Serious Illness Conversation with Substitute Decision Maker (SDM) in LTC  
(At risk of COVID-19)

**Purpose:** This is a guide for conversations with SDM or families in LTC in advance of a COVID-19 outbreak to inform them that care will take place in the home. Families and residents are encouraged to think about how they would like the team to provide care if their loved one becomes infected with COVID-19, knowing that there is no cure or vaccine available at present time.

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<tr>
<th>CONVERSATION FLOW</th>
<th>SUGGESTED LANGUAGE</th>
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<tbody>
<tr>
<td>1. Introduction</td>
<td>“We are connecting with all families and residents about the impact of COVID-19. How are you doing during this difficult time?”</td>
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| 2. Purpose & Permission | “I’d like to talk with you about what might lie ahead with your [loved one]’s health and get a better understanding of what’s most important to [him/her]”  
**Permission:** “Is this okay?”  
**Rationale if needed:** “The goal is to make sure that we know what matters most to you and your [loved one] so we can provide your [loved one] with the care you both want as the future is uncertain with COVID-19” |
| 3. ASK  
• Assess understanding | “What is your understanding about how the virus is impacting someone living with [underlying health conditions]?” |
| 4. TELL  
• Share information & prognosis  
• Use “wish ... worry” or “hope ... worry” statement  
• Allow for silence  
• Explore emotion | “In light of how rapidly COVID-19 is spreading, I would like to share with you what we are doing to prepare in the event of an outbreak and I think it’s important to consider how the virus might impact your [loved one]’s health.  
“We are preparing to care for our residents in our care home if they become infected with COVID-19. This is the safest and most comfortable place for seniors. We want you to know that our main priority is to ensure that your [loved one] is comfortable and cared for.  
Most COVID-19 symptoms are related to cough, fever, fatigue and shortness of breath. There are medications and therapies that can improve these symptoms and they can be provided in the care home to keep your [loved one] comfortable.”  
“We wish that we weren’t in this situation, but we are worried that if your [loved one] were to get the COVID-19, that [his/her] other health conditions leave [him/her] vulnerable and will make it difficult for [him/her] to survive. I wonder if we can talk about what would be most important to your [loved one] if [she/he] did become sicker?”  
[Allow space for silence and a response] |
| 6. ASK  
• Explore key topics | Goals / Priorities: “Given what I just shared, what are your goals and priorities for […] at this time and if they become infected?”  
Fears / Worries: “What are your greatest fears and worries?”  
Resident-Centred Focus: “If I asked your [loved one] these questions, would [she/he] give me the same answer?” |
| 7. Closing the conversation  
• Summarize & provide recommendations | “I’ve heard you say that ______ is really important to you. Keeping that in mind and knowing what we know now about the COVID-19, I recommend that we ______”  
**Affirm Commitment:** “We will do everything we can to support you and your [loved one] through this.”  
Document the conversation in detail and share with the team. |

This was adapted for VCH RPACE from Wallace Robinson, PHC Leader for Advance Care Planning  
And Ariande Labs: Serious Illness Care Program  
Updated March 27, 2020
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<th>Conversation Don’ts... Things to avoid</th>
<th>Conversation Do’s: Instead.... Try these</th>
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| Do not provide facts in response to emotions. Do not assume that you know the reason for their emotions. | Allow for silence.  
   Explore their emotions. Ask them “Tell me more…” |
| Do not make the conversation more about what you have to share. | Try to speak less than 50% of the time  
   Listen and empathize.  
   Gather information about them so that you can make recommendations that resonate with their situation and their wishes. |
| Do not use formal medical terminology | Use vocabulary appropriate to the family’s level. Check their understanding.  
   Check that you have understood their responses correctly by paraphrasing what you’ve heard them say. |
| Do not give false hope or make premature promises. | Be open and honest. Use “I wish/hope... but I worry... and I wonder...” statements.  
   Your “wish/hope” should align with what you’ve heard them say. This allows them to feel heard. |
| Do not provide families with a list of menu options. | Make a recommendation that aligns with what matters to them and what is likely to assist them in achieving their wishes. |
| Do not make this about life or death. | Recognize that there is more to life than quantity/time. This is about quality of life and the circumstances that patients find acceptable and unacceptable for their unique future. |

**Potential Recommendations:**

- Revisit MOST Level (if they are MOST 3+ to M2 or M1)  
  - Collaborate with General Practitioner (GP) or Nurse Practitioner (NP) to share outcome of conversation and prompt for review of MOST level  
  - GP / NP can use the Special Comments box to indicate special instructions  
- Update care plan (to include activities families often do when they visit)  
- Share with family what your site is doing to reduce the risk of infection

**Consider the following precautions regarding hospital visits at this time:**

- Increased risk of acquiring and spreading COVID-19 or any other infections as a result of exposure to other hospital staff and patients  
- Long wait times while staff prioritize patients requiring emergency services  
- Resources may be adjusted to assist with COVID-19 initiatives, potentially impacting the ability for staff to assist with eating, toileting, and supervision  
- Busy and noisy environments are difficult for people with dementia