

Serious Illness Conversation Guide with Substitute Decision Maker

* Decide how you will refer to the patient or resident based on your relationship with the Substitute Decision Maker (SDM). Will you refer to them by their [name or as your loved one/relative/friend] and consider appropriate pronouns [she/he/they/...]

* Consider who should be involved in this conversation – additional family members, spouse, friends, ...

Conversation Flow	Suggested Language
1 Set up the conversation	"I'd like to talk about what is ahead with [...] health and what is important to [...] so that we can make sure we provide [...] with the care [...] would want – is this okay?"
2 Assess understanding	"What is your understanding now of [...] health?" "What changes have you observed in [...] over the past (3 - 6 months)?"
3 Share prognosis	"I want to share with you my understanding of where things are with [...] health." "[...] is (give examples such as: staying in bed more, not participating in activities, eating less). It can be difficult to predict exactly what will happen and when; but generally, for someone with [...] condition(s), we can expect (describe trajectory) in the near future." Select one – most appropriate sentiment. (<i>Uncertain</i>) "I hope [...] will continue to be as well as [...] is /are now for a long time but I'm worried that [...] could decline quickly, and I think it is important to prepare for that possibility." (<i>Time</i>) "I wish we were not in this situation, but I worry that [...] may be nearing the end of [...] life in (days/weeks/short months)." (<i>Functional</i>) "I hope that this is not the case, but I'm worried that this may be as strong as [...] will feel, and things are likely to get more difficult."
4 Explore key topics	"Has [...] discussed with you [...] priorities and wishes in regards to [...] health?" "Does [...] have any previous advanced care planning documents?" " If [...] could express [...] wishes and make [...] own care decisions, what would [...] say was most important to [...]? (Attempt to understand the values and beliefs of both the client and the SDM)" "What might [...] biggest fears and worries be? What are your biggest fears and worries for [...]?" "If [...] becomes sicker, how much would [...] be willing to go through for the possibility of gaining more time?" "Has [...] spent any time in hospital ? How did [...] seem to feel about being there?" "How much do other family members know about [...] priorities and wishes?"
5 Close the conversation	"I've heard you say that ____ is really important to [...] and to you. Keeping that in mind, and what we know about [...] health, I recommend that we _____. This will help us make sure that the treatment plan reflects what's important to [...] and to you." "How does this plan seem to you?" "We will do everything we can to help [...] and you through this."
6 Document your conversation	
7 Communicate with key care team members: MRC (Most Responsible Clinician), Long Term Care Home, Home Health, ...	

Conversation Flow

1 Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

2 Assess understanding

3 Share prognosis

- Explain changes and illness trajectory
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

4 Explore key topics

- Goals and critical abilities
- Fears and worries
- Tradeoffs
- Past care
- Family

5 Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

6 Document your conversation

7 Communicate with key care team members