLICIES

1. TERMINOLOGY

a. SUBSTITUTE DECISION MAKERS (SDMs)

Do the forms and policies at your hospital / long term care home refer to “next of kin” or “POA” when what in fact you want to record the patient/resident’s future Substitute Decision maker (SDM)?



REMEMBER

If you want to record the name of the patient/resident’s SDM who will make decisions for the patient/ resident when the patient /resident is not mentally capable to give or refuse an informed consent, include the complete hierarchy list of SDMs from the *Health Care Consent Act* in the form to require staff to record that information so that it is clear who is the SDM if needed.

Make it clear in the policy/ form that the SDM is the treatment decision maker only if the patient/resident is not mentally capable to make his or her own decisions.

Confirm that the SDM meets the REQUIREMENTS to be SDM (see requirements below). If not, record as SDM the next SDM that meets the requirements.

It may be advisable to include contact information for the NEXT highest ranking SDM if the SDM that is acting as decision maker is not AVAILABLE when a decision needs to be made.

HCCA s. 20(1) – Hierarchy of SDMs

- 1 Guardian of person
2. Attorney in POAPC
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner
5. Child or parent or CAS (person with right of custody)
6. Parent with right of access
7. Brother or sister
8. Any other relative
9. Office of the Public Guardian and Trustee

SEE TIP SHEET #2 for explanation of terms in the hierarchy

HCCA s.20 (2) Requirements to be SDM

The person highest in the hierarchy may give or refuse consent only if he or she is:

- a) Capable in respect to the treatment;
- b) At least 16 years old unless the parent of the incapable person;
- c) Not prohibited by a court order or separation agreement from acting as SDM;
- d) Available (including via electronic communications); and,
- e) Willing to act as SDM.

b. ADVANCE CARE PLAN OR PATIENT'S / RESIDENT'S WISHES, VALUES. BELIEFS

Do the forms and policies refer to “advance care directives” or “living wills”, when, in fact, what is intended to be referenced is the patient/ resident’s “advance care plan” or “wishes, values, beliefs” about future care?

Do the forms and policies refer to “advance care plans” when in fact the forms are intended to record Informed consent to a treatment or a refusal of a treatment (such as a consent to No CPR when the patient/ resident is at end of life)?

REMEMBER

The terms “advance directive” and “living will” are not in Ontario law and may cause confusion. It is preferable to use the generic term “advance care plan” or the term used in the HCCA which is the patient’s / resident’s “wishes, values, beliefs” to record a patient’s / resident’s wishes about future care .

This will distinguish the wishes or advance care plans from the patient’s / resident’s INFORMED CONSENTS as the health practitioners and other staff need to implement the decisions made when an informed consent is obtained.

The advance care plans and wishes are primarily GUIDES to the patient’s / resident’s future SDM when the SDM is making health treatment decision for the incapable patient/ resident. The patient’s / resident’s wishes are relevant to health practitioners only in an emergency when no informed consent may be obtained to the treatments needed.

2. WHAT IS HEALTH CARE CONSENT AND WHAT IS ACP AND WHAT IS THE CONNECTION?

Do health practitioners and staff have a common understanding that before ANY treatment that an informed consent must be obtained from the patient/ resident if mentally capable for this purpose?

Do they understand that they cannot use any form of advance care plan as a consent?

Do staff have a common understanding of what Advance Care Planning is and in particular that it is NOT a guide to them about care and treatment except in an emergency? Is this explained in the facility guideline on ACP?

Do the forms and policies at the hospital / long term care home reflect legally correct explanations of Informed consent and advance care planning?

Are there separate forms / places to record the consents and to record advance care plans so that these are easily distinguished by staff when they are taking care of patients/ residents?

Is it clear on the advance care plan forms that what has been recorded are wishes of the patient/ resident and that the advance care plan is NOT a CONSENT? Is it clear on the advance care plan form that the wishes recorded are primarily a guide to the patient's SDM when the SDM is making decisions for the patient/ resident when the patient/ resident is not mentally capable ?



REMEMBER,

INFORMED CONSENT

Health practitioners **MUST** get an **INFORMED CONSENT BEFORE** providing ANY treatment to a patient/ resident, except in an emergency when there is no time to obtain an informed consent. . Consent is not just done before surgery but must be obtained to any treatment, or to a plan of treatment / plan of care.

CONSENT must come from the patient/resident, if capable, or from their **SUBSTITUTE DECISION MAKER (SDM)** if the patient/ resident is **NOT** mentally capable to make the specific treatment decision.

When seeking consent, **ALL** health practitioners have a duty to **COMMUNICATE** with patients/residents (or the incapable patient's /resident's SDM about;

- the patient's/ resident's present condition
- the available Treatment Options
- Risks and benefits and Side Effects of the treatments
- Alternatives to the treatment
- What may happen if not agree to the treatment

An Informed consent is a **DECISION**.

ADVANCE CARE PLANNING (ACP)

Advance Care Planning (ACP) is

1. IDENTIFYING the capable patient/resident's future Substitute Decision-Maker (SDM), by either
 - confirming that the patient/resident is satisfied with their default/ automatic Substitute Decision-Maker in the hierarchy list that is in the *Health Care Consent Act*

OR

 - the patient/resident choosing someone else to act as SDM by preparing a Power of Attorney for Personal Care (a formal written document).
2. WISHES, VALUES, AND BELIEFS – discussing with the capable patient/resident about his/her wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of incapacity to give or refuse consent.

ACP focuses on the life of a person rather than just the end of one's life.

ACP deals with wishes about treatment as defined by the *Health Care Consent Act* but also wishes about where a person lives, what he/she eats, his/her social life, his/her spiritual; needs, personal interests such as music, contact with family and anything else that is important to this person. ACP may reflect what the patient/ resident believes is "quality of life".

ACP focuses on discussions and communication between a person and his/her future SDM so that the SDM will know how to make decisions for the patient when the patient is not mentally capable and not able to make their own treatment and care decisions.

ACP may be done orally, in writing, or communicated by alternative means. ACP does not need to be done only on the health facilities forms.

ACP is about WISHES, VALUES, BELIEFS not decisions because the patient/ resident does not yet have the information relevant to making a treatment decision (consent).

If the patient/ resident is at end of life and therefore has information about his/her health condition to then make decisions about treatment, then he/she is providing an INFORMED CONSENT or refusal TO A TREATMENT and is NOT advance care planning.

2. VOLUNTARY

Does the facility guideline on ACP reflect that ACP is voluntary and can only be done by a person when mentally capable to do so?

Do staff understand that patient/residents do NOT have to complete any ACP forms prior to admission and do not have to complete any ACP forms or give specific directions about future care when they live in the facility?

REMEMBER

What is key to the delivery of care is the process of talking with patients/residents about their present condition, their goals of care and specific treatment options to then lead to an informed consent to a treatment or to a plan of treatment or plan of care.

The fact that someone has not expressed advance care plan wishes, values, and beliefs is not a deterrent to proper care. The health practitioners or the health facility staff should at a minimum find out from the patient/ resident who would be their SDM should the patient/resident become mentally incapable to provide consent.

If the patient/ resident refuses to discuss the possibility that they may need an SDM, advise the patient/ resident who would be their automatic SDM so that they will be aware of who would be called upon to make decisions for them if they are incapable for treatment decision making.

3. WHO CAN ACP – PATIENT/ RESIDENTS ONLY WHEN CAPABLE

Does the facility guideline make it clear that only patient/residents when capable may ACP and that SDMS cannot ACP for an incapable patient/resident? Does the guideline help staff understand the difference between ACP and consent?

REMEMBER

Patient/residents, if capable for treatment, must provide consent or refusals of consents to treatment but they do not have to ACP. If the patient/resident is incapable, SDMs must give or refuse **consent to treatment**. SDMs **cannot do ACP for the incapable patient/resident**.

Note that SDMs may provide consent/refusal of consent to the withholding or withdrawal of treatment **IN LIGHT OF THE PERSON'S PRESENT HEALTH CONDITION**. In these circumstances, the SDM is not doing ACP but is giving or refusing consent to treatment

See definition:

Plan of Treatment HCCA s 2(1)

- developed by one or more Health practitioners
- deals with one or more of health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and
- provides for the administration to the person of various treatments or courses of treatment and may, in addition, provides for withholding or withdrawal of treatment in light of person's current health condition.

PLANS OF TREATMENT MUST BE GROUNDED IN THE PATIENT'S PRESENT HEALTH CONDITION and these can be consented to – These may include Goals for Care and consent to withholding and withdrawal of treatments.

4. HOW SDMs MAKE TREATMENT DECISIONS ON BEHALF OF A PATIENT/RESIDENT WHO IS INCAPABLE

Does the facility guideline reflect how what the SDMs are supposed to make decisions on behalf of a patient/resident when that patient/resident is not capable at the time a treatment decision needs to be made? Does the guideline explain how SDMs are to apply the patient/resident's wishes, values and beliefs when making decisions for the patient/resident?

 **REMEMBER**

if a patient/resident, when capable, has expressed wishes about future care, then the SDM must follow these wishes, however expressed, when making decision about care.

Wishes may be expressed ORALLY, in WRITING, or Communicated by alternative means.

If no applicable wishes were expressed when the patient/resident was capable, the SDM must make decisions in the patient/resident's best interest (including considering the patient/resident's values, beliefs and any other wishes expressed by the patient/resident)

Does the guideline explain what are "best interests" as defined in the *Health Care Consent Act*?

HCCA s21 (2) BEST INTERESTS

SDM to consider:

- a) values and beliefs
- b) other wishes (i.e. expressed while incapable)
- c) whether treatment likely to:
 - i) improve condition
 - ii) prevent condition from deteriorating
 - iii) reduce the extent or rate of deterioration
- d) whether condition likely to improve or remain the same or deteriorate without the treatment
- e) if benefit outweighs risks
- f) whether less restrictive or less intrusive treatment as beneficial as treatment proposed

The SDM is the "interpreter" of the patient/resident's wishes, values and beliefs and must determine:

- whether the wishes of the patient/resident were expressed when the patient/resident was still capable (and were expressed voluntarily);
- whether the wishes are the last known capable wishes;
- what the patient/resident meant in that wish;
- whether the wishes are applicable to the particular decision at hand; and,
- If there are no applicable/capable wishes, how the patient/resident's values, beliefs, and incapable/inapplicable wishes would apply to the patient/resident's best interest.

5. DUTY OF HEALTH PRACTITIONERS

Does the guideline/ policy remind the health practitioners that it is their responsibility to explain to the SDM that when the SDM is making treatment decisions for the incapable patient / resident that the SDMs must make decisions for the patient/resident

a) by following the patients wishes, expressed when capable, if they know of these wishes, and

b) if there are no applicable wishes, that they have to make decisions in the best interests of the patient (as described in #4 above).

★ REMEMBER

This responsibility was confirmed in the Decision of the Ontario Court of Appeal in *M. (A.) v. Benes, 1999 CanLII 3807 (ON CA)*

“ s. 10(1)(b) of the Health Care Consent Act imposes a statutory obligation on health practitioners to ensure that substitute decision-makers understand the criteria specified in s. 21 of the Act when deciding whether consent to a proposed treatment should be given or refused”.

5. EMERGENCY RESPONSE BY STAFF WHEN NO TIME TO CONSULT WITH CAPABLE PATIENT/RESIDENT OR SDM OF INCAPABLE PERSON

Does the facility guideline make it clear what to do if an emergency occurs?

What if no wishes of the patient/resident are known that apply to the emergency?

What if the staff think the patient/resident DID express wishes that could apply to the emergency?

★ REMEMBER

If no wishes applicable to the emergency are known, then the staff do not need consent to provide treatment to the patient/resident.

If wishes of the patient/resident or consent/refusal of consent of an SDM to treatment are known, the staff should follow the wishes expressed/consent/refusal of consent previously given in the plan of care in the emergency.

6. HOW AN ADVANCE CARE PLAN MAY BE EXPRESSED

Does the facility guideline make it clear that an Advance Care Plan may be ORAL, written, or communicated by some alternative means (i.e. communication board)? Does the guideline explain that any advance care plan, however expressed is primarily a communication to the patients SDM and not directions to staff except in an emergency when an informed consent cannot be obtained?

Does the guideline direct staff on how to record oral wishes so that these will be known by any staff if an emergency occurs, the patient/resident is incapable, and there is no time to consult with the patient/resident's SDM?

★ **REMEMBER**

ACP can be done in many different ways and that forms are not necessary to do ACP. Facilities cannot require patient/residents to use a particular form. Facilities need to have staff that understand how to identify the proper SDM for a patient/resident if he/she should become incapable and to identify what is a valid POAPC. This needs to be communicated other staff providing care to that patient/resident.

Staff need to understand that any wishes expressed by a patient/resident when capable are directions to his/her SDM and that despite the presence of documents that contain wishes that the staff must still seek consent/refusal of consent from the patient/resident if capable or from the patient/resident's SDM if the patient/resident is incapable

Staff need to understand that a capable person may change their advance care plan orally even if the previous advance care plan had been recorded in a written form. The later oral statements expressed by the patient/resident when capable override the previous written advance wishes.

7. COMMUNICATION

Does the facility guideline indicate how staff are to record the oral wishes (or wishes communicated by other means than in writing) on the chart so that information is available for all staff in an emergency?

★ **Remember**

Last capable wishes, in whatever form expressed, are what are to be followed by the SDM and by staff in an emergency. These wishes may be expressed orally even if the patient/resident previously did a written advance care plan.

Does the guideline direct how a capable patient/resident's wishes are communicated to the person who would act as SDM for that patient/resident in the future?

★ **REMEMBER**

The facility does not have to be the communicator of these wishes but the capable patient/resident should be encouraged to talk with his/her future SDM so that the SDM is aware of the patient/resident's wishes should the SDM need to act as that patient/resident's decision maker.

8. CONFLICT

Does the facility guideline outline the options of what could be done if there is a conflict on health care decision making about care between:

- (a) a capable patient/resident and his/her SDM?**
- (b) Between multiple equally ranked SDMs?**
- (c) Between a health practitioner and a SDM?**

Does the guideline indicate the various applications that can be done to the Consent and Capacity Board either by SDMs, or by health providers at the facility to assist when conflicts arise? Does the guideline provide the information on where to get the information on how to do these applications and where to call to start one?

REMEMBER

A capable patient /resident makes his or her own treatment decisions. That capable resident/ patient may want to confer with others, their family, friends and future SDM, about their care before making a decision but in the end he or she makes that decision to give or refuse consent.

Even if the patient/resident has appointed an SDM by preparing a POA Personal Care, that person who is the attorney named in the POAPC does not get any authority for decision making for any personal care decisions, including for treatment, until the patient/resident is incapable. .

If there are conflicts between the capable patient/ resident and his or her future SDM, the patient/resident may want to appoint a new SDM by preparing a new POAPC. That new SDM who is the new attorney in a POAPC then trumps any of the automatic SDMs in the hierarchy list except a Guardian of the Person and would trump the previous attorney in the old, now revoked, POAPC.

If there is conflict between equally ranked SDMs who are acting for the incapable patient/resident, they must decide amongst themselves how to resolve the conflict.

If they fail to resolve the conflict, the health practitioner may turn to the Public Guardian and Trustee for the treatment decision for the incapable patient/resident. Advising the equally ranked SDMs that can't agree that the law provides that the health practitioner may turn to the OPGT for the treatment decision may act as an impetus to the feuding SDMs to find a compromise. That compromise may be them all agreeing to one decision on the treatment or some of them bowing out as SDMs, leaving one or two of the remaining SDMs equally ranked to work together to make decisions for the patient/ resident.

If there is conflict between a health practitioner and an SDM about a treatment proposal for a patient/resident, if the conflict cannot be resolved, and the health practitioner believes that the SDM is not acting in accordance with the patient/ residents previously expressed wishes or in the patient/ residents best interests, the health practitioner may apply to the Consent and Capacity Board for the Board to review whether the SDM is making decisions for the incapable patient/resident in compliance with the *Health Care Consent Act*.

In making their decision, the Board may direct the SDM to consent to the treatment proposed by the health practitioner. If the SDM refuses to comply, the Board will direct the health practitioner to turn to the next highest ranking SDM for the decision.

9. CULTURE AND RESPECT

Does the guideline indicate how to address cultural issues - such as how to comply with the *Health Care Consent Act* yet respect the desire of some people to have family decide for him/her even when the patient/resident is mentally capable? Or how to address the request of a family that directs that no information about the patient/resident's health condition be given to him/her although the patient/resident is mentally capable and the law requires that the patient/resident give an informed consent/refusal to treatments?

REMEMBER

In both instances, the health providers must still get consent from the individual, not family and cannot refuse to give information to the individual but both situations can be “managed” within the context of the *Health Care Consent Act* -- do staff understand how to do this respectfully?

10. WHO SHOULD DO ACP WITH CAPABLE PATIENT/RESIDENTS

Does the facility guideline make it clear that ACP can be done at any time by a patient/resident when he/she is mentally capable? Does the guideline reflect how this can be facilitated when a patient/resident is ready to do this?

Does the guideline help staff identify what to do if a patient/resident wants to do advance care planning?

REMEMBER

There are many different ways of organizing staff to support ACP. Some facilities may want all staff to be able to respond to questions about ACP and to know how and when to record wishes however expressed. Some facilities may want particular staff to be

more knowledgeable about ACP and be a key resource to patient/residents and their families. However even if organized in this fashion, does the guideline assist other staff in knowing what to do if a patient/resident wants to discuss wishes about care with them instead of the "designated staff"? Or wants to talk to others external to the facility about ACP? Does the guideline indicate how a capable patient/resident's wishes could be communicated to the facility to ensure that these wishes will be followed in an emergency and will be known by the appropriate future SDM?

Note to the Reader:

This is a first effort at creating a template to help guide people who are drafting various types of policies/ practice documents/ forms of things to think about when preparing their own documents related to Informed consent and Advance Care planning.

This is just a start and is not complete. Other information about consent and about advance care planning could be added to this document to act as a prompt for drafters of documents and policies and forms. For example, information on HOW to have a conversation to get an informed consent or how to have the conversation to prepare an advance care plan could be added. Information on what is capacity and how to assess capacity for treatment could be added.

I invite anyone using this template to send me YOUR ideas for additions. Or send me your comments on what should be removed.

Think of this as a “living” document that will benefit from YOUR input.

Send any comments, ideas for additions, critiques of the content to:

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Put the words TEMPLATE REVIEW in the Subject Line.

Anything sent to me will be considered for use in the next version of this template. Credit will be given on the document if the comments results in changes or additions.