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PALLIATIVE CARE CASE OF THE MONTH



What to do after the patient is made CMO Robert Arnold, MD

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Case: The patient is a 75-year-old man who presented with a severe headache and syncopal episode. His past medical history is remarkable for diabetes, hypertension, hyperlipidemia and an MI in 2009. His family brought him to his local emergency room where it was noted that he had a blown right pupil, and CT scan revealed a large subarachnoid bleed. He was intubated and life flighted to There he was seen by neurology and neurosurgery, and it was determined that he was not a surgical candidate. Over the next three days he had little neurological improvement, and after meeting with the family it was decided that he should be made comfort measures only. He was extubated and 24 hours had stable vital signs, although he was still comatose. The neurology and neurosurgery team are unclear about what should happen next or about the topics that need to be discussed with the family.

Discussion: Deciding to focus only on comfort is a major transition point for patients, families and health care providers. After making this decision, most families are not sure what comes next. They look to health care providers to reassure them that they are doing the right thing and to ensure that their loved one does not suffer and that they are prepared for the next few days. The following questions should guide one's action after a patient is made CMO:

1. Are the patient's symptoms adequately treated/prevented?

UPMC Health System has developed a comfort measures only order sheet in order to optimize symptom management in CMO patients. (see order on demand). It reminds clinicians that:

- a. All medications and laboratory tests that do not promote comfort should be discontinued.
- b. Most patients near the end of life are not awake enough to tell us when they have symptoms. Instead, clinicians should treat nonverbal signs such as rapid respiratory rate (>24/minute), grimacing, moaning, and restlessness presumptively as signs of discomfort or shortness of breath.
- c. The appropriate medications to treat pain or shortness of breath are opiates.

To promote rapid control of symptoms, prn opiates can be titrated rapidly (every 15-30 minutes for iv dosage and 60 minutes for oral opiates.) An infusion may be started if the patient has active symptoms requiring several boluses.

- d. Terminal delirium is treated using benzodiazepines.
- e. The only evidence-based treatment for secretions, or "the death rattle," is glycopyrrolate.

2. Does the family want information about what they are likely to see as their loved one dies?

Most families do not have a great deal of experience with death and dying. It is appropriate to ask them if they would like to hear what they are likely to see over the next hours/days. This information may decrease their fear of the unknown and reassure them that their loved one is "on the right trajectory" and not suffering. For example, one can tell families that as patients die it is normal that: ¹

- a. They are less responsive and sleep most of the time. Hearing may persist, however, and thus families should feel free to talk to their loved one.
- b. They eat and drink less. This is not uncomfortable and good mouth care relieves any thirst the patient may have.
- c. Their urine output will decrease, and their hands and feet may become cool.
- d. Their breathing may become irregular with periods of apnea.
- e. They may begin to "gurgle." This is not uncomfortable to the patient but can be distressing to families who are worried that their loved one is "drowning." Drawing an analogy to snoring may be helpful.

Finally, families often want to know how long their loved ones will live. This is an extraordinarily difficult question because of our limited ability to prognosticate the exact time of death.

For palliative care consultations please contact the *Palliative Care Program at PUH/MUH*, 647-7243, beeper 8511, *Shadyside Dept. of Medical Ethics and Palliative Care*, beeper 412-647-7243 pager # 8513 or call 412-623-3008, *Perioperative/ Trauma Pain* 647-7243, beeper 7246, *UPCI Cancer Pain Service*, beeper 644 –1724, *Interventional Pain* 784-4000, *Magee Women's Hospital*, beeper 412-647-7243 pager #: 8510, VA *Palliative Care Program*, 688-6178, beeper 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore, and Children's page 958-3844. With comments about "Case of the Month" call David Barnard at 647-5701.

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(Our ability to predict the time of death is no better than our ability to predict the time of birth—we can set boundaries but not determine exact times). Acknowledge your uncertainty, and then give your best judgment—whether hours to days or days to a week or two. Asking the family if they have any specific concerns is often helpful.

3. Does the patient or family have religious traditions that the health care team should be aware of?

Ask the family whether there are any spiritual or religious traditions that are important to them or their loved one. In Western Pennsylvania, the most common tradition one needs to be aware if is Catholic need for Sacraments of the Sick prior to death. The chaplaincy service at many hospitals is available 24/7 to meet with families and provide support.

4. Is there anyone else who needs to come and say goodbye?

It is useful to ask families whether there is anyone else who would like to say goodbye to their loved one. In addition, families are often unsure **what or how much to tell children** about their loved one's dying or whether to let them see them. Asking about this issue allows the family to express their discomfort and ask questions. This is a complicated topic about which social workers often have particular expertise.²

5. What dispositional issues should be discussed with the family?

There are three general options for patients who have been made CMO:

a. The family may wish to stay in the hospital, either with or without hospice. Given that roughly 70% of patients die within 24 hours of having life sustaining treatments stopped in the ICU, this is a reasonable option for the first day. Staying in the hospital for longer periods may not be the best option as the staff have competing responsibilities, hospitals are not set up to focus solely on comfort, and many hospitals have a 2-3 day time limit for inhospital hospice.

- b. For patients who have symptoms and are actively dying, the most appropriate location may be an inpatient hospice unit (either a stand alone unit or located in a long term care facility). These units are staffed by hospice nurses, social workers, and physicians and provide excellent palliative care as well as attention to families' psychosocial and religious needs. There are a number of these units within Western Pennsylvania.
- c. Taking the patient home with hospice may also be a good option for families, provided they have enough support and are willing to have their loved one at home. It is important to remember that when a patient is at home, hospices provide roughly 2-4 hours of care a day depending on the patient's needs. Thus, the family needs to understand and be willing to provide basic comfort care for their loved one (with direction and guidance from the hospice).

Which options are available and will fit the patient/family needs will vary depending on the patient's clinical status, the insurance, and family situation. Care managers and social workers in most units are knowledgeable about these issues and can help guide the family about the appropriate choice given their values. Given this, it is important to have them meet with the family shortly after the patient is made CMO. In difficult or complex cases, the palliative care social workers are available for consultation and help.

References:

- 1. The palliative care service can provide teams with informational brochures that describe the dying process.
- 2. The palliative care service has reading material that they can provide to the primary service to give to families.

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