



# Advance Care Planning and Goals of Care Discussion Guide for Healthcare Providers

## Advance Care Planning

A guide for making healthcare decisions  
with loved ones and healthcare providers



**CONVERSATIONS MATTER**

**Plan your healthcare together**

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# Personal Notes

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### Yes/No interrogative questions that encourage talk

- “Do you have something else to add to what we’ve talked about?”
- “Has a doctor or nurse told you about advance care planning?”
- “Would you like to learn more about advance care planning?”
- “Have you chosen a substitute decision maker?”
- “Does what I said make sense?”
- “Do you have some questions?” or “Do you have questions?”
- “Have you talked with your family about what care you want?”
- “Are you willing to be treated in the intensive care unit?”

- Negatively polarized questions are not ‘bad’ questions. They can serve a purpose when used intentionally.
  - If you are attempting to learn specific facts about a situation or it is necessary to wrap up a conversation, including negative polarity items in your questions can fast track the talk.

### Yes/No declarative questions seeking (dis)confirmation

- “Your doctor explained your illness to you?” ..... “Yes”
- “That medicine helped your pain?” ..... “Yes”
- “Your family knows your healthcare wishes?” ..... “Yes”
- “No questions for me now?” ..... “No”
- “You haven’t completed a personal directive yet?” ..... “No”
- “You’ve never been admitted to the ICU?” ..... “No”
- “You don’t have any pain right now?” ..... “No”
- “You haven’t completed a personal directive yet?” ..... “No”
- “You’ve never been admitted to the ICU?” ..... “No”
- “You don’t have any pain right now?” ..... “No”

## Introduction

The purpose of this guide is to provide evidence-based best practices for engaging in advance care planning (ACP) and goals of care discussions with older and/or seriously ill patients and their loved ones. The focus is on *functional ACP talk*. That is, talk that promotes patients/loved ones engagement in and understanding of ACP through both talk and body language.

This guide is organized into sections of the essential elements or topics of functional ACP talk. Each section contains:

- main points for discussion
- illustrative examples of ACP talk.

It is not necessary to follow the sections in a particular order, rather to address the section(s) that is/are most appropriate at a particular moment. The sections allow the essential elements of the ACP process to build upon each other. The sections can be discussed in one or two longer consultations, or over a series of shorter consultations.

During consultation(s), healthcare providers are encouraged to identify potential areas of conflict such as patients who have unrealistic expectations or expectations that do not align with their values or beliefs.

We recommend the use of ACP information materials as part of the conversations. Information materials provide the patient/loved ones with

- a visual aid to assist them during the conversation,
- a resource to take home to remind them of what was discussed, and
- a guide that can assist them to talk with their loved ones.

This booklet is intended to be a guide for ACP conversations, not a script. Although examples of talk are provided, conversations with each patient should be organic (i.e., talk should be adapted to the patient and the situation).

**Appendix A contains general tips for having ACP conversations and asking questions.**

**TIP: With practice comes competence.  
With competence comes comfort.  
With comfort comes confidence.**  
*(Anonymous)*

## Tips for Asking Questions

Question design can significantly impact the functionality of talk. When questions are designed to achieve a goal, the conversation will flow with fewer derailments from the topic. Below are explanations and examples of how to design your questions to meet a specific goal.

### Focus on Open Ended Questions:

#### Open ended questions

“What is important to you in your life right now?”  
“What was it like for you the last time you were in hospital?”  
“How have you been feeling since the last time we met?”  
“How does your family feel about you not wanting surgery?”  
“Please tell me about your family.”  
“Please tell me more about how that made you feel.”

- It is best to avoid using ‘why’ questions as they usually come across as accusatory. With some thought, all ‘why’ questions can be reframed as ‘how’ or ‘what’ questions.

### Yes/No Interrogative Questions

- The words ‘any,’ ‘ever,’ ‘at all,’ “no,” “never,” and “not” are called *negative polarity items*; they will usually encourage someone to answer ‘no’ and not elaborate on the answer even if he/she has something to add.
- The word ‘some’ is a *positive polarity item*; it will usually encourage someone to answer ‘yes’ and provide elaboration.

- ❖ Respond to emotion by verbalizing empathy
  - “I cannot imagine how difficult this must be for you right now.”
  - “I admire your determination to fight this.”
- ❖ Minimize the use of medical jargon. If a medical term is used, follow with a lay-person description. Then ask the patient if he/she understands.
- ❖ If the patient goes off topic, allow him/her to complete his/her thought, then acknowledge the contribution before gently redirecting the conversation.
- ❖ Summarize what you have heard (i) before going onto another topic and/or (ii) at the end of your consultation. This assesses and reinforces mutual understanding of what has been discussed.

Wasylynyuk, B. A. & Davison, S. N. (2016). Advance care planning in advanced chronic kidney disease: Practical communication tips for clinicians. *Canadian Association of Nephrology Nurses and Technologists Journal*, 26(3), 20-25.

## Introducing ACP to Patients

Some patients will provide a natural lead in to ACP by telling you about a healthcare experience he/she or someone he/she knows had that concerned him/her.

### Example of talk:

Patient: My daughter had a serious illness and it was awful watching them do all those painful things to her. I don't want any of that.

HCP: You don't have to go through your daughter's illness journey. Most people, when they hear of a serious illness, think about the things that people they love went through. I want to provide you with the best possible care and make sure that you receive the care that you want. We can plan your healthcare together with something called advance care planning. (pause)

Advance care planning helps you to understand what healthcare options are the best for you. Together we can decide how you want to be cared for. (pause)

I would like to tell you more about advance care planning. Would that be okay with you?

### **Main points:**

- You want to provide the patient with the best possible care and you want to give the patient the care he/she wants.
  - ❖ These points together reassure the patient that you are there for him/her and that you care about his/her goals for care.
- ACP is open to all capable adults.
  - ❖ This helps to normalize the talk so the patient does not feel targeted.
  - ❖ Assessing capacity is beyond the scope of this guide.
- ACP aids patients in understanding what healthcare options are best suited to their goals of care.
- You want to tell the patient about ACP, followed by a positively worded request for acceptance.
  - ❖ Please refer to Appendix A: Tips for asking questions.

### **Explaining ACP**

When explaining ACP, it is helpful to give patients/loved ones ACP written materials to follow along with during your conversation and be able to take home to share with their loved ones.

### **Main points:**

- ACP
  - ❖ is a process that helps people to think about and talk about their goals for future healthcare should they be unable to speak for themselves.
  - ❖ helps people to create and put into place plans to describe the type of care they want.
  - ❖ is a gift people give to others. There is a lot less stress if their loved ones and healthcare providers know what care they want rather than having to guess.

- ❖ If the patient cries, offer a tissue, move closer to patient and use gentle touch (if patient comfortable with same).
- ❖ Be present in the moment by demonstrating you are actively listening (e.g., nod, say uh-huh, hmmm).
- ❖ Listen without interrupting; be comfortable with silence.

### ➤ **Verbal Communication Skills**

- ❖ Speak slowly and clearly in a tone that is friendly and comforting rather than business-like.
- ❖ Frequently insert pauses in your talk (count to four to yourself) to allow the patient time to reflect on what has been said and ask questions or make comments.
- ❖ Ask open ended questions. Open ended questions elicit responses that are often descriptive and elaborative. They provide opportunities to draw further questions from. Please refer to the section on page 37: “Tips for asking questions.”
- ❖ Explore the meaning of ambiguous words and phrases
  - “I don’t want to be a vegetable.” Ask: “What does being a vegetable mean to you?” or “What does being a vegetable look like to you?”
  - “I don’t want to be a burden.” Ask: “What do you mean by being a burden?”
  - “I want to die with dignity.” Ask: “What does dying with dignity look like to you?”
  - “I don’t want heroics.” Ask: “What do you mean by heroics?”
  - “Just pull the plug.” Ask: “What plug are you referring to?”
- ❖ Frequently paraphrase what you have heard. This shows you are listening but also ensures you have correctly understood what the patient said
  - “So what you are saying is.....is that correct?”
  - “It sounds like what you are saying...Did I get that right?”

- Ensure that patients have enough information to make informed choices for their care, but try to avoid overburdening them with too much information (e.g., information that is not compatible with their personal goals for care).
- Acknowledge and support patients' hopes whenever possible. Although you may not always be able to promise certain outcomes, you can promise that the HCPs caring for them will always be there to help and support them. This translates into reassurance that they will not be abandoned in a time of need.
- Try to find appropriate places in your conversation to share laughter. Laughter helps develop rapport and an atmosphere of normalization. It may also help relieve tension.

### Strategies to Enhance ACP Communication Skills:

- Take a few minutes at the beginning of the conversation to establish a relationship with the patient/loved one(s). Ask a few questions about him/her as a person in the context of his/her core network of loved ones/friends, not just a patient.
- **Non-Verbal Communication Skills**
  - ❖ Non-verbal communication can speak louder than words.
  - ❖ Sit facing the patient at their height maintaining a reasonable distance (about 1 meter).
  - ❖ Try to look relaxed and unhurried by maintaining an open and relaxed posture; do not fidget.
  - ❖ Remove obstacles between you and the patient (e.g., tables, electronic devices).
  - ❖ Make eye contact. Observe patient for cues suggesting they are uncomfortable with eye contact (e.g., gazing away).
  - ❖ When appropriate, gently touch the patient's hand, arm or shoulder to demonstrate that you care. Observe for cues suggesting patient is uncomfortable with touch (e.g., withdrawing hand/arm).

- Some people are able to guide their care right up until they die – other people are not able to speak for a period of time (e.g., they may be unconscious, in a coma, had a stroke, or have advanced Alzheimer's). In situations like these, it is best to have healthcare plans in place to allow someone else to speak for them so their voice is heard.
- It is best to do ACP when someone is feeling able rather than during a crisis.
- ACP is voluntary. Healthcare providers are there to give information, answer questions and help with the process.

#### Example of talk:

Advance care planning helps you to think about, talk about and document your wishes for healthcare should you ever be in a situation where you were unable to speak for yourself. (pause)

None of us know what life may throw at us. By planning ahead, at least our loved ones and the healthcare team know what we want if something were to happen. This can help relieve stress and anxiety, especially for our loved ones. (pause)

No one can make you do advance care planning. I am here to give you information, answer your questions and help you with the process. It's something you choose to do.

Do you have questions about what I have said so far? (pause)

## Outlining the ACP Process

### Example of talk:

I would like to take a couple of minutes to first give you a brief overview of what's involved in the advance care planning process. Is that okay with you? (pause)

We may end up meeting several times to talk about the different parts of the advance care planning process. Please feel free to invite people important to you to join our talks. (pause)

Each time we talk we'll build upon what we discussed before. If you have questions about something, please feel free to ask whenever you like. Okay? (pause)

We'll start by talking about what's important to you in your life and how those things can influence the type of healthcare you want. (pause)

Then we'll discuss how to go about deciding on a substitute decision-maker. A substitute decision-maker is someone who will speak for you and help us hear your voice if you can't speak for yourself. (pause)

We'll talk about the care options we can offer you and you'll decide what's going to be helpful to you to achieve **your** goals for a life worth living. (pause)

Over time, we'll revisit your healthcare goals to make sure that they still reflect your wishes. Nothing is set in stone. You can change your wishes. (pause)

It's my hope that through this process we'll work together so you can feel comfortable that you'll get the care you want while you're ill or injured, or until you die.

Do you have questions for me before we get started?

## Appendix A

### Tips for ACP Conversations and Asking Questions

#### Key message:

Older and seriously ill patients and loved-ones tend to be more involved/engaged in the ACP process when the communication style is conversational rather than an interview or an information session.

#### Points to consider:

- Say the terms 'advance care planning' and 'goals of care' several times during your conversation. These terms are often unfamiliar and repetition will help patients become more familiar with the terminology.
- Find ways to incorporate information given by the patient into your talk about the ways in which the ACP process can help him/her to achieve his/her personal goals for care.
- Focus more on what can be done to meet their goals for care and to make their life worth living rather than on what you cannot do for them.
- Take time to (a) reassure them that you are there to support them and their loved ones, (b) tell them that they are important to you, and (c) work to create a sense of community of care in which the patient is at the core (e.g., you will follow up with other involved healthcare providers to ensure plans for care have been communicated).
- Praise them for the steps they have taken toward completing components of the ACP process.
- Let the patient know that the ACP process is about working to help him/her to achieve his/her goals for care.



## Personal Notes

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## Explore the patient's current health condition

### Main points:

- Exploring how the patient interprets his/her health condition and what questions he/she has about their health can help you to frame later conversations about goals of care. Possible approaches:
  - ❖ “Please tell me about your current illness.”
    - This general approach provides healthcare providers with an opportunity to (i) identify knowledge gaps in the patient's understanding of their illness (ii) offer further information and resources and (iii) discuss treatments, expectations and outcomes.
  - ❖ “How have you been doing for the last while?”
    - This general approach allows the patient to discuss physical concerns and psychosocial issues (this tells you what is most salient to him/her at the time and aids in understanding the patient's perspective). The indeterminate time frame allows the patient to set parameters.
  - ❖ “Where do you see things going with your illness?”
  - ❖ “What concerns do you have about your health?”
    - The question assumes the patient has concerns. This is a fair assumption given that you are likely talking to seriously ill and/or older adults. If the patient does not have concerns, he/she will say so.
  - ❖ “Is there some health information you would find helpful?” or “What health information would you find helpful?”
    - This approach gives the patient an opportunity to express expectations, such as prognosis and healthcare options.

## Ongoing Maintenance

### Main points:

- Patients can talk to you or any healthcare provider if they have questions about ACP and/or GCD
- Goals of Care Designations are fluid; they can change as a patient's health condition changes. Therefore, a patient's GCD order should be reviewed on a regular basis, but especially when the patient
  - ❖ requests to have it reviewed or changed,
  - ❖ has had a significant change in their medical condition,
  - ❖ is seen in the emergency department,
  - ❖ is admitted to hospital or other care facility, or
  - ❖ has been transferred from one care facility to another.

### Example of talk:

Your Goals of Care Designation can change over time. It is important that your designation is always up-to-date, so you get the care you want at all times. Therefore, healthcare providers will be reviewing your designation with you, especially if your health condition changes or if you've been transferred or admitted to another healthcare setting. Of course, you can always ask your healthcare providers to review your designation with you at anytime, or have them answer questions you may have. (pause)

Do you have some questions for me?

## Advance Care Planning Tracking Record

### Goals of Care Discussions

You may wish to show the patient/loved ones the Advance Care Planning Tracking Record Goals of Care Discussions document.

#### Main point:

- The purpose of the Tracking Record is to document the decision/next steps/ outcomes of discussions related to ACP and GCD.
- Any member of the interdisciplinary team may initiate or participate in discussions related to ACP and/or Goals of Care and thus are expected to document their discussion(s) on the Tracking Record.
- The original Tracking Record is kept in the patient's Green Sleeve to allow easy access for healthcare providers to document goals of care discussions.

#### Example of talk:

The Tracking Record communicates the discussions you have had with healthcare providers as they relate to advance care planning and goals of care. This way healthcare providers will know the decisions you have made. They will also know who was involved in the discussion(s) leading up to your decision. However, you may still be in the process of making a decision and in that case, healthcare providers will know what has already been discussed with you and can continue the conversation where it left off without having to start it all over again. (pause)

Do you have some questions?

- Paraphrasing the patient's talk and asking for confirmation of your interpretation is a good way to ensure your understanding.
  - ❖ “It sounds like you are not too sure why your kidneys are not working properly anymore and that you would like to know more about what to expect down the road as they continue to worsen. Is that correct?”

#### Example of talk:

It's also important for me to learn about your health. How have you been doing for the last while? (pause)

It sounds to me like you have concerns about (XXXX). Please tell me more about that. (pause)

Is there some health information you'd find helpful?

## Explore the patient's values, goals and beliefs on living well

### Main points:

- Learning what living well means for the patient can help the healthcare provider discuss treatment options which will achieve the patient's goals for living well. Possible approaches include the following:
  - ❖ “Please tell me what gives your life purpose or meaning?”
  - ❖ “What makes you happy in your life right now?”
  - ❖ “What things must you be able to do to have quality of life? If you couldn't do these things, how would you feel?”
  - ❖ “What are your most important goals if your health condition worsens?”
  - ❖ “What are your biggest fears or worries about the future with regards to your health?”
  - ❖ “Are there religious, spiritual or cultural beliefs that are important to you? How do these beliefs influence your healthcare wishes?”
  - ❖ “Who or what helps you get through difficult times in your life?”
  - ❖ “How has your illness changed your life?”

### Example of talk:

The Green Sleeve holds all your advance care planning and goals of care documents. You are to take it with you when you go to your medical appointments, or if you go to the hospital. (pause)

It's important that you keep your Green Sleeve on or near your fridge because that's where emergency response people are trained to look for it. (pause)

If an ambulance or anyone takes you to the hospital, your Green Sleeve needs to go with you. If emergency response people can't find your green sleeve, healthcare providers at the hospital may give you care you don't want. (pause)

The hospital will put your Green Sleeve in your chart. It will be returned to you when you are discharged. If by chance it is left behind, the hospital will mail it back to you. (pause)

Do you have questions about the Green Sleeve?

## Green Sleeve

Give the patient/loved ones a Green Sleeve to see what it looks like.

### Main points:

- The Green Sleeve is a portable document holder to help patients manage their Advance Care Planning and GCD documents.
- The documents ensure that all healthcare providers have access to important decision related to the patient's goals of care and guidelines for direction of interventions that have been discussed with the patient.
- The Green Sleeve usually contains the following:
  - ❖ GCD Order, when one exists.
  - ❖ Advance Care Planning Tracking Record Goals of Care Discussions.
  - ❖ Personal Directive (copy), if one exists.
  - ❖ Guardianship Order, if one is in place for the individual.

### Example of talk:

Part of advance care planning is thinking about what's important to you. What gets you out of bed in the morning? Please tell me about the important people and things in your life. (pause)

It sounds to me like you are an independent person and that staying independent is very important to you. Is that how you see yourself? (pause)

It would be good to make sure that your family and healthcare providers understand what's important to you. You may want to plan your future care so you can stay as independent as possible. As we go through the advance care planning process, we can talk more about how best to do that for you.



**Example of talk:**

I want to spend some time talking with you about CPR or Cardiopulmonary Resuscitation. CPR is an emergency procedure used when a person's heart or breathing has stopped. It includes pushing on their chest, electrical shocks to their heart and putting a breathing tube down into their lungs and hooking them up to a breathing machine. (pause)

People often think CPR is more successful and less harmful than it really is. CPR works best in people who are young, healthy and when the procedure is started right away. It does not work so well in people who are older, weaker, have a chronic health condition such as kidney disease or kidney failure or when the procedure is not started right away. Studies have shown that for patients with kidney disease, the chance of surviving CPR is about 1 in 10 (10%). For patients on dialysis, the chance of surviving is even lower. Studies have also shown that for patients surviving CPR, only a quarter of them will return home to the life they knew. The others will either need help at home or will need to move into a nursing home. (pause)

Do you have questions about what I have just said?

If CPR works to restart the heart and breathing, there are usually serious side effects. The person may be on a breathing machine for a long time. The person may be left with brain injuries if not enough oxygen gets to their brain. Severe brain injuries are seen in about a half (25–50%) of CPR survivors. Pushing down on the chest may cause ribs to break. The person may be left in a worse health condition than before their heart or breathing stopped and as a result, may never be able to return home again. (pause)

We want to provide you with the best possible care that will allow you to achieve your goals for living well and dying well. (pause)

Do you have some questions for me?

What are your thoughts about CPR?

- Sometimes patients' healthcare experiences and/or those of others cause them to feel anxious or afraid. Take time to reassure patients that they will be provided with care and that healthcare providers will work to help them achieve their goals for their own care.

**Example of talk:**

I believe that the life experiences that you've had are important. You've lived them and you may have seen what choices other people made in different situations. Those situations can inform you about what you might want for your care. Does that make sense to you? (pause)

Do you have life experiences that make you think about the type of healthcare you'd want?

**Clarify goals for life-sustaining preferences****Main points:**

- Discussions around clarifying goals for life-sustaining preferences can only occur after the previous three ACP elements have been explored with the patient. Only then will the healthcare provider be able to help patients weigh the benefits/burdens of life support/prolonging treatments and recommend the treatments that align with the patient's goals for living and dying well.
- Inquire what the patient and their loved ones understand about life support, life prolonging treatments, and the Intensive Care Unit (ICU).
  - ❖ Often patients and loved ones are unaware what these treatments are, what they involve, and how they may impact the patient's life.

- ❖ Life support and life prolonging treatment replaces or supports critical bodily functions. The treatments are intended to keep patients alive, not to cure the underlying condition. Treatments can include the following: breathing machine, cardiopulmonary resuscitation (CPR), feeding tube, artificial hydration, blood transfusions, antibiotics, dialysis and major surgery.
- Discuss hypothetical scenarios having different potential health outcomes (e.g., physical impairment, cognitive impairment, coma).
  - ❖ Health outcomes are generally what are most important for patients; therefore discussions about outcomes help patients clarify their decisions around treatment choices.
  - ❖ Explore what would be an acceptable health outcome?
  - ❖ Explore what would be an unacceptable health outcome?
- Discuss benefits/burdens of treatment choices and how treatment choices can achieve an acceptable health outcome.
- Use themes identified during previous discussions to reiterate the patient's values and goals.
- Ensure treatment choices are consistent with the patient's expressed goals for living and dying well.
- For a discussion around CPR, please refer to "Example of Talk" on Page 26.

- For further information about the GCD, please refer to Side B of the GCD Order form and/or AHS Advance Care Planning and Goals of Care Destination Policy and Procedure.
- The earlier discussions around exploring the patient's values, goals and beliefs, their past health experiences and discussions around clarifying goals for life-sustaining treatments should assist the healthcare provider to focus on the approach for care that aligns with the patient's wishes.
- Patients should tell all healthcare providers caring for them that they have a GCD order and a personal directive.

**Example of talk:**

The next type of care is what we call Resuscitative Care. The pamphlet describes Resuscitative Care as (read description). (pause)

Resuscitative Care focuses on extending or preserving a person's life by using any medical or surgical interventions and, if needed, resuscitation and admission to an Intensive Care Unit. (pause)

If we don't know what a person's healthcare wishes are, healthcare providers tend to do everything possible to revive the person in the event of an emergency. However, this may not be what that person wants; especially if it's not likely they will do well or survive. Therefore, it's really important that we know what a person wishes so they aren't put into a situation they wouldn't have wanted.

Do you have questions about Resuscitative Care?



### Example of talk:

The next type of care is what we call Comfort Care. The pamphlet describes Comfort Care as (read description). (pause)

Comfort care is care and treatment focused on controlling any symptoms and making sure people have the best possible quality of life for the time remaining. It's also about caring for people at the end of their life and making sure they have a comfortable and dignified death in the location that they want. Comfort care includes emotional and spiritual support for the person and those close to them. (pause)

Comfort Care is offered in many places – people's homes, the hospital or in a hospice. A hospice is different from a hospital in that it has a gentler and calmer atmosphere, feeling much like a person's home. Hospices have a specialized team that works with the person to improve their quality of life and ensure that the remainder of their life is not journeyed alone.

Do you have questions about Comfort Care?

- **Resuscitative Care** has three designations that are based on the intensity of interventions appropriate for the patient.
  - R1:** The patient is expected to benefit from and is accepting of any appropriate investigations/interventions that can be offered including attempted resuscitation and ICU care.
  - R2:** The patient is expected to benefit from and is accepting of any appropriate investigations/interventions that can be offered including attempted resuscitation, intubation and ICU care, but *excluding* chest compressions.
  - R3:** The patient is expected to benefit from and is accepting of any appropriate investigations/interventions that can be offered including attempted resuscitation and ICU care, but *excluding* chest compressions and intubation.

Alberta Health Service. (2014) Goals of Care Designation-Guide for Clinicians

### Example of talk:

I'm going to describe some situations that could happen if your kidney failure gets worse. Discussing your thoughts about each situation will help you make choices that reflect what is most important to you. This will guide your care if you cannot speak for yourself. You can change your choices any time in the future. Do you have some questions before I begin?

Imagine, you have a serious health event that has left you unable to speak and your substitute decision-maker needs to make an immediate medical decision about using life-sustaining treatments. Doctors believe you have a good chance of living through this event. You expected outcome is:

- You will never be able to care (walk, dress, bath, toilet) for yourself again once you recover. (pause)

Would you want life-sustaining treatments to prolong and preserve your life, because it is the quantity of life that matters most to you no matter what? (pause)

Or would you want to allow a natural death to occur because your comfort and quality of life is what matters most to you? (pause)

Repeat substituting the above situation with the following outcome:

- You will have permanent and severe brain damage (you will be able to open your eyes, but unable to speak or understand).
- You will be in a permanent coma from which you are not expected to recover from and you will have brain damage.

If your heart suddenly stops beating, would you want CPR attempted?

## Identity a substitute decision-maker

### Main points:

- A substitute decision-maker is someone the patient trusts to speak and make healthcare decisions on their behalf if they are unable. The substitute decision-maker should be the person with the most knowledge of the patient's healthcare wishes and who understands the patient's values, beliefs and goals. Following are some important characteristics of a substitute decision-maker:
  - ❖ Must be over the age of 18 years and have capacity to make healthcare decisions.
  - ❖ Must be willing to take on this responsibility.
  - ❖ Must be able to make healthcare decisions under stressful situations.
  - ❖ Must be able to honor the patient's wishes.
- Healthcare providers are encouraged to become familiar with their provincial/territorial legislation around the responsibilities of the substitute decision-maker.

### Example of talk:

Most people automatically go to family when considering who to ask to be their substitute decision-maker. However, there are some things you might want to consider.

Does this person do well in a crisis?

Are you able to discuss your wishes very openly with this person?

Will this person be able to follow your wishes and not their own? Does that make sense? (pause)

Do you have someone in mind who you would like to be your substitute decision-maker? (pause)

### Example of talk:

The first type of care I want to talk with you about is what we call Medical Care. In this pamphlet (show the patient a resource that explains Medical Care) it describes Medical Care as (read the description). (pause)

Another way to think about this is that some people say to us, 'I want to go to the hospital to get better, but if my health were to get very bad, I do not want life support treatments, nor do I want to go to an intensive care unit.' Other people say to us, 'If I am sick, I do not want to go to the hospital to get better. Instead, I want to get better receiving treatments in the place I am living.' This may be the person's lodge, long term care facility, or their home.

Do you have questions about Medical Care?

- **Comfort Care** has two designations with the main differentiating point being proximity to death:
  - C1:** Interventions and care are aimed at maximal symptom control and maintenance of function without cure or control of an underlying condition for which the patient is expected to die from (in the coming weeks to months). New illnesses are not generally treated unless control of symptoms is the goal.
  - C2:** Terminal care where care is directed at preparation for imminent death (usually hours to days) with maximal efforts directed on symptom control.

- There are three general approaches to care within the GCD.
  - ❖ **Medical Care:** Medical tests and interventions focused on curing or managing an illness but without the use of resuscitative or life support measures. This approach is appropriate when either resuscitative and life support measures will likely not be of benefit or when the patient chooses not to receive such treatment. Medical care can be provided in many locations, but does not include an ICU.
  - ❖ **Comfort Care:** Care and interventions focused on optimal symptom control and quality of life when cure or control of an underlying condition is no longer possible. This includes psychological and spiritual support for the patient and those close to them in anticipation of death. Care is provided in any location best suited for these aims, but does not include an ICU.
  - ❖ **Resuscitative Care:** Care and interventions focused on curing or managing the patient's condition. The patient would desire and is expected to benefit from attempted resuscitation and ICU care if required.
- **Medical Care** has two designations that are based on decisions about location of care:
  - M1:** Medical care that is offered in an acute care setting.
  - M2:** Medical care that is offered in the patient's current non-hospital location (i.e. supportive living facility, nursing home, private residence). If the patient does not respond to available treatments in this location of care, discussions should occur to change the focus to comfort care.

## **Encourage the patient to communicate with their substitute decision-maker and other loved ones**

### **Main points:**

- Stress to the patient that it is important that they
  - ❖ inform their substitute decision-maker that they have been chosen for this role.
  - ❖ explain to their substitute decision-maker what this role entails.
  - ❖ communicate their wishes for future healthcare in detail with their substitute decision-maker.
  - ❖ ensure the substitute decision-maker is willing and able to take on the responsibility.
- It is also important to stress to the patient that they communicate their wishes for future healthcare with other loved-ones. Their loved ones can then support the substitute decision-maker when carrying out the patient's wishes, thereby helping to avoid future conflict.
- Because wishes can change over time, the patient is encouraged to have ongoing conversations with their substitute decision-maker and loved ones so their wishes remain current and known.
- Explore any barriers to having these conversations with their substitute decision-maker and/or loved ones.
  - ❖ "Have you talked to your substitute decision-maker and your loved ones about your wishes for future healthcare?"
  - ❖ "How comfortable are you talking about this with your substitute decision-maker and loved ones?"

**Example of talk:**

I encourage people who are involved in advance care planning to have detailed talks with their substitute decision-maker and their family. It's important to make sure these important people know your healthcare wishes and that they have copies of your documents if they need them. (pause)

When talking with your substitute decision-maker, you can say something like, 'I've given it a lot of thought and if something happens to me and I can't communicate my wishes, I'd really like you to be my substitute decision-maker. That's the person who tells my doctors what type of care I want.

Are you willing to be my substitute decision-maker?'

Do you feel comfortable talking with the person you want to be your substitute decision-maker?

**Defining Goals of Care**

When defining goals of care, patients and their loved ones should be given written Goals of Care Designation (GCD) information materials.

**Main points:**

- Goals of care have two parts.
  1. A conversation with a healthcare provider about the patient's goals for what healthcare they want if they are unable to make a decision for themselves in the future.
  2. A doctor or nurse practitioner completes a GCD Order form and signs it.
- The GCD Order complements the Personal Directive.

**Example of talk:**

Part of advance care planning is deciding your goals of care. Goals of care are your way in communicating what healthcare best fits with how you want to be cared for. You can talk about goals of care with any healthcare provider. You don't have to wait for a healthcare provider to start the conversation. (pause)

We want to make sure that you know what care is available to you. That way you'll be able to choose treatments that are right for you. (pause) Does that make sense?

Part of goals of care is talking with a doctor or nurse practitioner about completing what we call a Goals of Care Designation form (show patient the form). This form tells healthcare providers what care you want if you can't speak for yourself and your agent is not with you. The Goals of Care Designation form goes along with your personal directive. It's really important to have both forms. (pause)

I'm going to talk with you about goals of care next, but first, do you have questions about what I've said so far?

**Personal Notes**

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