



## HEALTH

# Painful new choices in end-of-life care

By Priya Anand and Joanna Sharpless

ON GEORGE'S EIGHTH DAY ALONE IN THE ICU, HIS DOCTORS told him he had months to live. With his family listening by phone, the doctors offered two options: he could continue to receive intensive hospital care, with a small chance of getting home before his next medical crisis. Or he could go home with hospice, focusing on comfort and the people he loved.

Though George (a pseudonym) didn't have COVID-19, the pandemic made his decision even more excruciating. In an effort to stop the virus, George's hospital, like others, had enacted policies banning visitors. If George chose the hospital path, it would be weeks before he could see his family in person.

Hospitals today face an impossible predicament regarding visitors for terminally ill patients. On one hand, a visitor might spread the virus within the hospital or become exposed and bring it home. On the other, depriving people of the chance to make life-and-death decisions and say goodbye in person is cruel and may even influence the choices they make.

Many hospitals seek to walk this line by allowing visitors for dying patients, with stringent restrictions. For example, the New York State department of health recommends hospitals permit one visitor for patients expected to die within 24 hours. Some hospitals allow only a single hour-long visit. And even generous policies have unintended consequences: though medical teams don't intend to coerce families into transitioning patients to comfort-focused care before they feel ready, the fact that they cannot visit until their loved one is dying can seem like an incentive.

For families that opt to discontinue ventilators, the calculus becomes more brutal. COVID-19 is especially contagious during the removal of a breathing tube, so many hospitals prohibit visitors during this procedure. If a hospital allows just one visit, families must choose between seeing their loved one before the tube is removed, while she is

guaranteed to be alive, and waiting until after—with the uncertain hope of witnessing her final moments.

Physicians are also notoriously inaccurate at predicting when patients will die. When visits are allowed only for an hour, it may be impossible to time a visit with the moment of death.

**SINCE GEORGE'S TIME** was limited, he and his family decided he should come home so they could be together. But hours before he was to leave, his blood pressure dropped. His doctors called his wife and told her he was actively dying. She raced toward the hospital, but George died before she arrived. She was alone when she learned of his death. She wiped tears from above her mask as she visited her husband's body. Then she drove herself home.

Even for families that are miraculously present when a patient dies, the experience is drastically altered. Before COVID-19, patients sometimes died surrounded by family members, who might have found comfort in physical contact. Now, one or two people grieve alone, separated by gloves and gowns.

Medical teams have made impressive efforts to help families spend time together using technology. And many staff risk their own well-being to linger in hospital rooms, holding hands and smoothing brows, filling in for families that can't be there. Still, we cannot underestimate the distress that these policies create for health care workers, who must weigh the trauma of enforcing limitations on end-of-life companionship against the fear that every exception exposes them to danger.

By the time this pandemic ends, hundreds of thousands will have died. Restricting the number of people they had contact with in their final days will save hundreds of thousands more. The value of those lives is incalculable, but many of the saved will still be suffering. We are only starting to understand the reverberations of our patients' isolated deaths and the complicated grief we will be processing for years to come.

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*Anand is a neurologist at Boston Medical Center; Sharpless is a palliative-care physician at Beth Israel Deaconess Medical Center*