

# Jimmy Carter's example shows the worth of hospice care

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OPINION

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Nearly two years ago, hospice hype gripped the United States after the announcement that former president Jimmy Carter had elected to receive care at home. This month, he turned 100.

While many lauded the decision of the then-98-year-old to forgo further hospital trips for medical treatments and opt to focus his care on comfort measures, few would have predicted that this approach would result in such longevity and quality of life. Yet every day, many people in both the U.S. and Canada are deprived of opportunities to spend the end of their lives surrounded by those they love in their own homes or hospice facilities because they are never offered the chance.

As medical technology has become more sophisticated, a grey zone has developed that doctors, including myself, have difficulty navigating. Struck with hope and ego, we press on, adding machine after machine to support failing

organs, even when it's clear recovery is unlikely, if not impossible.

Whether taking over your lungs, heart or kidneys, machines allow health care teams to support nearly every organ in the body artificially. Intravenous feeds and fluids, blood transfusions and an expanding array of antibiotics add to the arsenal of what doctors can keep adding to avert death. Usually, something is lost when technology is introduced; comfort and consciousness are often sacrificed, diminishing quality in the battle for quantity. As these technological wonders have become commonplace, our collective wisdom to know when to apply them and, more importantly, when to withdraw them has not kept pace.

This has created a death dilemma - tethered to machines that can't make you well again, it's actually very hard to die in an intensive-care unit, and just as hard to live. A new liminal space results, where families and doctors fret over micro-improvements while the body wastes away, depriving people of meaningful moments as death nears.

Historically, this wasn't possible; if your lungs were too sick to exchange oxygen or your heart too sick to beat, you simply died, often in your own bed surrounded by those you cared about

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most. As death historian Stephen Berry told me, a hundred years ago people fulfilled "the most important role of their lives: they showed other people how to die."

Death, more common and less preventable back then, was normalized. While people feared it, as they do today, they didn't deny that it would appear at some point. Now, society has developed a degree of death denialism: With life lasting longer, and death occurring behind hospital curtains, patients and their doctors seem to reject the truth that everyone eventually dies.

The medical culture around end-of-life is evolving, but not quickly enough. Where I trained, at Stanford University, managers would tell us that people don't come to Stanford to die. There was a culture that there was always something to do - an inspiring ethos that has borne discoveries we could never dream of, such as organ transplantation and advanced cancer therapies. But at some point, every one of us will die, and to deny that fact deprives people of the choice to pursue hospice care while they can still enjoy aspects of living. This can lead to prolonged suffering, isolation and an untimely death in the middle of the night, surrounded by health care workers so distracted with trying to keep you alive that they fail to be present as you die.

Jessica Zitter is a doctor who practices both critical care and palliative care. "I straddle both worlds," she told me. Dr. Zitter describes scenes in hospitals where "surgeons fire palliative doctors all the time. They get angry and act like they have some right to be territorial over a person." In some ways, accountability metrics meant to improve care can actually disincentivize doctors from offering hospice care. The metrics don't always value humanism.

The blame cannot be laid sole-

ly at the feet of doctors. Patients and their families similarly fail to recognize death's approach. Sometimes, despite weeks of conversations where the tone of doctors escalates to be more and more blunt, families struggle to accept the end of life, compelling physicians to press on with procedures, surgeries or technologies that can't offer a cure.

In this new era where the ability to keep people alive clashes with a denial of death's inevitability, a natural death evades many. Natural death, often supported by hospice methods such as pain medications and relief of symptoms such as nausea and breathlessness, can for many be a beautiful experience. Indeed, many patients and families have found that palliative care brings an improvement in mood and capabilities, allowing for special bonds to be forged. Photo albums are dusted off, letters are penned and affairs are sorted.

These final days can be the most meaningful of someone's life. Medical culture must move away from its indiscriminate, throw-everything-plus-the-kitchen-sink approach to people who can't be saved. Until that happens, it's up to patients and their families to speak up and request hospice care when the end is near. Or, in Mr. Carter's case, not so near.