ATTENDEE HANDOUT

PALLIATIVE CARE: SERIOUS ILLNESS

MI-CCSI
Center for Clinical Systems Improvement

CONTENTS

Palliative Care: Serious Illness Training

Optimizing Serious Illness Conversations,
Conducting a Comprehensive Assessment and Care Coordination

Training Agenda

7:45	**8:00**	**Log in & Welcome**
8:00	**10:15**	**Serious Illness Conversation Guide (providers and care team)** ***Mode of Learning**: Didactic presentation and practical application participation* ***Presenter**: Mary Beth Billie, DNP, RN-BC, CCM* ***Objective**: Review the key components of the Serious Illness conversation*
10:15	**10:30**	**Break**
10:30	**11:15**	**PDCM Billing and Care Coordination** ***Mode of Learning**: Didactic presentation and practical application participation* ***Presenters**: Sue Vos, BSN, RN, CCM & Robin Schreur, RN, CCM* ***Objective**: Review key considerations and available codes for billing of services related to serious illness.*
11:15	**11:45**	**Lunch**
11:45	**12:45**	**Psychosocial/Behavioral Assessment** ***Mode of Learning**: Didactic presentation and practical application participation* ***Presenter**: Ellen Fink-Samnick, DBH, MSW, LCSW, ACSW, CCM, CCTP, CRP* ***Objective**: Identify key components of a psychosocial assessment for patients living with serious illness (SI) (e.g., social determinants of health, cultural aspects of diversity and inclusion)*
12:45	**1:45**	**Biomedical/Physical Assessment** ***Mode of Learning**: Didactic presentation and practical application participation* ***Presenter**: Carol Robinson DNP, RN, CHPN* ***Objective**: Review of the comprehensive assessment to include areas sensitive to Serious Illness, end-stage conditions*
1:45	**1:50**	**Break**

1:50	**5:00**	**SERIOUS ILLNESS SIMULATIONS: (Includes simulation & feedback)** ***Objective:*** *Practice conducting the serious illness conversation with a trained standard patient to build skill and confidence.* *Review feedback of the simulation with the instructor/evaluator to identify strengths and opportunities.* Group 1 – 1:50 - 2:35 pm Group 2 – 2:35 - 3:20 pm Group 3 – 3:20 - 4:05 pm Group 4 – 4:05 - 4:50 pm EACH ROUND IS 45 MINUTES
		Training Evaluation (following each simulation)

Additional information

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

"I would like to **talk together** about what's happening with your health and **what matters to you. Would this be ok?"**

ASSESS

"To make sure I share information that's helpful to you, can you tell me **your understanding** of what's happening with your health now?"

"How much **information about what might be ahead** with your health would be helpful to discuss today?"

SHARE

"Can I share my understanding of what may be ahead with your health?"

Uncertain: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that you could get sick quickly**, and I think it is important that **we prepare** for that."

OR

Time: "I **wish** this was not the case. I am **worried** that time may be as short as *(express a range, e.g. days to weeks, weeks to months, months to a year).*"

OR

Function: "It can be difficult to predict what will happen. **I hope you will feel as well as possible** for a long time, and we will work toward that goal. **It's also possible that it may get harder to do things** because of your illness, and I think it is important that we prepare for that."

Pause: Allow silence. Validate and explore emotions.

EXPLORE

"If your health was to get worse, what are your **most important goals**?"

"What are your biggest **worries**?"

"What **gives you strength** as you think about the future?"

"What **activities** bring joy and meaning to your life?"

"If your illness was to get worse, **how much would you be willing to go through** for the possibility of more time?"

"How much do the **people closest to you know** about your priorities and wishes for your care?"

"Having talked about all of this, **what are your hopes** for your health?

CLOSE

"I'm hearing you say that ___ **is really important to you** and that you are **hoping for** ___. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your **care reflects what's important to you. How does this plan seem to you?"**

"I will do everything I can to support you through this and to make sure you get the **best care possible."**

ARIADNE LABS

EMPATHIC RESPONSES

Naming	Understanding	Respecting	Supporting	Exploring	"I Wish"
This must be… • Frustrating • Overwhelming • Scary • Difficult • Challenging • Hard	What you just said really helps me understand the situation better.	I really admire your • Faith • Strength • Commitment to your family • Thoughtfulness • Love for your family	We will do our very best to make sure you have what you need.	Could you say more about what you mean when you say… • I don't want to give up • I'm hoping for a miracle	I wish we had a treatment that would cure you (make your illness go away).
I'm wondering if you are feeling … • Sad • Scared • Frustrated • Overwhelmed • Anxious • Angry	This really helps me better understand what you are thinking.	You (or your dad, mom, child, spouse) are/is such a strong person and have/has been through so much.	Our team is here to help you with this.	Help me understand more about…	I wish I had better news.
It sounds like you may be feeling …	I can see how dealing with this might be … • hard on you • frustrating • challenging • scary	I can really see how (strong, dedicated, loving, caring, etc.) you are.	We will work hard to get you the support that you need.	Tell me more…	I wish you weren't having to go through this.
In this situation, some people might feel …	I can see how important this is to you.	You are such a (strong, caring, dedicated) person.	We are committed to help you in any way we can.	Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you.	I wish that for you too. [In response to what a patient or family members wishes, such as a miracle]
I can't even imagine how (NAME EMOTION) this must be.	Dealing with this illness has been such a big part of your life and taken so much energy.	I'm really impressed by all that you've done to manage your illness (help your loved one deal with their illness).	We will go be here for you.	Can you say more about that?	I wish we weren't in this spot right now.

God's going to bring me a miracle.	**How much time do I have left?**	**Are you saying there is nothing more you can do?**

• I hope that for you, too. (**Remember: no buts**!) (**I WISH**)
• I really admire and respect. your faith (**RESPECTING**)
• Having faith is very important. (**RESPECTING**)
• Can you share with me what a miracle might look like for you? (**EXPLORING**)
	NOTE: This question may mean many things – they are scared, they want to know so they can plan, they are suffering, etc. Exploring what they want to know can be very helpful.
	• That is a great question. I am going to answer it the best that I can. Can you tell me what you are worried about? **(EXPLORING)**
	• That is a great question. I am going to answer it the best that I can. Can you tell me what information would be most helpful to you? **(EXPLORING)**
		• I can't even imagine how (**NAME EMOTION**) this must be. (**NAMING)**
		• It sounds like you might be feeling … (**NAMING)**
		  ○ Alone
		  ○ Scared
		  ○ Frustrated
		  ○ Etc.
		• I wish we had a treatment that would cure you. (**I WISH**) Our team is here to help you through this. (**SUPPORTING)**

Are you telling me my dad is dying?	**Are you giving up on me?**	**My dad is a fighter!**

NOTE: These responses will affirm the question empathically – so do not use them if the patient is not dying.
• This must be such a shock for you. (**NAMING**)
• I can't even imagine how difficult this must be. (**UNDERSTANDING**)
• I wish I had better news. (**I WISH**)
	• I wish we had more curative treatments to offer. **(I WISH**) Our team is committed to help you in every way we can. (**SUPPORTING**)
	• We will be here for you. (**SUPPORTING**)
	• It sounds like you might be feeling … (**NAMING/EXPLORING)**
	  ○ Alone
	  ○ Scared
	  ○ Etc.
	• We will work hard to get you the support that you need. (**SUPPORTING**)
		• He is. He is such a strong person and he has been through so much. (**RESPECTING**)
		• I admire that so much about him. (**RESPECTING**)
		• I really admire how much you care about your dad. (**RESPECTING**)
		• It must be (**NAME EMOTION**) to see him so sick. (**NAMING**)
		• Tell me more about your dad and what matters most to him. (**EXPLORING**)

***Note: These phrases are examples of empathic continuers. Patients may not immediately respond to your first empathic statement. They will often need multiple successive empathic responses to their questions to work through an emotion. ***

Goals of Care Conversations training materials were developed and made available for public use through U.S. Department of Veterans Affairs contracts with VitalTalk [Orders VA777-14-P-0400 and VA777-16-C-0015]. Updated June 2018.

PDCM BILLING CODES (UNIQUE TO BCBSM/BCN AND PRIORITY HEALTH)

Code	Description	Use/Times	Considerations	Notes
G9001*	Coordinated Care Fee	Initial Assessment		
G9002*	Coordinated Care Fee	Maintenance or follow up	Quantity billed >45 minutes	
98961*	Group Education	2–4 patients for 30 minutes	Quantity billed	
98962*	Group Education	5–8 patients for 30 minutes	Quantity billed	
98966*	Phone Services	5-10 minutes		
98967*	Phone Services	11-20 minutes		
98968*	Phone Services	21-30 minutes	*No payment beyond 30 minutes	
99487*	Care Management Services	31-75 minutes per month	Care coordination in medical neighborhood	
99489*	Care Management Services	every additional 30 minutes per month	Care coordination in medical neighborhood	
G9007*	Team Conference			
G9008*	Physician Coordinated Care Oversight Services	Physician only service and can only be billed by a physician		
S0257*	- End of Life Counseling			

** Priority Health Notation: PDCM codes applicable for the care manager are defined as QHPS*

CMS MLN Guide: https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/advancecareplanning.pdf

Edmonton Symptom Assessment System

(ESAS-r)

Numerical Scale

Patient name: _____

Address: _____

Date of birth: _____

Phone #: _____

PHN: _____

PATIENT LABEL

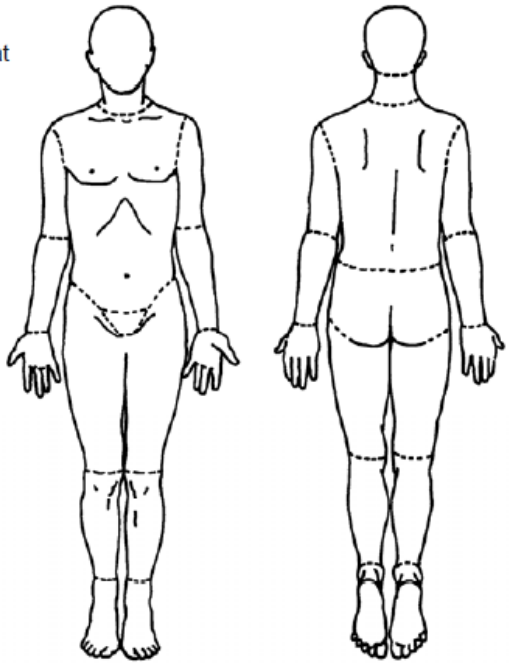
Please circle the number that best describes how you feel **now**:		
No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
No tiredness *(tiredness = lack of energy)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
No drowsiness *(drowsiness = feeling sleepy)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
No nausea	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
No lack of appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible lack of appetite
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath
No depression *(depression = feeling sad)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
No anxiety *(anxiety = feeling nervous)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Best wellbeing *(wellbeing = how you feel overall)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible wellbeing
No _____other problem *(for example constipation)*	0 1 2 3 4 5 6 7 8 9 10	Worst possible _____

Completed by: (check one)

- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

Date and time: _____

Please mark on these pictures where it is that you hurt:



KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of· disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort· some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying about of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance· but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled· requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent
	20	Very sick· hospital admission necessary· active supportive treatment necessary.
	10	Moribund· fatal processes progressing rapidly.
	0	Dead

Doctors usually classify patients' heart failure according to the severity of their symptoms. The table below describes the most commonly used classification system, the **New York Heart Association (NYHA) Functional Classification**[1]. It places patients in one of four categories based on how much they are limited during physical activity.

Class	Patient Symptoms
I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.
Class	**Objective Assessment**
A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
D	Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.

For Example:

- A patient with minimal or no symptoms but a large pressure gradient across the aortic valve or severe obstruction of the left main coronary artery is classified:
  - **Function Capacity I, Objective Assessment D**

- A patient with severe anginal syndrome but angiographically normal coronary arteries is classified:
  - **Functional Capacity IV, Objective Assessment A**

[1] *Adapted from Dolgin M, Association NYH, Fox AC, Gorlin R, Levin RI, New York Heart Association. Criteria Committee. Nomenclature and criteria for diagnosis of diseases of the heart and great vessels. 9th ed. Boston, MA: Lippincott Williams and Wilkins; March 1, 1994.*

Original source: Criteria Committee, New York Heart Association, Inc. Diseases of the Heart and Blood Vessels. Nomenclature and Criteria for diagnosis, 6th edition Boston, Little, Brown and Co. 1964, p 114.

Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity Level & Evidence of Disease	Self -care	Intake	Conscious level
PPS 100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
PPS 90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
PPS 80%	Full	Normal activity & work *with* effort Some evidence of disease	Full	Normal or reduced	Full
PPS 70%	Reduced	Unable normal activity & work Significant disease	Full	Normal or reduced	Full
PPS 60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance	Normal or reduced	Full or confusion
PPS 50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance	Normal or reduced	Full or drowsy or confusion
PPS 40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
PPS 30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Reduced	Full or drowsy +/- confusion
PPS 20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal sips	Full or drowsy +/- confusion
PPS 10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma
PPS 0%	Dead	-	-	-	-

Instructions: PPS level is determined by reading left to right to find a 'best horizontal fit.' Begin at left column reading downwards until current ambulation is determined, then, read across to next and downwards until each column is determined. Thus, 'leftward' columns take precedence over 'rightward' columns. Also, see 'definitions of terms' below.

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. **Ambulation** (Use item **Self-Care** to help decide the level)
   - **Full** — no restrictions or assistance
   - **Reduced ambulation** — degree to which the patient can walk and transfer with occasional assistance
   - **Mainly sit/lie vs Mainly in bed** — the amount of time that the patient is *able to* sit up or *needs* to lie down
   - **Totally bed bound** — unable to get out of bed or do self-care

2. **Activity & Evidence of Disease** (Use **Ambulation** to help decide the level.)
   - **Activity** — Refers to normal activities linked to daily routines (ADL), house work and hobbies/leisure.
   - **Job/work** — Refers to normal activities linked to both paid and unpaid work, including homemaking and volunteer activities.
   - Both include cases in which a patient continues the activity but may reduce either the time or effort involved.

   Evidence of Disease
   - **No evidence of disease** — Individual is normal and healthy with no physical or investigative evidence of disease.
   - **'Some,' 'significant,' and 'extensive' disease** — Refers to physical or investigative evidence which shows disease progression, sometimes despite active treatments.

   - Example 1: Breast cancer:
     some = a local recurrence
     significant = one or two metastases in the lung or bone
     extensive = multiple metastases (lung, bone, liver or brain), hypercalcemia or other complication

     Example 2: CHF:
     some = regular use of diuretic &/or ACE inhibitors to control
     significant = exacerbations of CHF, effusion or edema necessitating increases or changes in drug management
     extensive = 1 or more hospital admissions in past 12 months for acute CHF & general decline with effusions, edema, SOB

3. **Self-Care**
   - **Full** — Able to do all normal activities such as transfer out of bed, walk, wash, toilet and eat without assistance.
   - **Occasional assistance** — Requires *minor* assistance from several times a week to once every day, for the activities noted above.
   - **Considerable assistance** — Requires *moderate* assistance every day, for *some* of the activities noted above (getting to the bathroom, cutting up food, etc.)
   - **Mainly assistance** — Requires *major* assistance every day, for *most* of the activities noted above (getting up, washing face and shaving, etc.). Can usually eat with minimal or no help. This may fluctuate with level of fatigue.
   - **Total care** — Always requires assistance for all care. May or may not be able to chew and swallow food.

4. **Intake**
   - **Normal** — eats normal amounts of food for the individual as when healthy
   - **Normal or reduced** — highly variable for the individual; 'reduced' means intake is less than normal amounts when healthy
   - **Minimal to sips** — very small amounts, usually pureed or liquid, and well below normal intake.
   - **Mouth care only** — no oral intake

5. **Conscious Level**
   - **Full** — fully alert and orientated, with normal (for the patient) cognitive abilities (thinking, memory, etc.)
   - **Full or confusion** — level of consciousness is full or may be reduced. If reduced, confusion denotes delirium or dementia which may be mild, moderate or severe, with multiple possible etiologies.
   - **Full or drowsy +/- confusion** — level of consciousness is full or may be markedly reduced; sometimes included in the term stupor. Implies fatigue, drug side effects, delirium or closeness to death.
   - **Drowsy or coma +/- confusion** — no response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period. Usually indicates imminent death

SIMULATION

STEP BY STEP TO SIMULATION FEEDBACK

1. Have available for the call the documents titled the **"SI Guide Care Manager Conversation"** and the **"Empathic Response Guide"**.
2. Click on this link: https://www.surveymonkey.com/r/2024-SI-Self-Eval and have it ready. You will fill out the SurveyMonkey form *after* completing the Serious Illness conversation. *Do Not fill out at this time.*
3. Join the breakout room with the instructor and assigned patient.
4. Review the patient's background and purpose of the simulation with the instructor and prepare to begin the simulation with the patient.
5. Complete the SI conversation using the **SI Guide**.
6. After the SI conversation dialogue, complete the **SurveyMonkey Self-Assessment** (the form you previously opened). *This will take approximately 5-8 minutes.*
7. If you can't open the SurveyMonkey link, use the time to reflect on the following:
   i. Did you use the guide and follow it?
   ii. Identify the communication skills used to engage with the patient.

   Reflections, open-ended questions, summaries, I wish, or I hope statements

   iii. Did the interaction feel like a conversation versus a survey?
   iv. Did you refrain from wanting to talk about medical management?
8. While you are completing the self-assessment, the instructor is completing the Instructor Feedback Form.
9. When you have completed your self-assessment, let the instructor know you are ready for the feedback session.

   After the feedback, the simulation is complete, and you have a break.
10. A copy of your self-assessment will be provided to you. This is for your own learning and is not shared with others.

PURPOSE OF SIMULATION

The overall purpose of this exercise is to reinforce the importance of adhering to the evidence-based Structured Serious Illness Conversation Guide, with a focus on the four areas questions outlined in the guideline. You will utilize key communication skills (i.e. open-ended questions, reflection, exploring, affirmations, and I wish statements) in each of the areas to elicit more information and gain a fuller understanding of the patient's perspective.

To begin the conversation, the attendee provides an introduction of self and the purpose of the call today.

STANDARD PATIENT CASE: SERIOUS ILLNESS CONVERSATION

OVERVIEW

You (the attendee) are following up with the patient, who was recently discharged from the hospital and is scheduled to have a meeting with you today to follow up on the serious illness conversation.

PATIENT HEALTH HISTORY

- 68-year-old retired salesperson
- Patient has
    i. Severe Chronic Obstructive Pulmonary Disease (COPD)
        1. On steroids and home oxygen
    ii. Chronic kidney disease
    iii. Diabetes
    iv. Chronic hip pain
- This year the patient has had three hospitalizations (COPD exacerbations) and two ED visits (falls)
- Worsening shortness of breath, muscle weakness, fatigue, declining functional status at home, despite short stays in rehab after each hospitalization
- Spouse very involved and 28-year-old daughter lives nearby

PATIENT BACKGROUND

The patient was discharged from the hospital one month ago. Upon discharge, the patient was told by the primary care provider to use oxygen all the time (24/7) at home (previously it was only used during the day as needed). The physician didn't explicitly say anything to the patient about the prognosis.

At the end of your call last week with the care manager / attendee, the care manager / attendee sent you some information to share with your spouse and help you prepare for today's discussion. This call is not about that information sent to you– we do not expect the care manager / attendee to reference the information. It is about having a conversation to understand your values and wishes.

CARE MANAGER / ATTENDEE ROLE

The goal of the discussion today for the care manager / attendee is to use the Serious Illness Conversation Guide (standard communication tool), to explore the patient's values, goals, and priorities for care in the setting of illness progression. The tool the care manager / attendee should be using is the Serious Illness Conversation Guide.

Reminder: At the last visit, the care manager / attendee introduced him / herself and mentioned this meeting to continue the serious illness conversation topic. The care manager / attendee provided the patient with some reading materials to review with your family.

THE MEETING (SIMULATION)

The case manager/attendee reviews the patient background, the goals of the simulation exercise and informs the instructor when they are prepared to begin the simulation.

Ideally, the care manager/attendee will adhere to the structured communication guide and use key communication skills to elicit more information during the call.

For purposes of this simulation, we are limiting the time allotment for the simulated conversation to no longer than 35 minutes. The instructor/evaluator will serve as a timekeeper and will provide a 5-minute warning if need