Advanced Care Planning and Goals of Care Conversations in LTC During the COVID19 Pandemic

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There is no better time than now to review and practice the skill of having serious illness and goals of care conversations with patients and their substitute decisions makers. The challenges our healthcare system, clinicians and institutions are facing as a result of the COVID19 pandemic can become cumbersome enough to distract us from applying the principles of patient centred care, in favour of 'resource-centred' or 'pressure of the moment centred' care. By having these conversation as early as possible and at time of illness, we ensure patients are not subjected to invasive measures that contradict their wishes and dignity.

The importance of these dialogues is not only relevant for residents of LTC who are diagnosed or suspected of having COVID19 or acute critical respiratory illness, but also to patients who become seriously ill from any other medical causes.

Health Quality Ontario recently published 13 quality statements pertaining to the delivery of palliative end of life care, of which the first five require an early conversation that starts with needs assessment and ends with agreement upon goals of care before specific medical interventions and orders are implemented https://www.hqontario.ca/Evidence-to-Improve-Care/Quality-Standards/View-all-Quality-Standards/Palliative-Care/Quality-Statement-1-Identification-and-Assessment-of-Needs .

Fortunately, speakupontario.ca has a wealth of tools and resources for clinicians to educate patients, families and the multidisciplinary team to ensure the delivery of patient centred care. The Person Centred Decision Making Framework provides for a great summary of the process https://www.speakupontario.ca/person-centred-decision-making/.

In LTC settings, most patients present with some level of cognitive impairment, usually due to dementia, at which point advanced care planning (ACP) with the patient directly may have been missed (figure 1). Hopefully, ACP would have been completed earlier and there's a known SDM (Substitute Decision Maker) who is aware of the patient's values that ultimately drive goals of care and treatment decisions. When the values are known, it means that when the time of any serious or critical illness arrives, the clinical team is on the same page as the SDM or family as to what treatment orders are most consistent with the individual's wishes and values when they were able to state them. This is further reflected in the Person Centred Decision Making Framework below (figure 3).

When it comes to having the most difficult conversation at the time of illness, the best resource we have that takes into consideration the LTC setting, where conversations are often had with the SDM (usually a family member), is the serious illness conversation guide modified by Dr. Charlie Chen to be used with SDMs (figure 3). Full printable version of this guide is available here https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Professionals/Clinical-resources/Advance-Care-Planning---Serious-Illness/Serious_Illness_Conversation_Guide_with_Substitute_Decision_Makers.pdf .

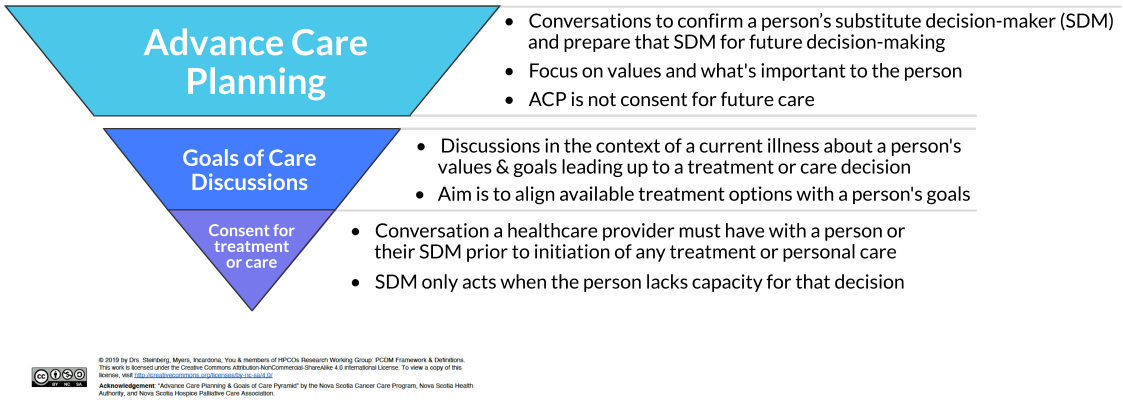

FIGURE 1: FROM ACP TO CONSENT FOR TREATMENT
https://www.speakupontario.ca/wp-content/uploads/2019/08/PCDM-Framework-Definitions-1.jpg

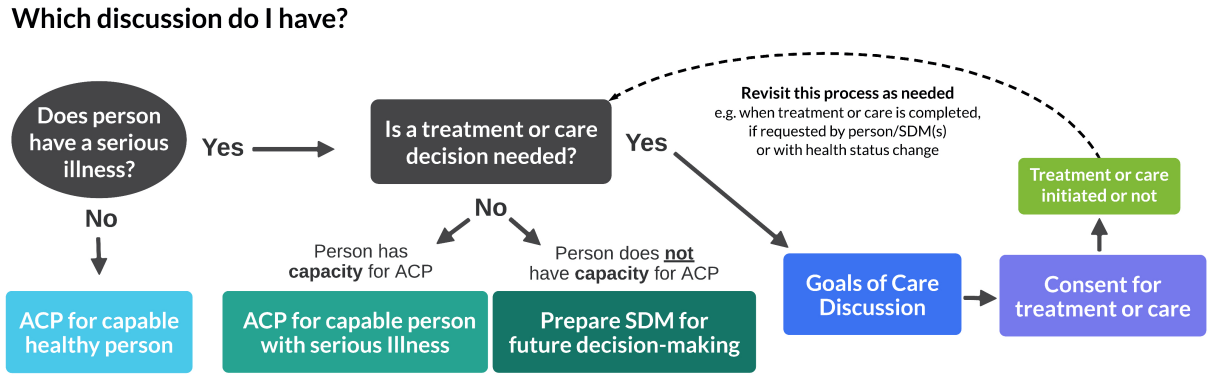

FIGURE 2: PCDM FRAMEWORK
https://www.speakupontario.ca/wp-content/uploads/2019/08/PCDM-Clinician-Algorithm.jpg

The guide is user friendly and starts naturally with setting up the conversation and asking for permission, progressing into attempting to explore prior ACP conversations and the SDM's understanding of the current illness their loved one is facing. When it comes to step 4, sharing prognosis and medical information, using the I wish, I worry, I wonder framework (figure 4). adapted from the original serious illness conversation guide by Ariadne Labs, has also been widely utilized https://www.divisionsbc.ca/sites/default/files/Divisions/Powell%20River/ClinicianReferenceGuide.pdf

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SERIOUS ILLNESS CONVERSATION GUIDE
SUBSTITUTE DECISION-MAKERS
A CONVERSATION TOOL FOR CLINICIANS

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. Set up the conversation • Introduce ideas and benefits • Prepare of future decisions • Ask permission	"I'd like to talk about what is ahead with your _____'s illness and do some thinking in advance about what is important to him/her so that I can make sure we provide him/her with the care that they'd want - **is that okay?"**
2. Explore prior advance care planning conversations and documentation	"How much has your _____ discussed with you about about his/her priorities and wishes, especially about his/her health and illness?" "Does he/she have any previous advance care planning documents?"
3. Assess illness understanding and information preferences	"What is your current **understanding** of your _____'s illness now and how it might change over time?" "How much **information** about what is likely to be ahead with your _____'s illness would you like from me?"
4. Share prognosis and medical information • Tailor information to expressed preferences • Allow silence, explore emotions • Provide a warning: "I have some bad news.", or "The news is not good." • Frame as "wish.., worry..."	"I want to share with you **my understanding** of where things are with your _____'s illness..." *Uncertain:* "It can be difficult to predict what will happen with your _____'s illness. I **hope** he/she will continue to live well for a long time but I'm **worried** that he/she could get sick quickly, and I think it is important to prepare for that possibility." **OR** *Time:* "I wish we were not in this situation, but I am **worried** that time may be as short as _____ *express as a range, eg. days to weeks, weeks to months, months to a year*)" ***OR*** *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as your _____ will feel and things are likely to get more difficult.
5. Explore key topics • Goals • Fears • Strengths • Functions • Trade-offs	"What would your _____ say would be his/her most important **goals** if/when his/her health worsens? "What would your _____say are his/her **biggest fears and worries** about his/her health?" "What gives your _____and you **strength** as you think about the future and your _____'s illness?". "What do you think your _____ would say are **abilities** that are so critical to him/her that he/she couldn't imagine living without them?" "If your _____ becomes sicker, how much would he/she say he/she would be **willing to go through** for the possibility of gaining more time?
6. Close the conversation • Summarize what you've heard • Make a recommendation • Check for alignment • Affirm commitment	"It sounds like _____ (sumarize goals and fears) is very important to your _____." "Given your _____'s goals and priorities and what we know about his/her illness at this stage, I **recommend**.... "How does this plan seem to you?" **"We're in this together."**
7. Document your conversation on the ACP record	
8. Communicate with key clinicians	

FIGURE 3: SERIOUS ILLNESS CONVERSATION WITH SDM

https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Professionals/Clinical-resources/Advance-Care-Planning---Serious-Illness/Serious_Illness_Conversation_Guide_with_Substitute_Decision_Makers.pdf

The "Wish/Worry/Wonder" framework

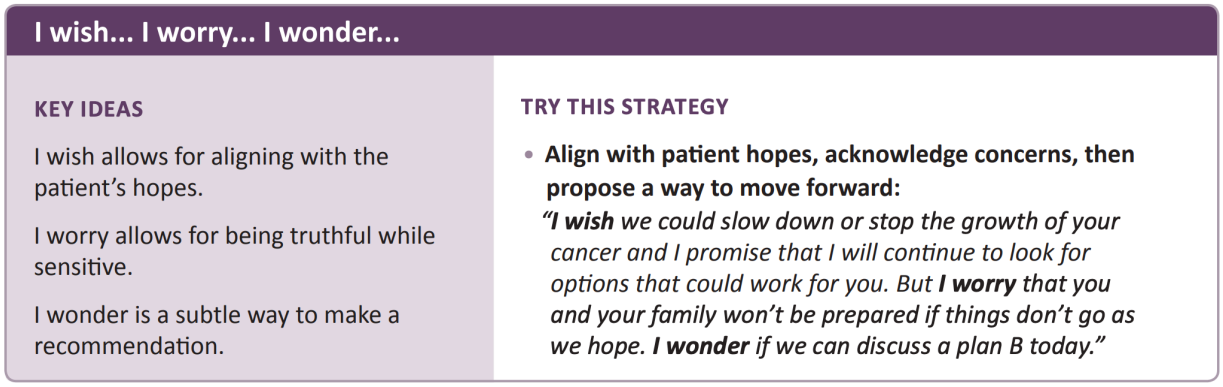

FIGURE 4: I WISH, I WORRY, I WONDER FRAMEWORK
https://www.divisionsbc.ca/sites/default/files/Divisions/Powell%20River/ClinicianReferenceGuide.pdf

Pertaining to COVID19 (or other serious respiratory illness), the clinician might consider stating the following (if consistent with patient values and context),

-I ***wish*** your mom/dad (or other) weren't struggling with this viral infection/ COVID19 infection/ chest infection, our home takes every possible measure to protect our residents
-I ***worry*** that given mom/dad's age and their co-existing illnesses, things are likely to get worse and mom/dad might go on to have respiratory failure. I also ***worry*** that pursuing invasive measures such as intubation or ventilation would not be helpful or considered if we send mom/dad to the hospital
-I ***wonder*** if we can talk about what mom/dad would have wanted in this scenario and discuss plan B to ensure they are comfortable and receive the best possible care with us

The clinician discusses next any goals and fears the SDM might have, which could bring up strong feelings such as guilt, commonly seen in caregivers. The topic of CPR might come up and the clinician may need to explain the known futility of CPR as an intervention overall and particularly in the critical ill elderly. The following is borrowed from the source shared earlier, https://www.divisionsbc.ca/sites/default/files/Divisions/Powell%20River/ClinicianReferenceGuide.pdf.

"CPR is a procedure for patients who have died in which we use machines to try to restart the heart or breathing. In patients with metastatic cancer, its effectiveness is extremely low — between 2% and 6% — and even those who can be brought back initially have to be kept alive on breathing machines and almost never leave the hospital."

Family might be reminded that the physician may withhold CPR if he/she does not deem it to be indicated, which is likely in this anticipated scenario. https://www.cmaj.ca/content/191/47/E1289 .

One consideration for providing recommendations, step 6, is to keep in mind that SDMs and family of LTC residents often develop a trusting working relationship not only with the clinician but the entire interdisciplinary team in the home. They come to feel ‘part of a bigger family’ and being direct and honest about our recommendations as clinicians alleviates the burden of guilt and uncertainty and enhances the security in their decision ‘to do what’s right’ for their loved one.

While this document may seem tedious, the principles are largely centred around the best possible narrative of the patient’s life story. When exercised regularly, they become second nature in clinical practice and provide excellent patient centred outcomes and family satisfaction with care. One recommendation to consider is to print a few copies of the serious illness conversation guide easily accessible through the link provided above, and use it as a template to start the first few serious illness conversations. With time, the vocabulary used becomes part of our language and communications with SDMs and family, and we begin to feel more comfortable having these dialogues earlier and more frequently.

Finally, please use own clinical judgement in applying these principles. While most LTC residents tend to be elderly and present with similar co-morbidities, a small precent of younger individuals as well as persons with a public trustee and guardian also reside in LTC. Tailoring the conversation to the individual’s needs in a medico-legally sound manner will optimize trust and outcomes for all involved.

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