

## Q&A Summary: *End of Life in Long-Term Care*

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1. With being at peace with God being the second most important item for patients and family members, how can we make certain we are using board-certified chaplains and how can we best ensure good interdisciplinary work?
  - a. This is especially difficult given that the majority of the interdisciplinary team's work is not reimbursed. Standard screening for spiritual distress can help the team know where to send their chaplains, who are undoubtedly a limited resource.
2. With it being seen as the worst of times when hospice takes over, what is the nursing home's view of the nurse case manager in the hospice collaboration?
  - a. Thank you for this question, and I'm sorry if I was not clear. Hospice can be either the best of times or the worst of times, depending on how well a partner works with the facility staff. Hospice coming in and providing end-of-life expertise, managing post-death details, helping with spiritual needs and communicating things like prognosis with the patient and family are all seen as significant positives. The negatives are when hospice involvement was too much or too little, either that they were needed but not referred or when they were involved and took over the care, pushing out the facility staff who often have longer relationships with residents. Ensuring that physical symptoms are managed can go a long way to creating a "best of times" relationship.
3. Does Medicare pay for hospice for a hospital inpatient?
  - a. Medicare will pay for general inpatient hospice for a patient who is in a hospital facility with uncontrolled symptoms requiring intensive nursing monitoring and active medical management. This is typically only for a few days. If a home hospice patient is in the hospital for a condition completely unrelated to the home hospice diagnosis or prognosis, home hospice services can continue even while the patient is in the hospital.
4. Having worked in hospice and palliative care, I found many physicians who wanted to keep residents on palliative care and under Medicare part B so that they had their accommodation under Medicare part A. Do you see a lot of this, and is it a trend?
  - a. This is so hard. There is a tremendous gap in end-of-life funding for the patient who was hospice appropriate and not living at home. Either families must pay for room and board or Medicaid will do it if the patient has few resources. What you are describing is keeping a patient on, for example, a skilled rehab benefit and using palliative care instead of hospice care. When the goals are comfort, I really struggle forcing a dying patient to work with physical and occupational therapy when they would rather spend their time with family. There is no good solution for this for the not-independently-wealthy patient who does not yet have Medicaid. I see the physician attempting to make the best out of the difficult situation by keeping them under Medicare part A for rehab and using palliative support.

5. Is there a way to differentiate between excessive sleeping due to dementia/apathy and the process of dying?
  - a. No! At least none that I know of. Sometimes the first can turn into the second. If patients are sleeping most of the day but are waking up and eating their meals, they can sometimes live for a very long time. If they're starting to sleep through meals and are losing weight, likely they will start to die. It is not until you see some of the late physical signs, like mottling or apnea, that you can be sure that dying is going on. Counseling the family that this could be the beginning of the dying process—framing dying as a process like we discussed rather than as an event—can be helpful to prepare families.
6. Our skilled nursing facility (SNF) is very fixated on bowel movements. When someone has not moved their bowels, they want to give suppositories and enemas if it has been 5 days or more with people on comfort care who haven't really had any intake. Do we really need to worry about regular bowel movements?
  - a. This is an interesting question, and there are 2 schools of thought. One is that the lining of the bowel still turns over even in a person who eats nothing, so that person should have 2 bowel movements per week. The other is that dying people, especially when their prognosis gets below 2 weeks, are not likely to accumulate enough stool to cause discomfort. My recommendation would be every few days to trial something per rectum and document that you were doing it. This will help to minimize the risk of a large fecal impaction that the patient simply cannot push out.
7. Can you please provide your opinion about medical marijuana for end-of-life treatment?
  - a. What a hot topic! The data here are spotty because research sponsored by the government is prohibited. There is an article that will be electronically available ahead of print publication in the next few weeks by Briscoe J, et.al. in the *Journal of Palliative Medicine* called "Top Ten Tips Palliative Care Clinicians Should Know About Medical Cannabis." It is a well-done article that offers guidance on when data support the use of medical cannabis (neuropathic pain, chemotherapy-induced nausea and vomiting, AIDS-related anorexia, and pediatric epilepsy) and where evidence is lacking (psychiatric symptoms, cancer cachexia, non-neuropathic pain). I recommend getting your hands on a copy when it comes out.
  - b. Admittedly a shameless plug: I co-edit the series in the *Journal of Palliative Medicine* where this article will be published with Arif Kamal from Duke. We have around a dozen articles (and 6 more planned) written by specialists in radiation oncology, medical oncology, neurology, nephrology, pharmacy, gynecologic oncology, cardiology and others in an easily digestible "Ten Tips" format that aims to bring specialist-level knowledge to palliative care and hospice teams. Search for "tips palliative clinicians" on pubmed.com to see the available articles.
8. Is there concern regarding bacterial resistance for using metronidazole for odor control for a pressure ulcer?
  - a. Another good question. Typically, by the time people have infected sacral ulcers in the hospice/comfort care setting, their time is down to less than a few weeks. While my colleagues in infectious diseases may have a heart attack when I say this, I would be less worried about resistance than about suffering for the patient, family and staff given the horrible smells that can sometimes come from these ulcers.

9. What if someone is allergic to morphine? What other pain relief would be used at the end of life?
- a. Essentially, all opioids are the same when it comes to pain and symptom relief. I would note that tramadol, technically an opioid, is a weak agonist and codeine is super delirio-genic, so I would not use these first line for the dying. Hydrocodone, mostly available attached to Tylenol, is also not for first line. Morphine, hydromorphone, and oxycodone would be my preference is for oral options and all 3 are available in a common solution form. Oxycodone is wildly expensive compared to the other 2 options. Hydromorphone 1 mg/mL is commercially available, though it is dosed from 4 to 8 mg and can start to turn into a lot of liquid in the dying. The 4 mg/mL and 10 mg/mL concentrations can be found or compounded.
  - b. I would be committing malpractice if I didn't point out that patients should not be given medications to which they are allergic, and morphine can build up in renal failure, leading to myoclonus. Oxycodone is quite hepatically metabolized, so if it is being used in patients with advanced liver disease, lower doses and less frequent administration is recommended.

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