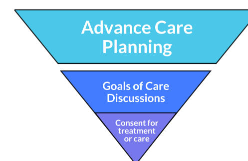
HPCO
Hospice Palliative Care Ontario

Speak Up Ontario

Guide for Clinicians

COVID-19 Goals of Care Discussion



This is to help you discuss the near future with ***seriously ill, frail or elderly*** people & substitute decision-makers (SDMs) in ***community, long-term care, complex continuing care or hospital*** settings.

Two Outcomes

1. In preparation for the coming weeks, *identify and document the wishes people have about future care* in the event of a possible clinical deterioration from an underlying condition or COVID-19 infection
2. *Prepare people and their SDMs* for the possibility that clinical deterioration may occur at a time of *surge protocol* i.e. critical care resources are scarce and care escalation (e.g. mechanical ventilation, transfer out) may not be possible.

Discussion Tips

- Discussion ideally occurs with both a person and their SDM
- If a person lacks capacity to participate, this discussion must occur with their SDM.
- Feel comfortable using this tool as a guided script. People are accepting if you explain you will be reading off the page: "I may refer to a Conversation Guide, just to make sure that I don't miss anything important."

Principles

- *You will not harm a person* by talking about their illness and the future
- *People want and need the truth* about what to expect as this enables making informed decisions

Practices

- Make a recommendation. In these distressing times, people need to hear your professional opinion.
- Allow silence as time permits and listen more than talking
- Acknowledge and explore emotion as it occurs. Do not just talk about facts and procedures
- Focus on person-centred goals and priorities, not medical procedures
- Do not offer a menu of interventions, especially those that are not clinically beneficial
- *Use the wish, worry, wonder framework e.g. "I wish we weren't in this situation, but I worry what might happen if you got sick with COVID-19 or your other health problems were to worsen. I wonder if we can talk about this?"*

Step 1: Prepare

Gather relevant information

- Know person's current clinical condition and ensure SDM is present in-person or virtually

Step 2: Introduce the conversation

Outline what will be discussed and gauge level of anxiety or worry

There is a lot of fear and uncertainty now. The situation in Ontario is changing quickly and we don't yet know the extent of what to expect.

Because of this, we are talking with as many people as possible who have (or have family who have) serious illness or who are at risk of becoming very sick if they were to become infected with coronavirus.

This is not to scare you, but to help you and your family be as prepared as possible. One way to prepare is to learn more about who you are and what's important to you as you think about the future.

What do you know about the situation with coronavirus and why our conversation today is important?

In the past, have you discussed with anyone your wishes about care in the future? This is called advance care planning.

Step 3: Explore understanding of underlying illness and COVID-19

Identify information requiring clarification e.g. serious illness being incurable or progressive in nature

What do you understand about your current health? 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?

Step 4: Give information about underlying illness

Ensure accurate understanding of the expected illness course and where the person is in their illness trajectory

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- Give information about underlying serious illness
- Expect emotion and respond with empathic statements
- Give short amounts of information
- Pause and check understanding

Step 5: Explore values & goals

If NOT in surge protocol, identify values & goals that can be translated into wishes about care escalation. It is important to understand baseline values, goals & wishes before discussing COVID-19.
If in surge protocol, skip to Step 6.

As you think about your future and your health, what comes to mind as being important?
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.

Think about the care you might need if you have a critical illness. What worries or fears come to mind?

(For people in institutional settings) How do you feel about being transferred to hospital? And, why?

Think about your life in the future. Describe the states that are acceptable and unacceptable for you.

Step 6: Give information about COVID-19

For a person in an institutional setting, sensitively inform them about the possible scenario that transferring to hospital may not be possible. ***For a person at home,*** sensitively prepare them for what might happen if they become so sick, they are considering going into the hospital. The overall message is one of being hopeful that all treatments and care will be available but preparing in the event they are not.

I'd like to talk about the effect of coronavirus on people who have other medical problems. It is difficult to talk about this, but many people prefer to have information so they can feel prepared. Is it ok to share this info with you now?

We know most people who get coronavirus will recover or might need some temporary treatments. Unfortunately, there is no cure for coronavirus, which is a worry for people with serious illness like heart or kidney disease or frailty.

People with other medical problems who get coronavirus have a much harder time recovering. These are the people who we worry most about dying from coronavirus. The reason is that their body is already dealing with illness and adding a viral infection means they might not have the reserve to fight the infection.

I don't expect this to happen to you, but I wouldn't be doing my job if I didn't bring this up with you.

(Pause for possible questions or emotions)

I also need tell you a bit about what might change in the health care system because of coronavirus.

In ordinary circumstances, people who become very sick have access to treatments like CPR and life support as well as the critical care unit. Unfortunately, if coronavirus gets very bad in Ontario, there will be changes to the health care system and the resources that are available.

The best evidence tells us that among people who are so sick they need critical care, the people who recover have no other health conditions and before becoming sick they are living at home, independently. The best evidence also tells us that for people who have serious illness if CPR or life support is needed it is very unlikely, they will survive. This is why if seriously ill people become even sicker, CPR, life support and critical care may not be offered.

I wish it were different but if coronavirus gets very bad in Ontario, I'm worried some of what we've talked about today might not be possible for you. I hope this won't happen, but we can be prepared if it does.

Many people I've spoken with are most worried about what it would feel like if they are dying and worry, they will suffocate and suffer. I want you to know that if you got very sick, we will be able to help you, to keep you comfortable with some very good medicines.

Step 7: Recommend & Document a plan

Agree on what was discussed, ensure understanding of recommendations & outline next steps

- Summarize key details of the discussion

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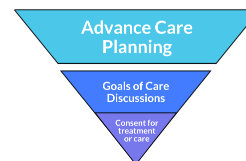

- Make recommendations

Just so I understand you correctly, if you become ill with COVID-19 or if your underlying illness were to worsen and a treatment decision needs to be made, you would prefer_______?

- Expect emotion and respond with empathic statements
- For people in institutional settings, document specific information about transfer status and code status

Guiding Principles for these conversations to be attached to all conversations:

General information about the conversation guides

- These are suggested conversation guides only. They offer you language to use, but you will need to adapt to the specific situation you are facing.
    - For example, if the emotion is not shock, but is sadness, name that emotion: "you are right to feel so sad...you obviously care so much about your (relative)..." "you are right to be frustrated and upset...it is difficult news that I am telling you..."
- Communicate with key health care team members who can help support these conversations and the patients
- Make sure you are talking to the correct SDM when the patient is incapable
- Document your conversations
- Know what's available at your own site or region
    - Visitor Policy
    - Resource allocation policies
    - Palliative care supports from regional palliative care team
    - Availability of social work and chaplaincy support
- Know what resources your institution has to provide patient/families about COVID-19 and any triage information

General tips about communication (from Fraser Health Services BC)

Within your own scope of practice, provide information directly and honestly to the best of your knowledge

- Allow silence as time permits
- Acknowledge and explore emotion as it occurs. Do not just talk about facts and procedures
- Make a recommendation. In these distressing times, patients & families need to hear your professional opinion.
- Listen more than you talk.
- Avoid premature reassurance, instead align with the patients in hoping things may improve
- Focus on patient-centred goals and priorities not medical procedures
- Do not offer a menu of interventions, especially those that are not clinically beneficial
- Use the wish, worry, wonder framework...
    - I wish allows for aligning with the patient's hopes
    - I worry allows for being truthful while sensitive
    - I wonder is a subtle way to make a recommendation

If you have any feedback about these guides, please email rachel.dragas@HPCO.ca

Additional Resources

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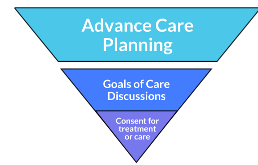

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Speak Up Ontario	speakupontario.ca
Ontario Palliative Care Network	ontariopalliativecarenetwork.ca
VitalTalk	vitaltalk.org

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