Spirituality in Goals of Care

10 Stages and Tools for Goals of Care Consultations

Supportive Care COALITION
Advancing Excellence in Palliative Care

These materials were created by the Supportive Care Coalition for a project designed to embed spirituality into palliative care goals of care consultations.

Interdisciplinary palliative care teams from twenty sites, representing Coalition member organizations across the U.S., used these stages and tools to become more intentional about integrating the patient's spiritual beliefs and values into patient/family conferences, as well as foster spiritual formation within the interdisciplinary team.

These resources offer suggested scripting with an emphasis on listening deeply for the patient's underlying spiritual concerns. Also included are three templates for use following a goals of care conference: team evaluation, after conference summary and a chart audit tool.

We express our gratitude to Dr. Woody English, clinical project leader, for his expertise and guidance in developing these resources.

10 Stages are adapted from: Weissman, DE, Conducting a Family Goal Setting Conference, Pocket Card, Palliative Care Center, Medical College of Wisconsin, with permission.

January 2017

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Practices that Honor the Sacredness of the Goals of Care Conference

Invite care team to be spiritually grounded and present
Dignity Question: “What do we need to know about you as a person to give you the best care possible?”
Inquire about the patient’s spirituality, hopes and fears
Honor silence that may facilitate deeper listening and sharing
Assess for spiritual distress/suffering
Draw upon patient / family’s spiritual strengths (faith, beliefs, values) in addressing goals of care
Express gratitude to patient and family
Team self-evaluation / reflection

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Goals of Care (GOC) Consultation: Stage 1
The First Encounter (Preparatory Visit)

Purpose	Description	Suggested Scripting
1. Explore patient/family's spiritual and cultural needs during initial contact prior to GOC consultation. 2. Identify how patient makes decisions, who patient trusts and would like to have participate in GOC consultation. 3. Inform interdisciplinary team of patient's concerns to be better prepared for GOC consultation. 4. Arrange GOC consultation with focused objectives and appropriate participants.	• One-on-one visit or call by a team member (chaplain, SW, RN). • Screen for distressing symptoms. • Be attentive to affect and screen for signs/sources of social distress and spiritual suffering. • Arrange for in-depth social and/or spiritual assessment prior to GOC consultation if appropriate and feasible. • Review medical records and contact key providers and family/other contacts. • Determine who will attend the GOC consultation, set the day and time for the meeting, and arrange for appropriate space.	➢ *Dr …X…has asked us to have a meeting with you to find out what is important, to help with decisions you might have to make, and to identify services to support you.* ➢ *When it comes to medical decisions, do you make these decisions alone or are medical decisions something your family likes to decide?* ➢ *Do you have a particular physician or clinical you really trust?* ➢ *Are there particular family members/loved ones you would like to include in our meeting with you?* ➢ *Are there things important to you and your family that your medical team should know about?* ➢ ***What do we need to know about you as a person to give you the best care possible? **** ➢ *Is spirituality important to you?* ➢ *Do you belong to a faith community?* ➢ *Do you have particular beliefs or spiritual practices we should be aware of?* *** Key question for this state*

Goals of Care Consultation: Stage 2

Briefing and Intentional Spiritual Grounding

Purpose	Description	Suggested Scripting
Team members huddle just before conference to share/review findings and objectives. Team members engage in spiritual grounding exercise.	• Each team member shares what he/she has learned and makes recommendations to the group. • Leader summarizes key facts and offers a strategy for the conference. • Attention is paid to the seating of participants in the room. • Silence phones and pagers. • Spiritual grounding focuses on personal centering so that each one may be open to the patient's agenda and to the sacred encounter.	➢ *For this conference, we should just take a moment for ourselves "to rest in the middle of things" so when we go into the room we will be open to this patient and family on their terms with none of our harried energy to distract from the flow of this encounter.* ***GRACE** Acronym* **G**round, be intentional **R**eflect what draws you to this work **A**cknowledge thoughts or emotions that may interfere with work that needs to be done **C**ompassionately detach from those emotions **E**nter the room

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Goals of Care Consultation: Stage 3
Introductions / Build Relationship

Purpose	Description	Suggested Scripting
Create a foundation for trust between the patient/family and the team. This should be given as much time as is reasonable to achieve this objective. Without the trust of the patient, the conversation will not get to where it should go.	• Each person introduces self and describes relationship to the patient. • This is the time to let the patient tell his/her story. • Focus on listening to the narrative and for the answers.	➢ *Let's go around the room and state our name and our relationship to …(name of patient)…* ➢ ***What do we need to know about you as a person to give you the best care possible?**** ➢ *It must be very difficult to see your loved one so sick.* ➢ *Can you tell me about your father/mother…, what kind of person he/she is?* ➢ *What has it been like for you these past months?* ➢ *Has anyone else in the family ever experienced a situation like this?* ➢ *Knowing your loved one, what do you think would be most important for him/her right now?* ➢ *What do you think are your loved one's primary concerns right now? (…avoiding pain?...being with family?)*

*A good open-ended question is one for which you have no idea what the answer could be

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Goals of Care Consultation
Deepening the Conversation

Purpose	Description	Suggested Scripting
These are tactics and sample scripting that will deepen the conversation at any stage.	• Pay close attention to the affect in the patient, in the family, and in the room. • Permit periods of silence as needed. • Follow up with short, open-ended clarifying questions.* • Look for signs of spiritual distress • Explore spiritual strengths. • Invite the family to reflect on what they heard the patient saying.	➢ *Tell me more about that.** ➢ *I noticed that you looked away when I said….* ➢ *I want to get back to something you said earlier….* ➢ *Where do you find strength to get through this? ** ➢ *What does this mean to you? ** ➢ *What makes you worry? ** ➢ *What do you hope for? ** ➢ *What did you hear the patient say?(Directed to family who are listening).* ➢ *Knowing your loved one, what do you think would be most important for him/her right now? ** ➢ *What do you think are your loved one's primary concerns right now? (…avoiding pain?...being with family?)**

*A good open-ended question is one for which you have no idea what the answer could be

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Goals of Care Consultation: Stage 4

What Does the Patient / Family Know?

Purpose	Description	Suggested Scripting
This is to understand if the patient and family have a reasonable grasp of what has happened and to explore what they know.	• This is the time to learn how the patient/family process information received from other clinicians and what they are likely to understand from you. • Continue to listen for the patient's narrative. • Seek clarification when and where appropriate.	➢ *Can you tell me what you understand your medical condition to be at this time?* ➢ *What have you been told about your situation?*

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Goals of Care Consultation: Stage 5

What Have the Patient / Family Been Told to Expect?

Purpose	Description	Suggested Scripting
Understand and clarify what the patient has been told about the future and what he/she believes may happen.	• Ask if the patient or family have been told about the patient's prognosis and what to expect. • Patient can be invited to speak from his/her own intuition or feelings about how he/she sees the future unfolding. • Are there unreasonable expectations that can be re-framed in a way that is consistent with the patient's values and goals? • Are there reasonable expectations that should modify the current care plan?	➢ *What have the doctors told you to expect?* ➢ *What do you think will happen?* ➢ *What do you anticipate in the next days, weeks, months?*

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Goals of Care Consultation: Stage 6
Medical Review and Prognosis

Purpose	Directions	Suggested Scripting
Recount a customized and meaningful narrative. Then, offer to prognosticate.	• Shape the narrative with guidance from what has been learned in stages 3, 4, and 5 above. • After giving the narrative, check for understanding and credibility. • Then offer to prognosticate using Ask-Tell-Ask. • In prognosticating life expectancy, use categories of time: hours, days, weeks, months, etc…. • Embrace the paradox of simultaneously knowing and not knowing. • Focus especially on function (what day-to-day living and ADL's will be like).	➢ ***I have had a chance to read your medical record, review your tests, and talk with your doctors (..Drs X, Y, and Z..). Now that you have told me what you know, I believe you have a pretty good idea of what is going on. I would like to offer what I have learned. Is that okay? **** ➢ *A concise retelling of the patient's history should build on what the patient has disclosed to clarify areas of distress, to reinforce the patient's (and family's) integrity, and to give meaning (in the context of the patient's values) to events and decisions that have occurred. This is a creative process for the physician or nurse practitioner and cannot be scripted in advance.* ➢ ***I have also had a chance to think about where things are going and what to expect, would you like me to share these thoughts with you as well? **** ➢ *I can tell you that doctors and nurses cannot predict exactly how things will turnout. However, based on experience with others in your situation, we have a general idea about what to expect. Would you like me to talk about that now?* ➢ *Would you like me to tell you what I know about what it is like to live with this kind of medical condition?*

***The key question for this section.

Goals of Care Consultation: Stage 7

Be Present for Lamentation and Suffering

Purpose	Description	Suggested Scripting
This is the time for the team to be fully present to the patient's and family's suffering. The prognostication discussion may precipitate profound social and spiritual distress. (The suffering may have been surfacing throughout the conference.)	• Be grounded, open, and present in yourself. • Create a safe space (a circle of trust). • Honor the depth of emotion with silence. • Use the strength and energy of the team. • Opportunity to practice empathy. • Opportunity for defining hope and/or transforming expectations.	➢ *Name the emotion. Acknowledge and validate it.* ➢ *This conversation has been pretty intense. Why don't we just take a moment to absorb it.* ➢ *I'm sorry this is such a difficult experience for you and your family.*

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Goals of Care Consultation: Stage 8
Offer Options and Recommendations

Purpose	Description	Suggested Scripting
Name hoped for outcomes and feasible options. Frame the offerings in the context of the patient's stated goals and values.	• Ask for patient's permission to offer options and recommendations. • Offer patients/families a range of options, use "both…and" language; avoid using "but" when connecting ideas. • Plan A, if we get what we hope for. • Plan B, to prepare for alternatives if we do not get what we hope for (and the patient gives permission to discuss this). • When the prognosis is uncertain, plans should specify concrete milestones (time and function) at which point the next short-term milestone or plan would be established. Examples might be: -endotracheal tube trial for 2 weeks before tracheostomy - NG tube feeding in "x' amount of time to recover swallow functions before G-tube would be necessary.	➢ *This is what I understand to be most important to you at this time…..* ➢ *If this goes the way we hope, then we will do....* ➢ *Here's what could be done....* ➢ *Here's what we would recommend based on what we know and what you have said about your loved one.* ➢ *Continuing the antibiotics may cure the infection in your lungs and that is what we are all hoping for. However, we do not always get what we hope for. Would it be helpful for us to talk about how we will care for you if we don't get what we hope for?* ➢ *If the cancer is no longer able to be controlled, this is what we can do to support you.* ➢ *We understand your mother does not want to be kept alive with artificial breathing support. We will continue the ventilator until next Monday and if she can be weaned off the ventilator by then, that is what we hope for. If she cannot come off the ventilator, we would not do a tracheostomy and would anticipate withdrawing her from the ventilator at that time.*

Goals of Care Consultation: Stage 9
Summarize, Express Gratitude and Hope, Plan Next Steps

Purpose	Description	Suggested Scripting
Formal closure, wrap up, opportunity for clarification, and mechanism to exit as a team together.	• Restate patient's values, goals, strengths, and hopes. • Summarize recommendations, ask for clarification by patient and family (teach back). • Thank participants with sincerity and grace, even if there had been contention and conflict. • Set up expectation that everyone on the team has to leave the room now and that someone from the team will be available for the family if other needs arise.	➢ *This is what I understood is most important to you…..* ➢ *This is what we can do to support you….* ➢ *Knowing your loved one, does our recommendation/plan seem right for him/her?* ➢ *Do you think another plan would be better, given his/ her values, preferences, and relationships?* ➢ *Ask patient or family member (if present) to repeat back what they understand the next steps to be.* ➢ *Thank you for your participation and willingness to be open and candid with us. It has been an honor for us to get to know you and your family and be able to offer some support to you.* ➢ *We will now leave you so that we can start to work on this plan. The (name the team member) will return (specify time) to check back with you and provide a brief summary of this visit.*

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Goals of Care Consultation: Stage 10
Debrief and Document

Purpose	Description	Suggested Scripting
Team huddle in a private location immediately after the conference to gather insights from each team member, formulate plans, and make assignments.	• Identify a scribe to complete the after conference summary. • Debrief on differing perspectives of what was learned about patient and family in the conference. • Account for any moral distress among team members. • Make note of any lessons learned about how members functioned as a team and give consideration to incorporating changes in the team's practice. • Clarify team assignments for follow-up communication and tasks (who, what, when). • Give patient/family a brief written summary of the visit to validate things hoped for and recommendations presented. • Formal documentation of findings, recommendations, and follow up plans into the medical record.	➢ *What did we learn about the patient/family that was new?* ➢ *How did you feel about how this meeting went?* ➢ *What did we learn about ourselves, what is working, what is not working?* ➢ *Are we being stimulated, given a chance to work "at the top of our licenses"?* ➢ *What would we do differently next time?* ➢ *How satisfied are we that the team listened intently for the patient/family's spiritual concerns/beliefs/values and integrated these into the goals of care and treatment discussion?*

Team Evaluation

Teams are encouraged to have a short team debriefing session following these conferences. This tool serves as a guide for this self-evaluation and reflection.

		YES	NO
1.	Preparatory visit with patient/family prior to conference preferably in-person, by phone if necessary. If yes, by who: (circle) Physician APN RN SW Chaplain Other _____		
2.	Team spiritual grounding reflection/meditation prior to conference?		
3.	Introductions to build relationships?		
4.	Dignity Question asked: What do we need to know about you as a person to give you the best care possible?		
5.	Patient/family invited to articulate personal/social/cultural strengths/resources?		
6.	Patient/family invited to articulate spiritual strengths/resources?		
7.	Patient/family asked about fears/distress?		
8.	Patient/family asked what they know about medical condition?		
9.	Patient/family asked if they were told what to expect?		
10.	PC clinician provided medical review and prognosis?		
11.	Patient's goals/preferences addressed?		
12.	Patient/family invited to explore what they hope for?		
13.	PC clinician provided summary of conversation and outlined next steps?		
14.	Team expressed gratitude to patient/family?		
15.	PC team debriefed following meeting with patient/family?		
16.	How satisfied were you that the team listened intently for patient/family's spiritual concerns/ beliefs/values and integrated these into the goals of care and treatment discussions? (Circle) **5-Very satisfied** **4- Somewhat satisfied** **3- Neutral** **2- Somewhat unsatisfied** **1- Very unsatisfied** **Comments:**		

After Conference Summary

Use this template for a written conference summary for patients and families.

Name of Patient _____

Family Members Present _____

Thank you for helping us understand what is important to you as you live through this difficult time.

This is a summary of the conference we had with you on _____ with
(date)

- **Members of our Palliative Care Team**:
  Name & Role
  Contact information

- **Reason for Visit:**

- **What We Heard From You:**
  What matters most to you
  What you hope for

- **Our Recommendations:**
  We recommend
  Our next steps are

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Chart Audit

This chart audit tool can be used to review/evaluate the documentation of goals of care conferences.

PC team participants in conference: (circle) Physician APN RN SW Chaplain Other_____

	YES	NO
1. Patient physically present in conference		
2. Family/significant person(s) present in conference		
3. Preparatory visit with patient/family for Goals of Care Conference took place If yes, by whom: (circle) Physician APN RN SW Chaplain Other_____		
4. Spiritual assessment by palliative care chaplain in chart		
5. Patient's beliefs/values documented in Goals of Care Conference Note		
6. Assessment of spiritual/existential distress/suffering documented in Goals of Care Conference Note		
7. Explanation of patient's medical condition and prognosis documented		
8. Discussion of options for treatment documented		
9. Patient's goals/preferences documented		

10. How satisfied were you that the chart documentation for this Goals of Care Conference identified the patient/family's spiritual concerns/beliefs/values and integrated these into the goals of care and treatment discussions? (circle)

5-Very satisfied **4- Somewhat satisfied** **3- Neutral** **2- Somewhat unsatisfied** **1- Very unsatisfied**

Comments:

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