Choice in Dying and End of Life Emergencies

The Exit Guide Program has worked with multiple people who had been accepted for guide support and then had a medical emergency that could have ended their lives if they had been prepared to take advantage of it. One got a case of severe peritonitis requiring surgery, another collapsed with an undiagnosed urinary tract infection that was about to go septic, a third's blood pressure critically spiked, and the fourth got an infection in diabetic wounds that were not healing. In each situation, aggressive treatment was provided to stabilize the person. In only one of the situations did the person recover sufficiently to be able to continue with the guide process. Two died in residential care facilities and we lost contact with the fourth, so do not know what happened.

Post-emergency conversations with the three people with whom we did not lose contact provided a window into how incredibly difficult it can be to decline treatment, request palliative care, and use a medical emergency as a path to a chosen death. There were a few challenges that their situations had in common, which may be instructive to those who do not want to be swept along by medical momentum in a crisis. Those common challenges were: not expecting the expected, a debilitated but competent patient, the human crisis response, and a medical system geared to save.

Not Expecting the Expected

The human mind tends to presume that tomorrow will be much like today. We know it isn't true, but we don't tend to plan as though we will collapse tomorrow. We tend not to expect an emergency, and so don't have an action plan for when one occurs. As one becomes debilitated from illness or age, a medical crisis becomes a question of when, not if. Yet even people who are actively considering hastening their death often don't think to instruct their healthcare representative or loved ones on how to approach a medical emergency that presents an opportunity to conclude their lives.

A Debilitated but Competent Patient

There is a wide cognitive gray area between when a person is fully functional versus clearly incapacitated. In the above-mentioned situations, the person was, at some point in the treatment decision-making process, conscious, verbal, and able to speak for themselves. But they were also exhausted, debilitated from their conditions, and probably on pain medication. They were squarely in this cognitive gray area. Technically, they retained decisional capacity, but, as a practical matter, they likely did not have the cognitive energy or focus to dispassionately consider the big picture, rapidly make an extremely difficult decision, and effectively be their own advocate.

The Human Crisis Response

People often say, “I was in crisis mode,” to explain their decisions or actions in an emergency. When a crisis hits, the human response is to survive first and ask questions later. This is true not only for the patient but also for the healthcare representative and loved ones. To go against that instinct takes incredible presence of mind and force of will. Imagine an exhausted and stressed family member in the emergency department with their loved one in some stage of agony and the medical team in full fix-it mode. Now imagine that exhausted family member having the presence of mind to say, “you said your quality of life is poor; what do you think about getting palliative care only and letting this condition conclude your life?”

A Medical System Geared to Save

The medical system has the momentum of a fully loaded super tanker. Particularly in emergency departments, any suggestion that a life-threatening condition not be treated will be met with incredulity at best. The patient and loved ones should be prepared for accusations of incompetence, malfeasance (you’re trying to kill your mother?!), stupidity, and possibly even criminality, though it is legal for a patient or the patient’s healthcare representative to decline any or all medical treatment, even if death will result. Prepare to hold your ground when faced with fierce resistance and emotional manipulation.

The Takeaways

Perhaps the first takeaway from these situations is to appreciate how incredibly difficult it is to decline lifesaving treatment in a crisis. To use a medical emergency as an opportunity to end your life, you must first anticipate such an emergency, despite not knowing its nature or timing. If you have determined and communicated your wishes to loved ones beforehand, everyone can better navigate the crisis, even when you are in that cognitive gray area and everyone is mentally exhausted and emotionally strained.

Prepare your healthcare representative and loved ones to consider the possibility of declining treatment in an emergency, and to support you by reminding you of your priorities when you are cognitively exhausted. Assure them that you want this support and that it is a sign of love to help you achieve your end-of-life wishes, even if they feel uncomfortable raising the possibility of declining treatment. Finally, prepare your healthcare representative and loved ones for the pushback you and they will likely get from medical personnel. Expect it to be intense.

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