## Examples of medical torture caused by indefinite interventions on terminally ill patients.

- 1. A nurse was visibly shaken after doing chest compressions on a patient who died after attempted CPR. He said he had just turned the patient's chest into "mush" due to multiple broken ribs that squished with each compression. He said it felt like pushing on a "bloody sponge." The patient was terminally ill and there was no expectation he would survive CPR.
- 2. A terminally ill patient had chronic contractures in his legs so severe that his kneecap covered his collarbone. Chronic contractures occur when the muscles weaken and shorten, causing a loss of flexibility. In his case the leg had become unmovable. The family members were insisting on CPR, which caused great distress among the doctor and nurses. The nurses would have to break the patient's leg in order to do chest compressions. The patient died after few days in the ICU.
- 3. A dying bed-bound woman had to have a tube stuck in her rectum (a <u>bowel management system</u>) to capture stool and prevent bowel movements from infecting her wounds. She had it in so long that her rectum could not stay closed and became several inches wide (anal atony). This is a rare but known complication for this treatment. Her rectum was so large that it was difficult for the tube to stay in and feces commonly spilled out the side. She died after several weeks in this condition.
- 4. A two-year-old boy with an untreatable brain tumor which has caused severe hydrocephalus. Because of his age, his cranial sutures split and so he has incredibly severe macrocephaly and cannot move his head. He has a tracheostomy and g-tube. He cannot interact with the world, and just lies in bed. Every night there is concern from the medical teams (nursing, residents, etc.) about if they would actually have to do compressions and resuscitate him should his heart stop, as he has no meaningful interaction with the world, but his mother continues to refuse to make him DNR, but also at times refuses to allow for basic medical care, vital signs to be taken, or medications for potential discomfort to be given. She is trying to find homeopathic doctors to take him to, as all physicians and surgeons have said he isn't a candidate for any medical therapies, as his disease is terminal and irreversible.

- 5. A four-year-old young girl was involved in a severe motor vehicle accident that left her with a high cervical spine fracture that was the equivalent of an internal decapitation. She only maintained enough brainstem function to breathe, but otherwise had no meaningful interaction with the world. Because of not only the severity of her spinal cord injury, but multiple other injuries associated with the accident, she had significant hemodynamic instability. Performing CPR on her would finish severing the spinal cord so it did not make sense to put her through this; however, she was so unstable, sending her to the operating room for halo and brace was also not possible because the brace would cover her chest and make it impossible to perform CPR when she needed it. The mother would intermittently block the door to the ICU room and not let physicians and nursing staff in the room because the teams "only said negative things." A neurosurgery resident volunteered to be the one to do CPR on her if her heart stopped so that the bedside nursing staff and ICU teams wouldn't feel like "they killed her" by doing CPR and what it would do to her spinal cord.
- 6. Mr. J is an 82-year-old bed bound nursing home resident suffering with renal failure, congestive heart failure, and advanced dementia. He no longer swallows, talks, or meaningfully communicates beyond groans and grimaces. He receives artificial nutrition and hydration via a surgically implanted gastric tube. He transfers to a dialysis center by ambulance 3 times a week. On his 3<sup>rd</sup> hospital admission in 6 months with breathing failure due to heart failure, pneumonia, and fluid overload, the family demands intubation in the ED, even though comfort is recommended. He is admitted to the ICU. The patient is always in distress, requiring restraints, sedatives, and pain medications. The treatment team again attempts to guide the family towards a comfort plan of care, something his dialysis physician has been recommending for 2 years. The two adult children reject this, refuse to even talk to hospice because "they just kill people" and repetitively attempt to block the administration of comfort medications. The children are perceived by staff as argumentative, physically threatening (son) and litigious. A palliative care consult is requested. Palliative care finds the patient moaning and grimacing in a fetal position with diffuse contracture. After an hour of exploring family views and listening to their beliefs, no opinion is changed. The family is again told they cannot block the administration of medications to keep their father comfortable. The family is again angry and threatening. An ethics consult is requested.

- 7. Mr. C is a 68-year-old gentleman suffering with end stage kidney and heart disease on chronic dialysis. He is transferred from an outside hospital for higher level of care. Evaluation reveals a bed bound gentleman, so weak he cannot position even his head in bed. He has severe cardiomyopathy (ejection fraction of 10%, normal > 50%) and a stage IV pre-sacral pressure ulcer to bone. Palliative care is consulted to help with pain management and care planning. He is helped to understand that he is dying and accepts recommendations for better symptom management and a DNAR order. Upon learning of his DNAR and symptom management consent, his family insists he is confused. They demand full code and refuse pain medicines. Neither the palliative care nor primary physician can convince them otherwise. Psychiatry is consulted and also validates the patient has intact decisional capacity, understands he is dying and the meaning of the DNAR order. The patient's wife and son now angrily threatened to sue and demand all new doctors. An ethics consult is requested and upon meeting the wife and son say "It is against our religion to tell a person not to try everything to stay alive."
- 8. Ms. A is a 38-year-old woman with widely metastatic infiltrating ductal cell cancer of the breast. It has eaten into the chest wall and nerve plexus in the arm pit. She is delirious, essentially non-verbal, and clearly lacks decision making capacity. She can be heard screaming day and night about the pain from pathologic fracture of the ribs and invasion of the chest wall and arm nerves. The pain is relieved by opioids but the nurses are only able to administer when her mother, her legal decision maker, is gone. Her mother insists that the pain is a punishment for her daughter having lived a sinful life. She also insists on full code status (attempt CPR at death), even though CPR can't be performed because 2/3 of her chest is covered by the fungating, ulcerated mass eating in to the chest wall and breaking her ribs. The mother "camps out" in the hospital room, physically blocking the staff rom administering pain meds and threatening to sue if the doctors and hospital don't start doing what she says. An ethics consult is requested.

- 9. A newborn was admitted after a severe anoxic brain injury due to hypoglycemia. The baby was born at home, thrown in the trash can by her parents, and found several hours later (at least 4, possibly 12) by her grandmother. She was admitted to the NICU, evaluated, found to have devastating, irrecoverable brain injury leading to frequent seizures, complete inability to interact with her environment. She would live the remainder of her life on a ventilator, attached to tubes, unable to interact with those around her, and unaware of their existence. She would be poked and prodded, stuck with needles, subjected to tests, prone to infections, all in a clinical environment rather than a loving home like she deserved. Children often make these sacrifices during an illness, but they do so with the prospects of returning to a state of health. Continued vent support had no achievable purpose to justify the pain and suffering it entails, pain that she might feel but would never understand. Her problem was in the brain, not the lungs. Her parents were arrested for child abuse/neglect and in jail. After several weeks on the ventilator, and with multiple consultations from multiple pediatric neurologists, her physicians concluded that she would not recover. Her parents were still technically the legal surrogate decision makers despite their conflict of interest in keeping her alive in order to avoid murder charges. Since this hospital was not in Texas, they were forced to go to court to have a guardian ad litem appointed which took almost 2 months and extended the patient's suffering unnecessarily.
- 10. Baby born at 24 weeks (the limit of viability at the time), experienced devastating brain bleed after birth (grade 4 intraventricular hemorrhage) and would require ventilation and total care her entire life. As a complication, she developed severe hypotension that could only be managed with the extended use of vasopressors which led to her fingers and toes dying. She eventually was able to come off the pressors but not the ventilator. She was still too unstable for surgery to remove the dead extremeties, so they remained for almost two months before she died. During that time the other NICU families frequently complained about the smell from the dead tissue. By the time she died, she had lost most of her feet and some of her leg. (not in Texas)
- 11. 17-year-old girl admitted after a car wreck with severe brain injury. Within 24 hours of being admitted she progressed to brain death. Death was declared by neurological criteria yet her family refused to take her off the ventilator. Her corpse remained on the ventilator for 6 days until it was turned off. I have also seen a few cases of family members refuse to agree to turning off the ventilator in cases of cardiopulmonary death because "her heart stopped but she's still breathing". (was in Texas)

- 12. Man admitted with an anoxic brain injury due to a severe heart attack. He developed seizures that grew progressively worse and more frequent. Eventually he progressed to the point that he was seizing constantly despite the maximum efforts with anti-epileptic medications. He was in the ICU for 50 days before an ethics consult was called. The family agreed to comfort care after the ethics consult. But for that, he likely would have remained on the ventilator for several weeks until his seizures killed him. (was in Texas)
- 13. An 93-year-old man was admitted for sepsis. He had a long history of uncontrolled diabetes which led to numerous amputations over 5 years. He first lost his small toes on this left foot, then all the toes, then his forefoot, entire foot, below the knee, above the knee, and then up almost to his hip. He also began losing his other leg during this time and had an above-the-knee amputation on it. Both stumps were infected, which led to his sepsis. He had osteomyelitis (bone infection) in his left hip from the wound, which is almost an irrecoverable event in itself. His sepsis led to him needing intubation and was on the ventilator for over a month. The reason he needed the ventilator was due to respiratory depression cause by his hip infection which was incurable (despite multiple debridements and weeks of IV antibiotics). His wife was very clear she wanted to continue the ventilator because she wanted his social security check. The longer he stayed alive, the more she collected, and she did not care how much he was suffering. This conflict of interest is sometimes a concern among caregivers, but usually it's unfounded. In this case (and several others) the family made no attempt to hide the reasons for their decisions.
- 14. A patient with an unresectable brain tumor was intubated for respiratory support at endof-life per request of the patient's surrogate decision-maker. The care team recommended
  palliative care and hospice, but the surrogate insisted she knew what was best for the
  patient demanded aggressive treatment be continued. Although the surrogate wanted
  aggressive treatment and prolonged intubation, she refused to consent to tracheostomy
  placement to protect the patient's airway. She refused because she "knew the patient would
  get better and breathe on his own". Prolonged intubation without tracheostomy resulted in
  the erosion of the oropharynx and soft palate.
- 15. 50-year-old woman with Covid on ECMO (<u>Extracorporeal membrane oxygenation</u>) for 60 days with no recovery or transplant option. The Covid contracted from son, who is now MPOA. The son is ridden with guilt and wouldn't withdraw care. She finally died after 162 days on ECMO.