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WELCOME

Advance Care Planning & Goals of Care Discussions: Getting us all on the same page (plus practical tips!)

Host and Moderator: Dr. José Pereira

Presenters: Dr. Jeff Myers & Dr. Leah Steinberg

Housekeeping

- Your microphones are muted.
- Use the Q&A function at the bottom of your screen to submit questions. Please do not use the chat function for questions.
- This session is being recorded and will be emailed to webinar registrants within the next few days.

Conflict of Interest

Pallium Canada

- Non-profit
- Partially funded through a contribution by Health Canada.
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook.

Presenters

- Dr. José Pereira – Paid by Pallium Canada as Scientific Officer
- Dr. Jeff Myers – Clinical advisor for Hospice Palliative Care Ontario
- Dr. Leah Steinberg – Clinical advisors for Hospice Palliative Care Ontario

Presenters

Host and Moderator

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Presenters

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Learning objectives

At the end of the presentation, participants will be able to:

1. Outline the similarities, differences and relationship between ACP & GOCD
2. Understand how values can inform decision-making
3. Describe processes and communication tips for both ACP & GOCD
4. Explore a framework that clarifies ACP & GOCD in support of knowledge, skill and implementation

Acknowledgements

Dr. Nadia Incardona

Hospice Palliative Care Ontario ACP, GOC & HCC Leadership

There is a great deal of interest in improving experiences and getting ACP & GOCD right

There is recognition that these conversations matter

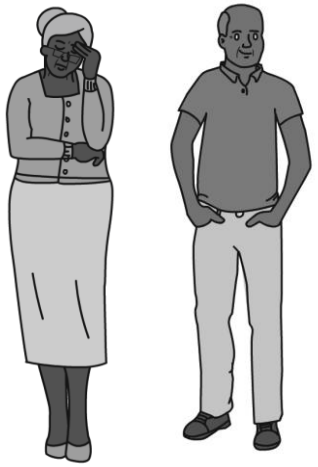
BUT…

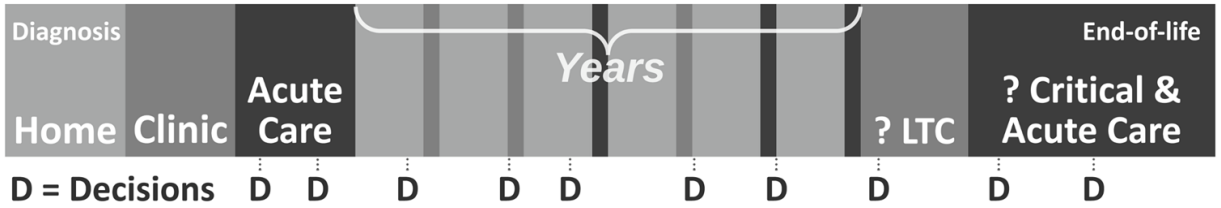
- A variety of terminology – clinical settings, educational contexts, literature, etc.
- Creates obstacles when individuals, teams, institutions try to apply them
- A framework that acts as a scaffolding for ACP & GOCD intends to support knowledge, skill & implementation

Meet Joe & his wife Sandy.

Joe was recently diagnosed with Parkinson's Disease.

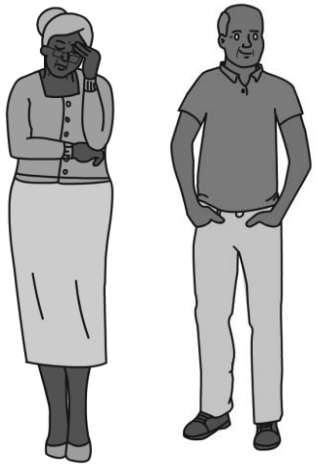
Sandi is Joe's substitute decision maker (SDM) and over the next few yrs, Joe & Sandi will interact with several clinicians in different settings.





Many care and treatment decisions will need to be made.

There's a good chance Joe & Sandi will not understand what having a serious illness means and will not be prepared for decision-making



Improving care & experiences requires teams to ensure both Joe **and** Sandi:

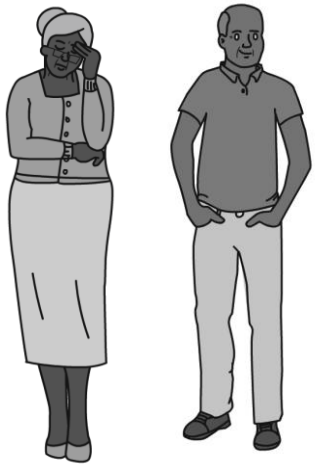
- understand Joe's illness
- are prepared for decision-making

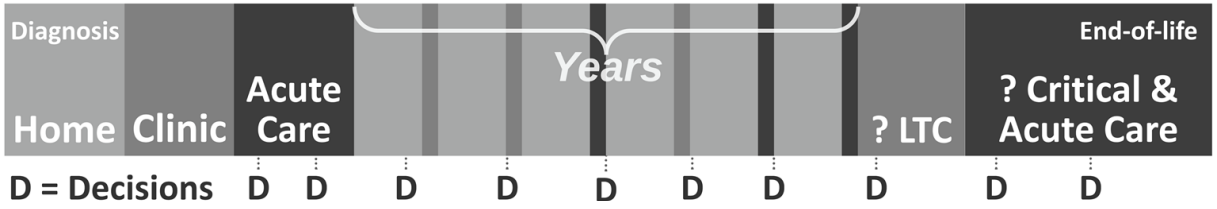
End-of-life

? Critical & Acute Care

Examples of decisions that might need to be made:

- A lung lesion is found incidentally on x-ray. Should Joe have this biopsied?
- He develops atrial fibrillation but is high risk for a fall. Should he begin anti-coagulation?
- As Joe's function worsens, Sandi wonders if LTC would better meet his care needs?





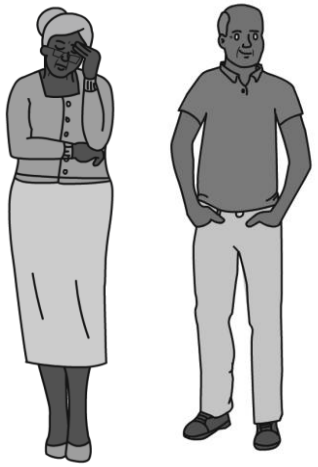
Goals of care discussion:

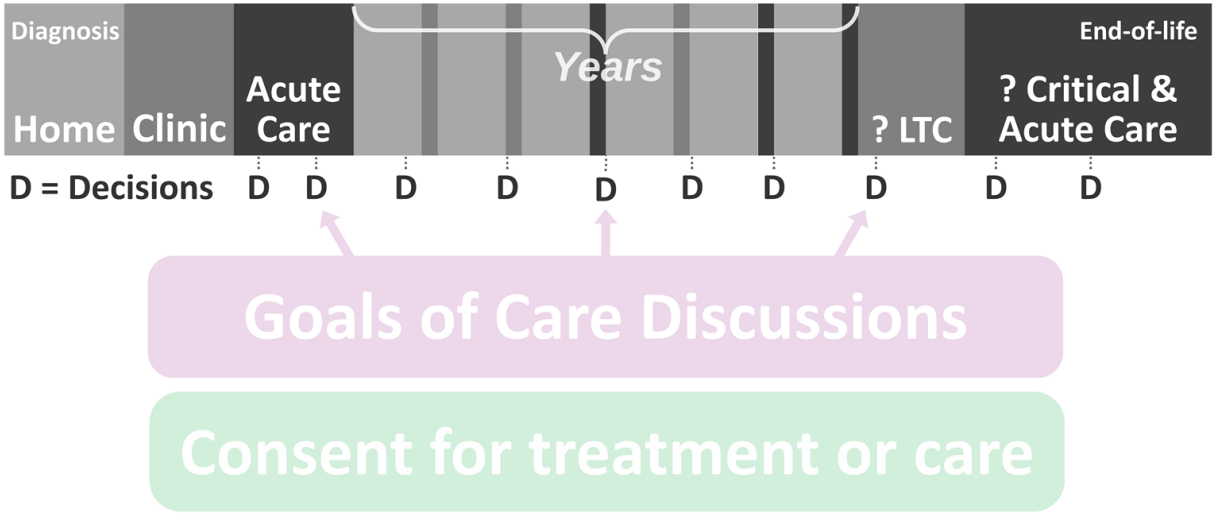
- values-based discussion when a treatment or care decision is needed
- ensures illness and what to expect are understood
- align a person's goals with available approaches or options proposing treatment or care

Consent:

- Risks, benefits and alternatives are fully explored by the clinician

What will help prepare both Joe & Sandi for decision-making in the future?





Advance care planning…preparatory conversations that:

- confirm a person's SDM
- ensure illness is understood
- enable values-based decision-making in the future

Acknowledgement:
Nova Scotia Health

Outcomes

- ❑ **SDM is identified**
- ❑ **Patient & SDM are prepared for decision-making (illness understanding, values & goals)**

- ❑ **Illness is understood**
- ❑ **Decisions are guided by patient values and goals**

- ❑ **Risks, benefits and alternatives are fully explored by the clinician proposing treatment or care**

What do we mean by values-based decision-making?

Thought Experiment: What would you do?

You suffer a life-threatening injury and offered a surgery that could save your life.

However, with the surgery there is 80% chance of paralysis (upper and lower limbs).

Would you have the surgery?

YES NO

Thought Experiment: What would you do?

You have a debilitating motor condition and offered a medication that allows most patients to function independently.

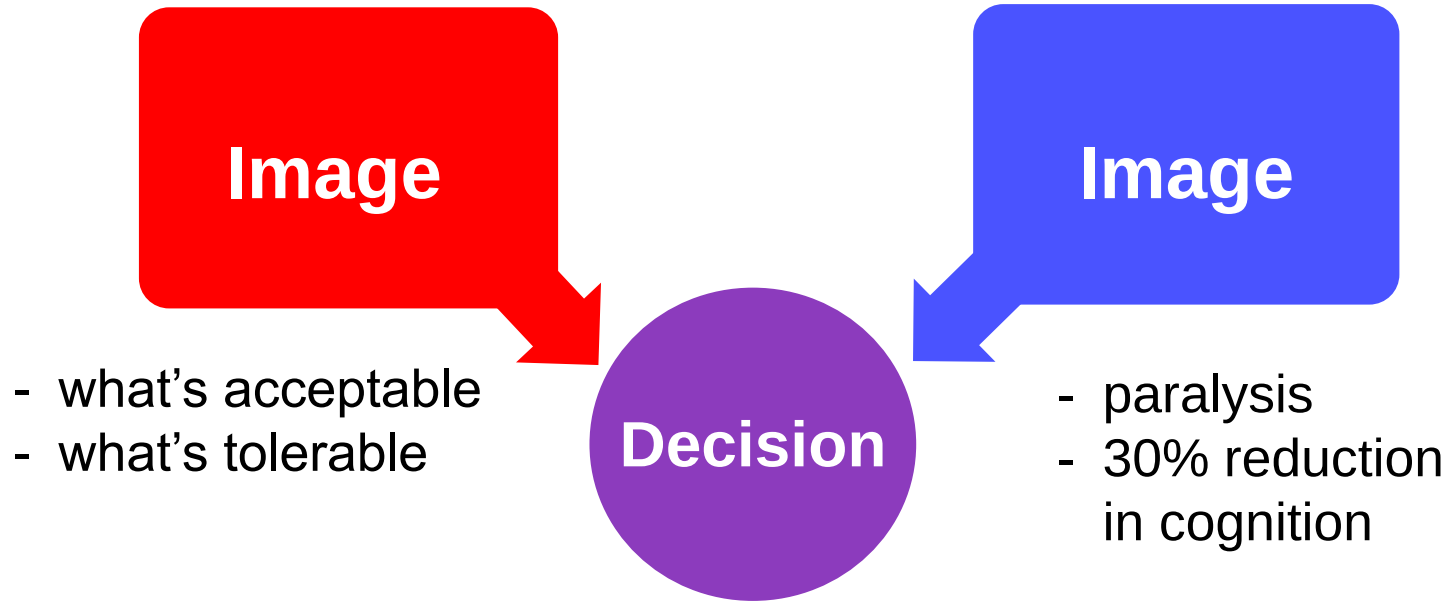
However most patients also experience a 30% reduction in cognitive function.

Would you take the medication?

YES NO

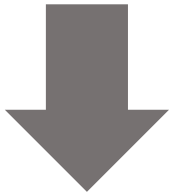
What did you do?

How did you arrive at these decisions?
What went through your mind?



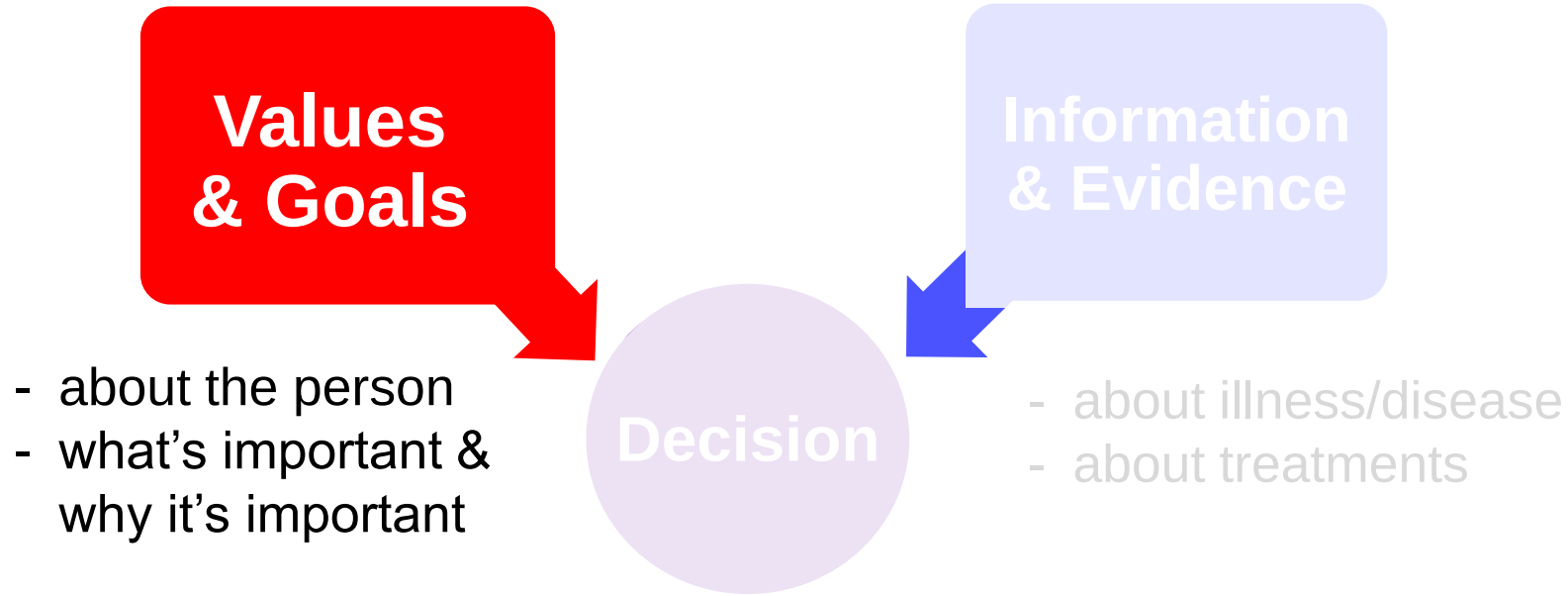
What patients consider

- People do not envision their future health in terms of their FEV1 or % tumour burden or kidney function and wanting dialysis or not
- They think about the outcomes of treatments…



- What they imagine life to look like and how it will be affected by illness and treatments

Effective decision-making



Both sources of information are needed for decisions to be effective

Goals of Care **Advance Care Planning** **Shared Decision Making** **Informed Consent**

Clinician Guidance

Another way to think about the framework

Illness understanding becomes a priority

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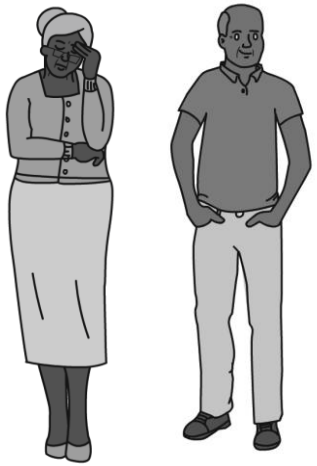
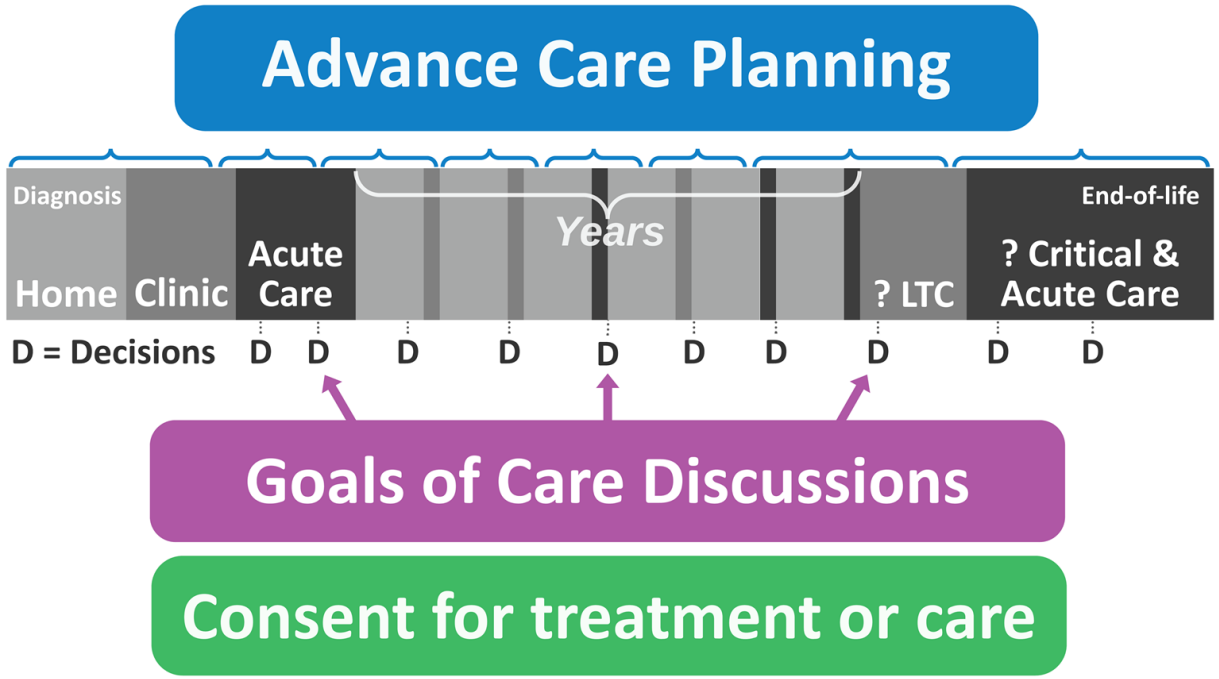
ACP & GOCD are setting agnostic





ACP Tools, Conversation Guides & Communication Skills

- Serious Illness Conversation
- VitalTalk
- Speakup
- PlanWell
- Respecting Choices
- Prepareforyourcare.org
- CPAC
- CardioTalk
- MOST

GOC Tools, Conversation Guides & Communication Skills

- VitalTalk
- Respecting choices
- CPAC
- CardioTalk
- GCD

The process is similar: A hybrid guide

Prepare

Prepare yourself

- know medical information – trajectory, treatment options,
- put aside your agenda – the goal is to see the world as they see it

Explore

Explore illness understanding

- Patient should talk more than you
- Encourage with Silence/Reflection/Open-ended questions

Inform

Give information: concise, clear, and meaning

- Speak slowly and be clear about impact on life
- Pause often and expect emotional responses

Explore Values

Ask about values

- What is most important to you?
- What are you most worried about?

Recommend

GOC: Make recommendations;

ACP: follow up with SDM

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Acknowledgments: Many resources teach a model to have these conversations. See a partial list below

Ian Anderson Continuing Education Program in End-of-Life Care, University of Toronto https://www.cpd.utoronto.ca/endoflife/Modules.htm

Landzaat, L “The Communication Tool Belt”

Hallenbeck, J., http://www.eperc.mcw.edu/fastFact#026

You, J et. al. Just ask: discussing goals of care with patients in hospital with serious illness. CMAJ 2013

Vital Talk

Ariadne Labs Serious Illness program

Overarching Principles

- Outcome is uncertain – values-sensitive
- Team: All health care providers can do this
- Iterative
- Guidance and coaching
- Expect and respond to emotions
  - Essential to do this well
  - Not taught how to do this

In the next slides, we will highlight just a few skills and phrases that are helpful

This is just a quick overview – for more information on this process, see

Goalsofcaremodule.com

Check out your provincial groups to learn about training opportunities to learn these skills

Prepare

- Know medical information
- Leave your agenda aside
- Take a supportive attitude

ACP	GOC
• Pro-active • Practice ways to start the conversation that fit your context	• Reactive • Practice Communication Skills

Prepare

- Know medical information
- Leave your agenda aside
- Take a supportive attitude

ACP Introduction:

“you’ve had a few changes in your health and we may have some decisions coming up in the future…

many people find it helpful to talk about what is going on with their health and start to get prepared for a time when will have decisions to make…

this is called advance care planning…have you ever heard of that?”

Explore

- Person's illness understanding
- Person should be talking more than you
- Use good listening skills to encourage person to talk
- See the world from their perspective

Three skills encourage a person to talk…

- Open ended questions
- Reflections
- Silence

You are looking for the person to tell you something you can invite them to say more about…

Explore

- Person's illness understanding
- Person should be talking more than you
- Use good listening skills to encourage person to talk
- See the world from their perspective

This can be done by so many clinicians – MDs, nursing, allied health

If you learn that your patient needs more information –

"It seems like you aren't sure what might happen with your illness in the future…is that right? Would it be helpful if I asked someone to give you more information?"

Inform

- Use excellent communication skills
  - Slow, pauses, no medical language
- Give meaning of the information
- Expect **emotional response**

Start with asking for permission --

"I have some more information about dementia… would it be okay if I told you more information?"

- *"Alzheimer's dementia has 3 phases… "*
- *"The ups and downs of your heart failure are normal…let me show you the typical pattern…"*

Inform

- Use excellent communication skills
  - Slow, pauses, no medical language
- Give meaning of the information
- Expect **emotional response**

Providing illness education is a skill!

Means being able to explain trajectories of chronic, progressive illness;

Do you know how to describe illnesses, trajectories, complications?

Use visuals!

Goals and Values

- Ask about values
  - What is most important to you?
  - What are you worried about?

Once you have achieved some illness understanding and you want to think about next steps:

"Mr. Smith, you have a really good understanding of what is happening… I wonder…what would you say would be most important for you now? I wonder….is there anything you are worried about as you think about the future with this illness?"

Goals and Values

- Ask about values
  - What is most important to you?
  - What are you worried about?

He says:

"I know I'm dying…but I'd like to live as long as I can – I am spending time with my family…it is really important to me that I can be with them as much as possible. I'm worried though that I'll suffer at the end of life…"

But what if he says:

"I'm worried I won't be able to go back to work…that is what is most important – I have to get better and go back to work…

Goals and Values

- Ask about values
  - What is most important to you?
  - What are you worried about?

What can we do?

Better to know, acknowledge and explore

Don’t push medical facts on emotions or on resistance

I wish statements

Learn a Conversation Guide

Prepare

Prepare yourself

- know medical information – trajectory, treatment options,
- put aside your agenda – the goal is to see the world as they see it

Explore

Explore illness understanding

- Patient should talk more than you
- Encourage with Silence/Reflection/Open-ended questions

Inform

Give information: concise, clear, and meaning

- Speak slowly and be clear about impact on life
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Explore Values

Ask about values

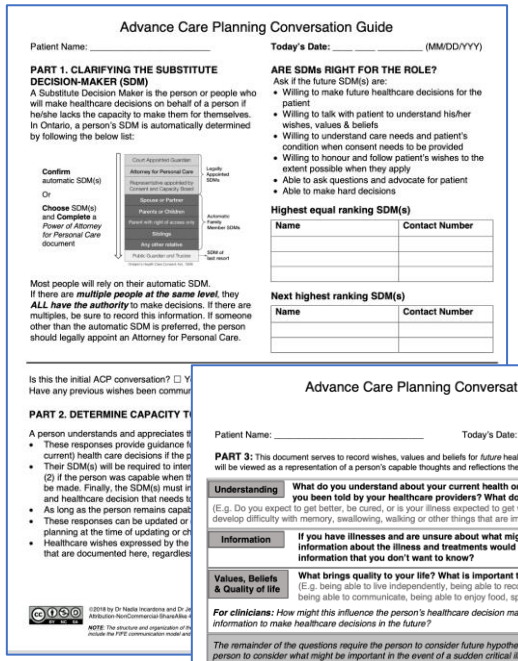
- What is most important to you?
- What are you most worried about?

Recommend

GOC: Make recommendations;

ACP: follow up with SDM

Resources


Advance Care Planning Conversation Guide

Patient Name: _____ Today's Date: ____ ____ _____ (MM/DD/YYY)

PART 1. CLARIFYING THE SUBSTITUTE DECISION-MAKER (SDM)

A Substitute Decision Maker is the person or people who will make healthcare decisions on behalf of a person if he/she lacks the capacity to make them for themselves. In Ontario, a person's SDM is automatically determined by following the below list:

Confirm automatic SDM(s)

Or

Choose SDM(s) and Complete a *Power of Attorney for Personal Care* document

Court Appointed Guardian
Attorney for Personal Care
Representative appointed by Consent and Capacity Board
Spouse or Partner
Parents or Children
Parent with right of access only
Siblings
Any other relative
Public Guardian and Trustee

Legally Appointed SDMs
Automatic Family Member SDMs
SDM of last resort

Most people will rely on their automatic SDM.
If there are ***multiple people at the same level***, they ***ALL have the authority*** to make decisions. If there are multiples, be sure to record this information. If someone other than the automatic SDM is preferred, the person should legally appoint an Attorney for Personal Care.

ARE SDMs RIGHT FOR THE ROLE?

Ask if the future SDM(s) are:
- Willing to make future healthcare decisions for the patient
- Willing to talk with patient to understand his/her wishes, values & beliefs
- Willing to understand care needs and patient's condition when consent needs to be provided
- Willing to honour and follow patient's wishes to the extent possible when they apply
- Able to ask questions and advocate for patient
- Able to make hard decisions

Highest equal ranking SDM(s)

Name	Contact Number

Next highest ranking SDM(s)

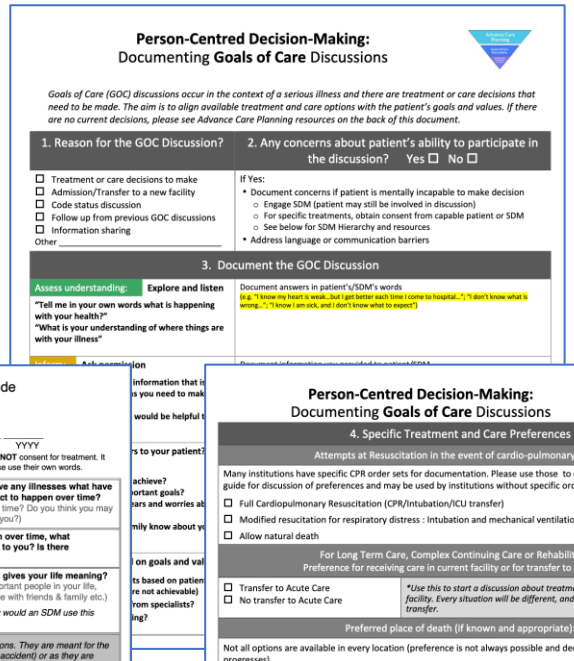
Name	Contact Number

Is this the initial ACP conversation? ☐ Y
Have any previous wishes been commu

PART 2. DETERMINE CAPACITY T

A person understands and appreciates t
- These responses provide guidance f current) health care decisions if the p
- Their SDM(s) will be required to inter (2) if the person was capable when th be made. Finally, the SDM(s) must in and healthcare decision that needs t
- As long as the person remains capab
- These responses can be updated or planning at the time of updating or ch
- Healthcare wishes expressed by the that are documented here, regardles

NOTE: The structure and organization of the s include the FIPE communication model and


Person-Centred Decision-Making:
Documenting **Goals of Care** Discussions

Goals of Care (GOC) discussions occur in the context of a serious illness and there are treatment or care decisions that need to be made. The aim is to align available treatment and care options with the patient's goals and values. If there are no current decisions, please see Advance Care Planning resources on the back of this document.

1. Reason for the GOC Discussion?

- ☐ Treatment or care decisions to make
- ☐ Admission/Transfer to a new facility
- ☐ Code status discussion
- ☐ Follow up from previous GOC discussions
- ☐ Information sharing

Other _____

2. Any concerns about patient's ability to participate in the discussion? Yes ☐ No ☐

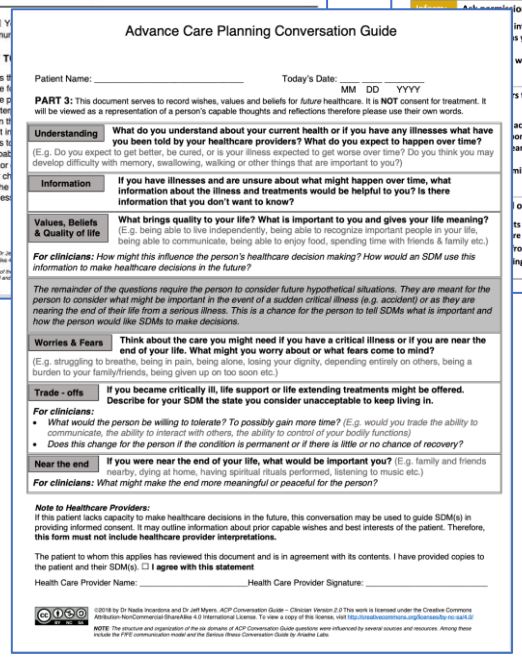
If Yes:
- Document concerns if patient is mentally incapable to make decision
  - Engage SDM (patient may still be involved in discussion)
  - For specific treatments, obtain consent from capable patient or SDM
  - See below for SDM Hierarchy and resources
- Address language or communication barriers

3. Document the GOC Discussion

Assess understanding: Explore and listen

"Tell me in your own words what is happening with your health?"
"What is your understanding of where things are with your illness"

Document answers in patient's/SDM's words
(e.g. "I know my heart is weak...but I get better each time I come to hospital..."; "I don't know what is wrong..."; "I know I am sick, and I don't know what to expect")


Advance Care Planning Conversation Guide

Patient Name: _____ Today's Date: _____ _____ _____ MM DD YYYY

PART 3: This document serves to record wishes, values and beliefs for *future* healthcare. It is **NOT** consent for treatment. It will be viewed as a representation of a person's capable thoughts and reflections therefore please use their own words.

Understanding — **What do you understand about your current health or if you have any illnesses what have you been told by your healthcare providers? What do you expect to happen over time?**
(E.g. Do you expect to get better, be cured, or is your illness expected to get worse over time? Do you think you may develop difficulty with memory, swallowing, walking or other things that are important to you?)

Information — **If you have illnesses and are unsure about what might happen over time, what information about the illness and treatments would be helpful to you? Is there information that you don't want to know?**

Values, Beliefs & Quality of life — **What brings quality to your life? What is important to you and gives your life meaning?** (E.g. being able to live independently, being able to recognize important people in your life, being able to communicate, being able to enjoy food, spending time with friends & family etc.)

For clinicians: *How might this influence the person's healthcare decision making? How would an SDM use this information to make healthcare decisions in the future?*

The remainder of the questions require the person to consider future hypothetical situations. They are meant for the person to consider what might be important in the event of a sudden critical illness (e.g. accident) or as they are nearing the end of their life from a serious illness. This is a chance for the person to tell SDMs what is important and how the person would like SDMs to make decisions.

Worries & Fears — **Think about the care you might need if you have a critical illness or if you are near the end of your life. What might you worry about or what fears come to mind?**
(E.g. struggling to breathe, being in pain, being alone, losing your dignity, depending entirely on others, being a burden to your family/friends, being given up on too soon etc.)

Trade - offs — **If you became critically ill, life support or life extending treatments might be offered. Describe for your SDM the state you consider unacceptable to keep living in.**

For clinicians:
- *What would the person be willing to tolerate? To possibly gain more time? (E.g. would you trade the ability to communicate, the ability to interact with others, the ability to control of your bodily functions)*
- *Does this change for the person if the condition is permanent or if there is little or no chance of recovery?*

Near the end — **If you were near the end of your life, what would be important you?** (E.g. family and friends nearby, dying at home, having spiritual rituals performed, listening to music etc.)

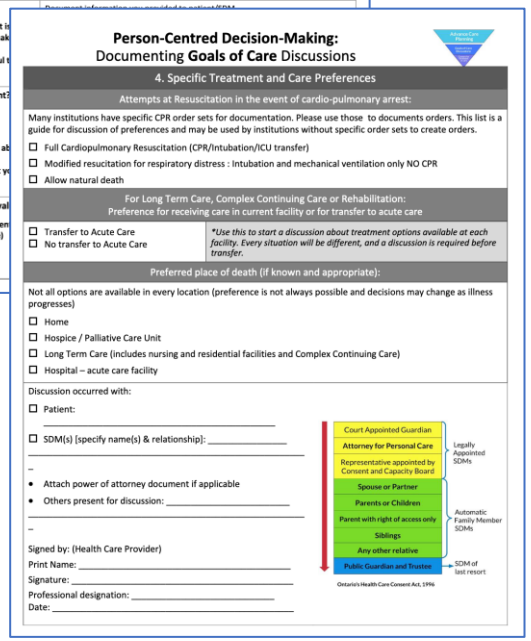
For clinicians: *What might make the end more meaningful or peaceful for the person?*

Note to Healthcare Providers:
If this patient lacks capacity to make healthcare decisions in the future, this conversation may be used to guide SDM(s) in providing informed consent. It may outline information about prior capable wishes and best interests of the patient. Therefore, **this form must not include healthcare provider interpretations.**

The patient to whom this applies has reviewed this document and is in agreement with its contents. I have provided copies to the patient and their SDM(s). ☐ **I agree with this statement**

Health Care Provider Name: _____ Health Care Provider Signature: _____

NOTE: The structure and organization of the six domains of ACP Conversation Guide questions were influenced by several sources and resources. Among these include the FIPE communication model and the Serious Illness Conversation Guide by Ariadne Labs.


Person-Centred Decision-Making:
Documenting **Goals of Care** Discussions

4. Specific Treatment and Care Preferences

Attempts at Resuscitation in the event of cardio-pulmonary arrest:

Many institutions have specific CPR order sets for documentation. Please use those to documents orders. This list is a guide for discussion of preferences and may be used by institutions without specific order sets to create orders.

- ☐ Full Cardiopulmonary Resuscitation (CPR/Intubation/ICU transfer)
- ☐ Modified resuscitation for respiratory distress : Intubation and mechanical ventilation only NO CPR
- ☐ Allow natural death

For Long Term Care, Complex Continuing Care or Rehabilitation:
Preference for receiving care in current facility or for transfer to acute care

- ☐ Transfer to Acute Care
- ☐ No transfer to Acute Care

**Use this to start a discussion about treatment options available at each facility. Every situation will be different, and a discussion is required before transfer.*

Preferred place of death (if known and appropriate):

Not all options are available in every location (preference is not always possible and decisions may change as illness progresses)

- ☐ Home
- ☐ Hospice / Palliative Care Unit
- ☐ Long Term Care (includes nursing and residential facilities and Complex Continuing Care)
- ☐ Hospital – acute care facility

Discussion occurred with:

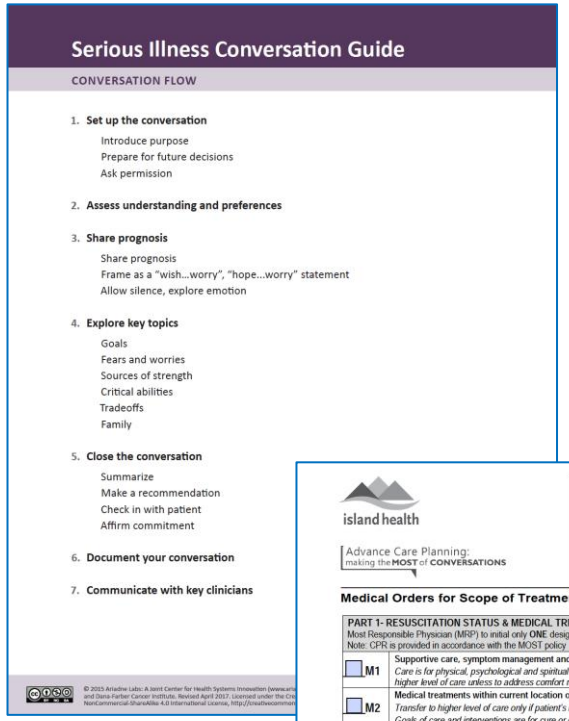
- ☐ Patient: _____
- ☐ SDM(s) [specify name(s) & relationship): _____
- Attach power of attorney document if applicable
- Others present for discussion: _____

Signed by: (Health Care Provider)
Print Name: _____
Signature: _____
Professional designation: _____
Date: _____

Court Appointed Guardian
Attorney for Personal Care
Representative appointed by Consent and Capacity Board
Spouse or Partner
Parents or Children
Parent with right of access only
Siblings
Any other relative
Public Guardian and Trustee

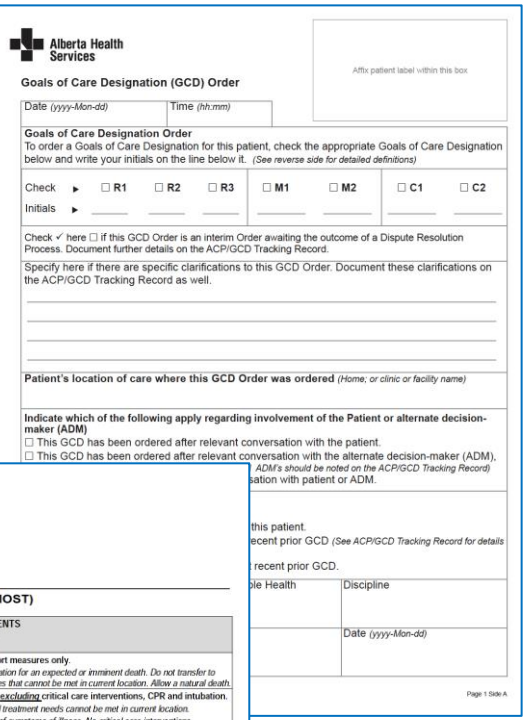
Legally Appointed SDMs
Automatic Family Member SDMs
SDM of last resort

Ontario's Health Care Consent Act, 1996


Serious Illness Conversation Guide

CONVERSATION FLOW

1. **Set up the conversation**
   - Introduce purpose
   - Prepare for future decisions
   - Ask permission
2. **Assess understanding and preferences**
3. **Share prognosis**
   - Share prognosis
   - Frame as a "wish...worry", "hope...worry" statement
   - Allow silence, explore emotion
4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family
5. **Close the conversation**
   - Summarize
   - Make a recommendation
   - Check in with patient
   - Affirm commitment
6. **Document your conversation**
7. **Communicate with key clinicians**


Alberta Health Services

Goals of Care Designation (GCD) Order

Affix patient label within this box

Date *(yyyy-Mon-dd)* Time *(hh:mm)*

Goals of Care Designation Order
To order a Goals of Care Designation for this patient, check the appropriate Goals of Care Designation below and write your initials on the line below it. *(See reverse side for detailed definitions)*

Check ▸	☐ R1	☐ R2	☐ R3	☐ M1	☐ M2	☐ C1	☐ C2
Initials ▸							

Check ✓ here ☐ if this GCD Order is an interim Order awaiting the outcome of a Dispute Resolution Process. Document further details on the ACP/GCD Tracking Record.

Specify here if there are specific clarifications to this GCD Order. Document these clarifications on the ACP/GCD Tracking Record as well.

Patient's location of care where this GCD Order was ordered *(Home; or clinic or facility name)*

Indicate which of the following apply regarding involvement of the Patient or alternate decision-maker (ADM)
☐ This GCD has been ordered after relevant conversation with the patient.
☐ This GCD has been ordered after relevant conversation with the alternate decision-maker (ADM), *ADM's should be noted on the ACP/GCD Tracking Record)*

sation with patient or ADM.

this patient.
ecent prior GCD *(See ACP/GCD Tracking Record for details*

recent prior GCD.

ble Health	Discipline
	Date *(yyyy-Mon-dd)*

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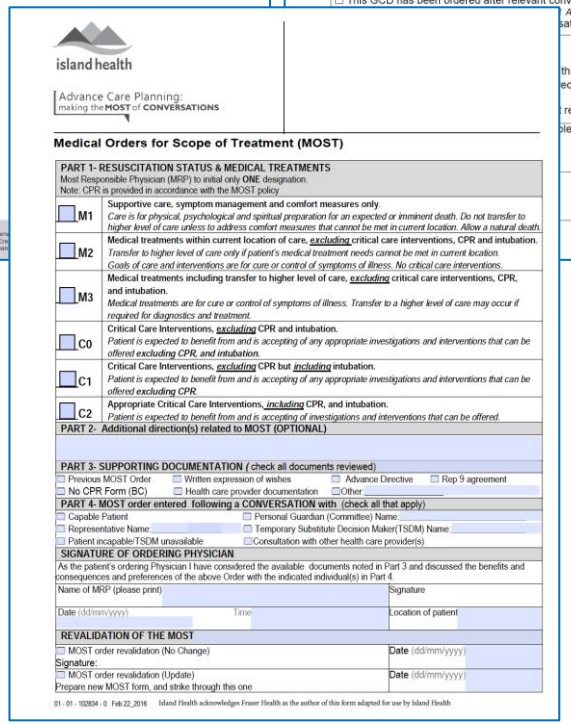
island health

Advance Care Planning:
making the MOST of CONVERSATIONS

Medical Orders for Scope of Treatment (MOST)

PART 1- RESUSCITATION STATUS & MEDICAL TREATMENTS
Most Responsible Physician (MRP) to initial only **ONE** designation.
Note: CPR is provided in accordance with the MOST policy

☐ **M1** — **Supportive care, symptom management and comfort measures only.**
Care is for physical, psychological and spiritual preparation for an expected or imminent death. Do not transfer to higher level of care unless to address comfort measures that cannot be met in current location. Allow a natural death.

☐ **M2** — **Medical treatments within current location of care, *excluding* critical care interventions, CPR and intubation.**
Transfer to higher level of care only if patient's medical treatment needs cannot be met in current location.
Goals of care and interventions are for cure or control of symptoms of illness. No critical care interventions.

☐ **M3** — **Medical treatments including transfer to higher level of care, *excluding* critical care interventions, CPR, and intubation.**
Medical treatments are for cure or control of symptoms of illness. Transfer to a higher level of care may occur if required for diagnostics and treatment.

☐ **C0** — **Critical Care Interventions, *excluding* CPR and intubation.**
Patient is expected to benefit from and is accepting of any appropriate investigations and interventions that can be offered excluding CPR, and intubation.

☐ **C1** — **Critical Care Interventions, *excluding* CPR but *including* intubation.**
Patient is expected to benefit from and is accepting of any appropriate investigations and interventions that can be offered excluding CPR.

☐ **C2** — **Appropriate Critical Care Interventions, *including* CPR, and intubation.**
Patient is expected to benefit from and is accepting of investigations and interventions that can be offered.

PART 2- Additional direction(s) related to MOST (OPTIONAL)

PART 3- SUPPORTING DOCUMENTATION *(check all documents reviewed)*
☐ Previous MOST Order ☐ Written expression of wishes ☐ Advance Directive ☐ Rep 9 agreement
☐ No CPR Form (BC) ☐ Health care provider documentation ☐ Other _____

PART 4- MOST order entered following a CONVERSATION with *(check all that apply)*
☐ Capable Patient ☐ Personal Guardian (Committee) Name:
☐ Representative Name: ☐ Temporary Substitute Decision Maker(TSDM) Name:
☐ Patient incapable/TSDM unavailable ☐ Consultation with other health care provider(s)

SIGNATURE OF ORDERING PHYSICIAN
As the patient's ordering Physician I have considered the available documents noted in Part 3 and discussed the benefits and consequences and preferences of the above Order with the indicated individual(s) in Part 4

Name of MRP (please print)	Signature
Date (dd/mm/yyyy) Time	Location of patient

REVALIDATION OF THE MOST

☐ MOST order revalidation (No Change) Signature:	Date (dd/mm/yyyy)
☐ MOST order revalidation (Update) Prepare new MOST form, and strike through this one	Date (dd/mm/yyyy)

01 - 01 - 102834 - 0 Feb 22_2016 Island Health acknowledges Fraser Health as the author of this form adapted for use by Island Health

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Q&A

Please use the Q&A function at the bottom of your screen.

THANK YOU

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