Robert, a senior patient with existing health issues, was admitted to a hospital after being discharged with a chest tube called a Pleurex catheter. The patient's wife, Dorothy, was understandably very worried about him and his declining condition.

The chest tube — which helps remove fluid from the chest cavity — was integral to helping Robert breathe. For the catheter to function properly, the Pleurex had to be replaced on a weekly basis. Unfortunately, Robert's previous hospital did not have this exact type of chest tube available; alternatively, the hospital planned to replace the Pleurex catheter with a standard chest tube that attached to the wall (for drainage).

Robert was already on a ventilator and his prognosis was poor. Dorothy did not want him to have to undergo any additional procedures, and with her husband's supply down to one last Pleurex, she was looking for assistance in obtaining more. Knowing her husband was in very serious condition, Dorothy wanted to make sure he could continue using the same chest tube to help him be as comfortable as possible in what would be his final days. She was having trouble expressing to the hospital staff how important the catheter was to her husband's care.

End-of-life planning is a complicated process; the added complications of COVID-19 make it even more urgent. Robert and Dorothy's story is just one of many affirming the urgency of end-of-life planning in our COVID-19 world. The high number of cases among older adults puts additional pressure on a sector of the healthcare system that was already stretched.

Families caring for an older adult during a pandemic are faced with emotionally heavy health decisions — and with very little time to engage in pertinent discussions:

- Do we bring an older loved one home from the hospital to recover there?
- What if doctors have to intubate my loved one?
- Is my loved one in a nursing home going to contract COVID-19?
- Should we put an older loved one on a ventilator if he/she contracts COVID-19?
- If I can't visit in person, how can I talk to my loved one about end-of-life planning?

To prepare for the worst-case scenario, more families are now seeking resources about end-of-life care. And fearing the complications related to COVID-19, many older adults are changing their living wills, according to Modern Healthcare. Providers across the healthcare spectrum should be prepared to support their patients and families during this time.

Avoidance and action: Disparities in end-of-life planning

In the midst of the unprecedented health care changes incurred by COVID-19, two things have remained constant: no one can predict end of life and no one knows what their decision-making capacity will be at the end of life.

Hence the utter importance of end-of-life planning.

According to a 2013 national survey conducted by The Conversation Project, 90% of people say that talking with their loved ones about end-of-life care is important. And in terms of decision making for advanced care, Pew Research Center data from 2013 said that 52% of respondents would "ask their doctors to stop treatment if they had an incurable disease and were totally dependent on someone else for their care." Another 35% said they would "tell their doctors to do everything possible to keep them alive — even in dire circumstances, such as having a disease with no hope of improvement and experiencing a great deal of pain."

Despite 90% of respondents agreeing on its importance, only 27% had moved forward with end-of-life planning. Most people feel unequipped to have uncomfortable decisions or make complicated decisions when faced with mortality. The emotional implications and the weight of perhaps having to decide for another can be extremely overwhelming.

The importance of communication

For physicians and clinicians to begin having end-of-life care discussions, it's important that they feel comfortable when doing so. While these conversations are some of the most difficult to have, they are valuable for setting appropriate goals for the patient, according to Dr. Gregory Gadbois, an executive medical director at naviHealth. Unfortunately, from the physicians' perspective, it can also be a sign of defeat.

Dr. Gregory Gadbois
Executive Medical Director
naviHealth

“If you ask a physician, we’ve been taught that our goal is to cure. In many cases, physicians feel like they’re in a battle they must win and that death equates to failure,” said Dr. Gadbois. “It comes down to understanding that end-of-life care is more than what it’s depicted as. This is another step in the healthcare journey for the patient. It’s important to understand how you can help with as much dignity and grace as possible. That’s where our goals should lie. But it is hard to figure out when to transition to these conversations.”

Dr. Gadbois believes that creating a strong line of communication between a patient, their loved ones and those who are treating the patient is key to alleviating some of the stress when planning for end-of-life care.

“These conversations are not just for those who have a terminal illness or are truly at the end of their life. These conversations should happen if you have an advanced disease, a chronic disease with no cure or any condition that may lead to special circumstances regarding treatment options,” Dr. Gadbois said.

End-of-life care has no age range — in the blink of an eye, you can find yourself in a turbulent situation.

One of Dr. Gadbois’ former patients, a 40-year-old who had just married the previous week, was suddenly diagnosed with Stage 4 colon cancer. For the next six months, the patient went through aggressive chemotherapy treatments. Unfortunately, a CAT scan of the patient’s abdomen showed that the cancer had metastasized.

One night after a shift, Dr. Gadois received a phone call from his patient, looking for some advice. The oncologist told the patient that they could try more treatment options and medicine but the patient was unsure if they could keep fighting.

“I mentioned hospice to let the patient know that it’s there, and I could immediately hear the sense of relief in their voice. The patient didn’t want to let down her family and friends,” Dr. Gadbois reflected. “But when I told them about hospice, it was almost as if they just needed someone to give them permission to stop fighting.” The patient passed away peacefully two months later while in hospice.

The stories of Robert and Dorothy and the 40-year-old cancer patient are all too familiar. In order to better understand the end-of-life care plan for Robert, Dorothy needed more than just the replacement Pleurex catheters. She needed someone she could connect with and openly communicate to during one of life’s most painful moments.

Thankfully, Robert’s care team was able to step in and help keep Robert as comfortable as possible while they searched for the correct catheter. While it may have only given Robert just a little more comfort in his final days, having clear communication with the clinical team helped give Dorothy a sense of relief in a time when she felt helpless.

Many resources are available to guide patients, families and providers through the complicated process of end-of-life planning, although starting the conversation is often the most difficult part. As for health care providers —particularly dealing with the uncertainty of COVID-19 — it may mean an extra level of open communication to help support patients and their loved ones.