Advance Care Planning Discussion Guide for Individual with Serious Illness

Set up and Start Advance Care Planning Conversation

I would like to talk to you about what you can anticipate with your illness moving forward and discuss future treatment plans that align with your values to ensure that you get the best care possible. May I discuss this with you today?

Assess patient’s perception of current illness

To make sure we are on the same page, can you tell me what your understanding is of your illness (correct any misunderstanding using the language that match patient’s level of education. After correction, confirm patient’s understanding) (Use Ask-Tell-Ask principle)

Invite patient to share his/ her information Preference

How much information about what is likely ahead with your illness would you like me to share with you?

Share Knowledge related to prognosis and medical treatment (in term of Time / Function / Uncertainty)

**Time:** I understand this is a difficult situation for you, but I am worried that your time may be as short as … (days, weeks, months, years, etc.).

**Function:** I hope that this is not the case, but I am worried:
- That your current ability to function might be your “new normal.”
- That this may be as strong as you will feel.
- That things may get more difficult for you moving forward.

**Uncertain:** It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time. However, I am worried that you could get sick quickly, and I think it is important to prepare for the unexpected. (use hope & worry principle)

Respond to Emotion empathically

**Non-verbal**
- Provide Tissues and Utilize Silence
- Appropriate physical reassurance (ex. hand on shoulder)
- Active listening and Consistent Eye Contact

**Verbal (Using “N-U-R-S-E”)**
- **N-ame** “You seem like you are frustrated”, “It would be fine for someone in your situation to feel [sad/angry/frustrated].”
• **U-nderstand** “I cannot imagine how hard this is for you and your family.”
• **R-espect** “I can see how much you are trying to honor your Dad’s wishes.”
  “You are asking a lot of really good questions.” “I am very impressed with how well you’ve cared for your mother during this long illness. “
• **S-upport** “We will be there to help advise you. We can talk again tomorrow.”
• **E-xplore** “Tell me more about what you are thinking/feeling.”

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**Explore Patient’s values**

(Goals/ Fears/ Strengths/ Critical Abilities/ Trade-Offs/ Family Awareness)

I think it would be helpful for me to understand what is most important to you:

1.) Given what we know about your illness, what are your treatment **goals**?
2.) What are your **worries** and **fears** about your illness?
3.) You have been through so much. What has kept you going? From where do you gather your **strength**?
4.) What **abilities** are so critical to your life that you can’t imagine living without them?”
5.) What is your line in the sand where you would say “enough is enough”? How much are you willing to go through to gain more time?
6.) How much does your **family** know about your values and wishes?
7.) **For incapacitated patients:**
   a. Tell me a few things about your loved one. (What he/she enjoyed doing, his/her work and passion, what is important for him/her, etc.)
   b. “Have you ever talk with your loved one about his/her treatment wishes and priorities when he/she faced serious illness?”

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**Strategize specific decisions & Summarize the conversation**

Keeping in mind the values you shared with me and the course of your illness, I recommend that we _____. This will help us make sure that your treatment plans reflect what is most important to you.

How does that sound?

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**Affirm continued Support**

“[I/our medical team] will be with you during this illness, no matter what happens.”

**OR**

For patient with life limiting illness

“As a cure for your illness is not possible at this point in time, we will help you to live as FULL a life as possible.”

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*Adapted from Ariadne Labs’ serious illness conversation guide*