ISSUE: It is clear that your patient is dying. When does palliative care begin?

WHAT IS PALLIATIVE CARE?
Medical palliation means to ease the severity of symptoms without curing the disease. Palliative care is often initiated at the end of life to allow a patient to die in comfort. In reality, we all try to reduce suffering in all patients by limiting pain, shortening the course of painful or adverse procedures, etc. So, palliation is central to every physician's practice, and anyone working in the Neuro-ICU likely has extensive experience in the pharmacology and practice of ensuring comfort.

Palliative care is a subspecialty of nearly all ACGME accredited residencies and typically requires fellowship training. Some experts have learned on the job and this field has grown rapidly. If your facility is fortunate enough to have a Palliative Care Consultation service, when is it appropriate to consult them and to what end?

ROLE OF PALLIATIVE CARE CONSULTS
It is common practice to engage palliative care expertise when a medical decision of limiting or withdrawing medical care is contemplated. An expert in this field is comfortable seeing the patient, summarizing their needs, and then talking with families about the goals of palliative care. Many patients are frightened by the thought that they could die in pain or of air hunger or “swallow their tongue” so having an experienced person in the dying process speak with the patient goes a long way to alleviate concerns. Palliative care teams are often composed of a physician, social worker, nurse and sometimes pharmacists.

Many also manage an inpatient hospice service were a patient can be transferred if they tolerate extubation for several hours. These comfort care suites offer room for the family to stay and some resemble a home environment. Critical to their success is a well-trained nursing staff with experience in dosing narcotics, answering questions, and providing compassionate care during the transition. Moving to comfort care typically involves the cessation of all medications (antibiotics, pressors), IV fluids and feeding. A good practice is to use oral atropine 1% ophthalmic solution as drops on the tongue to reduce secretions and prevent the “death rattle” of the oropharynx. Opioids are titrated to comfort, benzodiazepines can be used for any perceived anxiety, and acetaminophen can be used for fever. IV acetaminophen may be better than oral acetaminophen so that a feeding tube does not need to be kept in place.

USE OF FEEDING TUBES AND IV FLUIDS
Palliation as defined does not focus on curing but on alleviating suffering. The idea of continuing tube feeds or IV fluids is counter to this goal as nutrition and hydration prolong life and usually prolong suffering. This is hard for some families to accept as they may feel that discontinuing food is inhumane. It is certainly more comfortable for a patient to have the nasal tube removed, and we know from interview of sentient patients passing that discomfort can be minimized. However, keeping a feeding tube in at a low infusion rate seems like an acceptable compromise to a surrogate with cultural concerns about not feeding.

IV fluids may be another area of contention. IV catheters are frequently left in place so that parenteral opioids may be administered. Beyond keeping the access open, IV fluids should be minimized. An adult patient with a good respiratory drive can live significantly longer with hydration alone. Having a palliative care team who can explain this and work with the patient’s family may be critical to forego this treatment.

Patients who are in refractory status epilepticus represent a challenging group. Seizures appear uncomfortable and may be traumatic for the family and staff to see, so it is typical to continue anticonvulsants during the comfort care process. Use of IV midazolam may be of particular help here; usually one wants to avoid high dose benzodiazepines as this can suppress
respiration and unlike opioids does not have the same acceptance as following the rule of “double effect.” In the case of status epilepticus, one can argue that midazolam is helping stop the seizures (and therefore helping with comfort) at the risk of embarrassing respiration. Opioids alleviate suffering (pain, air hunger) at the expense of respiratory depression (Chapter 4.30).

**PALLIATIVE CARE OF CANCER**

Patients with metastatic or primary brain tumors should be provided the same opportunity to a comfortable death as anyone else. However, cancer survivors typically become engaged in “fighting cancer”, and oncologists join this fight by employing treatments with potentially uncomfortable side effects. The concept of palliation only comes when one “gives up” providing a sense of failure in the oncologist as the sympathy for their dying patient flows through their mind. This ethos of “killing the cancer” is understandable and is well chronicled in *The Emperor of All Maladies*.

Understanding that the oncologist mindset is similar to a surgeon’s may be helpful for you to advocate for palliative care earlier in the treatment process. Our professions are based on educating patients, and informing them of alternatives. As a medical professional in your Neuro-ICU your practice will intersect this dynamic and you will be faced with instituting a palliative process based on doing what is right. Keeping the patient’s best interests in mind is always the right thing to do.

**SUGGESTED READING/REFERENCES**
The Emperor of All Maladies: A Biography of Cancer, Siddhartha Mukherjee, 2010.