

Hopewell House hospice has closed. You should care about that

By Ira Byock and Eric Walsh

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For 28 years, Hopewell House in Portland, Ore., was an oasis that helped people die well. *Eric Walsh*

Hopewell House, an inpatient hospice facility in Portland, Ore., has closed its doors.

Should anyone care beyond the families of the thousands of people who would have died badly had it not been for Hopewell House? We believe that *everyone* should care, because its closing highlights a chasm in the continuum of health services needed to prevent people from suffering needlessly before dying.

People like Ray Friedman, who was a colleague of ours. A retired professor of radiology at Oregon Health and Science University, he was a researcher, an avid trombonist, and a writer with insatiable curiosity. He and his wife, Nancy, traveled to 71 countries. Artifacts of their trips graced their living room; so did a grand piano and a copy of Carl Jung’s “The Red Book.” As Ray’s health declined and he developed kidney failure, he realized he was approaching the end of his life and decided to forgo dialysis, allowing his body to die peacefully. His family and his doctors supported his decision.

Kidney failure usually causes people to lose interest in eating, become progressively sleepier, and gently fade from life. Ray wasn’t so fortunate. A catheter to empty his bladder caused bleeding. He became agitated and intermittently delirious. Daily home visits by hospice nurses and their urgent nighttime house calls weren’t enough to ease his misery. It became painfully clear that Ray’s symptoms and his family’s distress could not be adequately alleviated at home.

Hopewell House was the “hospice ICU” they needed. Its highly skilled clinicians got busy the moment Ray arrived. Aided by the specialized clinical equipment and expanded formulary of medications on-site, the hospice team was able to ease Ray’s symptoms. He relaxed — as did Nancy and their family.

Medications and kidney failure left Ray sedated, but he knew he was enveloped by the love of the family members and friends who held vigil. He squeezed their hands as they held his and, from time to time, he uttered a few words of affection and gratitude. As Ray slipped from life at the beginning of August, 2 1/2 days after arriving at Hopewell House, Nancy was lying next to him one last time.

Only a handful of freestanding inpatient hospice centers like Hopewell operate across the U.S. Each is an oasis where people with complicated, intractable distress benefit from technically sophisticated treatments for their symptoms that are delivered with tenderness in welcoming, home-like settings. Comfort reliably results. People's intimacy is respected; their dignity preserved.

By the time Hopewell House [closed its doors](#)² on Sept. 30, about 10,000 people had died there and another 9,000 or so had had their symptoms brought under control and returned home under continued hospice care.

What's forcing intensive hospice care facilities like Hopewell House to close is inadequate reimbursement for the services they provide. Overly restrictive Medicare and Medicaid regulations force programs to leave existing licensed hospice beds unfilled for fear of being fined for transgressing [strict eligibility rules](#)³. From 2012 to 2017, inpatient hospice use dropped nearly 30% at Hopewell House and 15% across Oregon, decreases that are consistent with national trends. For-profit companies now dominate America's hospice "industry" and, for the regulatory and financial reasons described, rarely open or operate hospice inpatient units.

The two of us are in our 60s and 70s. Statistically, we are next in line in our families to die, and are rightly worried about how the stresses of caring for us, and the ways we die, will affect those we love and will leave behind. Beginning in the 1960s, baby boomers reclaimed childbirth from the clutches of medicine and restored birthing as a natural part of life, albeit one that requires medical support. We insisted on allowing fathers in delivery rooms, developed birth plans, and turned to doulas, nurse midwives, Lamaze and La Leche classes, and birth centers.

It's now time to reclaim the other edge of life. People who are dying also deserve expert medical attention that at times is highly technical. Most of us would like to be cared for at home with hospice services, knowing that there's backup intensive care of the sort that inpatient hospice centers provide.

Public policy changes are necessary to fix this conundrum, because Medicare and Medicaid policies and payments are largely to blame. But having the capacity to meet dying patients' needs is a matter of basic human values. Our co-authorship underscores this point.

We are palliative care doctors who disagree vehemently about the issue of physician-hastened death. Eric firmly believes that, under some circumstances, people who are terminally ill have a right to a doctor's help in hastening death. He was [Brittany Maynard](#)⁴'s physician when she ended her life. Ira believes that doctors should not [intentionally end patients' lives](#)⁵. He worries that [data from Oregon](#)⁶ confirm the feared slippery slope of people choosing death because they feel undignified and a burden to others. He notes that safeguards within Oregon's Death with Dignity Act are increasingly referred to as [obstacles to a right to die](#)⁷.

But we stand together in saying loudly that dying people have a right to the best care possible.

Congress must update Medicare regulations that threaten the viability of inpatient hospice facilities. But we needn't wait for Congress to act.

Communities can take ownership of this problem. Baby boomers, in partnership with their children's generations, the Gen Xers and millennials, can rebuild caring continuums through a combination of community action, philanthropy, and local politics.

When the beloved Hyder Family Hospice House in Dover, N.H., closed in 2014 for many of the same reasons Hopewell House closed this year, the citizens demanded that the local government do something. Galvanized by the community, the Strafford County commissioners [bought the hospice](#)⁸, reopened it in 2015, and established a [nonprofit foundation](#)⁹ to help cover the financial shortfalls between what it costs to take superb care of dying people and what Medicare and Medicaid pay.

Dover exemplifies a community that does what it takes to care for its own, ensuring the best care for dying people and the families who love them. It is an example we would like to see emulated in Portland and other communities with endangered hospice facilities. We might need their intensive palliative services someday. You might too.

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