



When and How to Introduce Palliative Care

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Objectives

- Identify patients with serious illness who would benefit from palliative care services
- Communicate effectively with patients facing serious illness regarding palliative care services



What is Palliative Care?

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

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Medicare Hospice Conditions of Participation – Final Rule



When to introduce Palliative Care?

1. At **diagnosis** of a serious illness:

- Cancer, CHF, COPD, liver or kidney failure, dementia, ALS, accumulation of 'multimorbidity', etc.

2. At **time of change** in illness:

- Progression of disease, loss of function, loss of nutritional capacity, increased symptom burden

3. At time of illness **crisis**:

- Hospitalizations, ICU stays
- Consideration of advanced therapies
 - Dialysis, tracheostomy, PEG tube, transplant, LVAD, etc.

4. When **cued** by patient and/or family

At Diagnosis? ASK-TELL-ASK

- **ASK** what the patient/family knows, and what they want to know
 - *‘What did you hear from the (insert subspecialist) about what’s going on?’*
 - *‘People think about different things when they’re living with illnesses like yours. What’s been on your mind most?’*
 - *‘How much do you want to know about the future?’*

...ASK-TELL-ASK

- **TELL** what you need to communicate (bad news, prognosis, treatment options)
 - Keep it short, simple (9th grade-level)
 - No more than 3 ‘digestible chunks’ of info
 - *‘It sounds like the oncologist told you that your biopsy showed cancer. **That can be scary.** She is recommending that you start chemotherapy next week.’*
 - *‘It looks like you’ve got pretty bad heart failure, which is serious. That’s probably why you’ve been so tired and short of breath. We have medications that **can help you feel and function as well as possible.**’*

...ASK-TELL-ASK

- **ASK** what the patient understands about what you've talked about
 - *'We've talked about important things today. To make sure I've been clear, can you tell me in your words what we've discussed?'*
 - *'Who are you going to tell about our visit when you get home?'*
 - *'What questions do you have?' or 'What can I do for you today before we leave?'*

After every encounter

- **Clarify** plan for next steps
 - *'You'll see the lung doctors next week for your pulmonary function tests, and then me in 2 weeks.'*
 - *'We'll increase your pain medication as we discussed today, then see you back on the 18th. My nurse will call before that **to see how you're doing**.'*
- **Commit** to care, regardless of course
 - *'No matter what happens with your chemotherapy and radiation, we'll be here to help you **live as well as you can, for as long as you can**.'*
 - *'Sometimes questions or problems come up right after you leave here; **never hesitate to call**.'*



At Time of Change in Illness

- ASK

- *'I'm sorry to hear that your cancer is back. That's a lot to get your head around. Is it OK for us to talk about what that means?'*
- *'I agree that your mom's memory is getting worse. How much time is she spending doing things she enjoys? How much of the day does someone need to be with her? How are you doing with all of this?'*



At Time of Change in Illness

- TELL
 - *‘From what we know about your situation, talking about this information can help us make decisions together about what happens next.*
 - *‘When you started dialysis it helped you live pretty well, for several years. But now it’s getting harder to keep you out of the hospital, and harder to make the dialysis keep working.*



At Time of Change in Illness

- ASK

- ‘We talked before about what’s important to you in living. Given your recent change, have you been thinking any more about that?’
- ‘I can see it’s getting harder for you to take the chemotherapy. What are you hoping for from the treatment?’
- ‘Have you thought about what would happen when you can’t keep living the way you want to?’



At Time of Crisis

- ASK

- ‘You’re back in the intensive care unit, and I’m sorry about that. **Tell me what’s most on your mind about your situation?**’
- ‘It’s getting harder for your mother to swallow safely, and I know there’s been discussion about a feeding tube. **Have you ever talked with her about that?**’
- ‘I’m concerned that you’re very short of breath because of your lung disease. I want to help you breathe easier, **but then we’ll need to talk more. Is that OK?**’



At Time of Crisis

- TELL

- *‘We talked before about what was possible with treatment, but we’re in a different place now.*
- *‘I think your body is telling us that the radiation is probably doing more harm than good.*
- *‘It is possible to try resuscitation if your heart stops; but even if you live through it, you’ll be able to do even less than you can do now.*



At Time of Crisis

- ASK

- *‘We’ve talked about a lot of difficult things today. What questions do you have?’*
- *‘What or who has helped face tough situations in the past? What can I do to help?’*
- *‘It can be hard to think about what’s going to happen next. Are there things you want to do? **Is there anything you’re worried about?**’*



Patient and Family Cues

- 'He doesn't get it' → He's really scared
- 'Doesn't she see what's going on?' → He's worried his wife won't cope
- 'He insists on getting chemo' → He's unsure what to do if he's not being a fighter
- 'I'm not sure I can do this anymore' → I'm worried about the future
- 'Mom would want everything done' → I'm afraid to make the wrong decision



Responding to emotion

- **Name:** *'That was hard to hear'*
- **Understand:** *'I can't imagine what you're going through'*
- **Respect:** *'It's clear that you've cared so much for your mother'*
- **Support:** *'I'll be here for you as we go through this'*
- **Explore:** *'This is a lot to hear. What are you thinking?'*



If you're stuck...

- 'Tell me more...'
- 'What are you hoping for?'
- 'What are you worried about?'
- 'We want to get you the **best care possible.**'



Introducing Hospice

- Lead with what services can help, be specific
 - Stay at home, care can come to them
 - 24/7 access to help, by phone or in person
 - Support caregivers, through bereavement
 - Can help you help them ('my eyes and ears').
- Consider asking about previous experiences
 - *'Have any friends or family members had hospice care before? What was your experience?'*
- Anticipate ambivalence, preconceptions



Summary

- Words matter
- Be alert for key opportunities
 - Diagnosis, Disease Progression, Crisis, Patient/family cues)
- Try *Ask-Tell-Ask* model (and practice it).
- Anticipate emotion (NURSE)
- Emphasize tangible benefits of services
- Make recommendation

Palliative Care Practical Applications for the Care Manager

Chris M. Bookheimer, RN, BSN, CHPN



Asking the Big Question

- Would you be surprised if your patient died in the next 6 to 12 months?



Who Should Be Part of This Process

- Discussing with physician/provider
 - Understanding your providers readiness level
- Care Managers role
 - Understanding your own comfort level



Meet Mr. Smith

71 year old male patient COPD. History of Diabetes, Hypertension, Anxiety, and Obesity. Recently hospitalized, shortness of breath with moderate exertion, oxygen dependent, fatigues easily, requires assistance with ADL's. Hobbies include watching football, going to his grand children's events, morning coffee with the guys at the diner and riding around on his tractor.

Understanding Patients Priorities and Goals

- As we think about treatment options, what is one thing about you that you think is important to share with me?
- What is your biggest fear when you think about your diagnosis?
- What is your biggest fear about the treatments being offered?
- What does quality of life mean to you?
- As your illness progresses, how much do you want to know about your disease and the various treatment options? With whom do you want me to share information, and how much?



Mr. Smiths Answers

My father had lung problems and I watched him take more and more meds, it didn't seem to help and that scares me. I'm really worried that I won't be able to breathe. I'm concerned that I will get dependent on the medications. Being able to do the simple things I like to do is what I would consider quality of life, right now I can't even get in and out of the shower. I really want you to share everything with me even the hard stuff and make sure my wife and kids know too.

Palliative Care as an Approach Not as a Department

- Treatment options to address patients needs that are reflective of palliation vs. cure
 - what is important to the patient
- Putting it all together to formulate a comprehensive care plan
 - ask, tell, ask to identify what is needed

Lets Put It All Together

Care Plan/Goals

- Medications: Patient will be able to state purpose of each current medication by April 30th.
- DME: (1) Portable oxygen prescription will be obtained, sent to DME of patients choice and set up in patients home by April 1st. (2) Patient will obtain bath bench from his local senior center and implement in his home by April 15th.
- Resources: Patient will attend appointment as set up at local counseling center on April 20th.
- Specific Teaching: Patient will be able to state 2 interventions to utilize during episodes of increased shortness of breath by April 1st.
- Caregivers: Family meeting will be arranged with spouse Barbara, Son Tim and Daughter Sue by April 15th.



Lets Revisit Mr. Smith

72 year old male patient with end stage COPD. History of Diabetes, Hypertension, Anxiety, and Obesity. Frequent hospitalizations (4 in last 6 months), shortness of breath with minimal exertion, oxygen dependent, fatigues easily, relies on caregivers for most ADL's. Hobbies include watching football, going to his grand children's events, morning coffee with the guys at the diner and riding around on his tractor. Stating "I just can't do this anymore".



Understanding the Patients Needs

- Are you comfortable?
- Do you feel that any of your treatments are causing you more harm than good?
- Do you feel like you have good quality of life right now?
- If we could do one thing other than cure your illness to bring you quality of life, what would it be?
- Let's talk again about how much information you want to have about your disease?



Mr. Smiths Answers

I am really having a harder time catching up with my breathing, been having times when I get panicked. Seems like when I go to the hospital they just run all the same tests with all the same answers. That is costing us a lot of money. My quality of life is really starting to go down. I miss going to Johnny's basketball games. I think the most important thing I need help with is handling these breathing attacks so that I can get out a little more. Please be up front with me, if this is getting worse I want to know.

Palliative Care as an Approach Not as a Department

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Lets Put It All Together

Care Plan/Goals

- Medications: (1) Patient/family will obtain new medications prescribed today by PCP by tomorrow. (2) Patient/family will be able to state purpose, dose, schedule of new medications by end of this week.
- Resources: Referral will be made to home care agency of patients choice today with PT/OT/HHA/RN/MSW services in place by end of week
- DME: (1) Home care agency will make recommendations related to DME needs in home by end of next week. (2) Patient/family will obtain all needed DME either thru private pay, loaner closets, or prescription by end of next week.
- Caregivers: Family meeting including patient, spouse Barbara, son Tim and daughter Sue is scheduled for next Friday at 2:00 pm.



Palliative Care As A Sub-specialty

- How provided
 - interdisciplinary team
- Where provided
 - hospitals, clinics
 - getpalliativecare.org
- How to make referrals
- Working together with the sub-specialty provider



Palliative Care Future Growth

- Palliative care in the community
- Palliative care in the primary care setting