


When I started making house calls for seriously ill patients after their hospital discharge, I had no idea how much time I would spend wiping tears on the porch.

I DON'T KNOW HOW MUCH LONGER I CAN DO THIS. HE'S UP EVERY 20 MINUTES AT NIGHT, CALLING OUT. I'M GIVING HIM MEDS EVERY HOUR. . . . IT'S JUST ME HERE WITH HIM, DAY AFTER DAY.



For the first time since the early 1900s, more Americans are dying at home than in the hospital. Most patients say that they prefer to die at home, but cost incentives as well as quality measures tracking in-hospital deaths have further driven health systems to embrace serious illness care outside the hospital at the end of life.



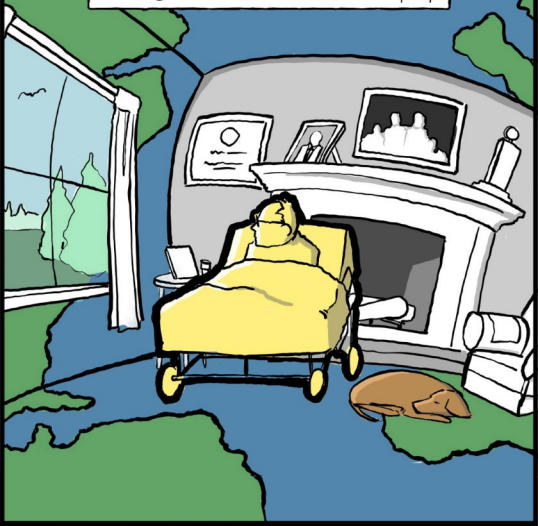
A person with dark curly hair, wearing a white t-shirt and grey pants, stands in a doorway looking out at a parking lot. The parking lot is filled with several yellow cars. The scene is drawn in a simple, sketchy style with a limited color palette of greens, yellows, and greys. The person is positioned in the lower center of the frame, looking towards the left. The doorway is on the right side of the frame, and the parking lot extends to the left and into the background. The sky is a pale blue with some white clouds. The overall mood is contemplative and somewhat somber.

While it might seem like more people spending their last days at home would be better for everyone, seeing the brutal realities of caring for a sick loved one at home has sobered my enthusiasm for sending people home to die.

Often it feels like we're failing patients and families at the end.

Visiting patients at home introduces you to their world in a way you never get to see in the hospital.

The things that give life color and meaning for them are on full display.



But when you stand with caregivers on the porch,
you can also sense the overwhelming weight. . .

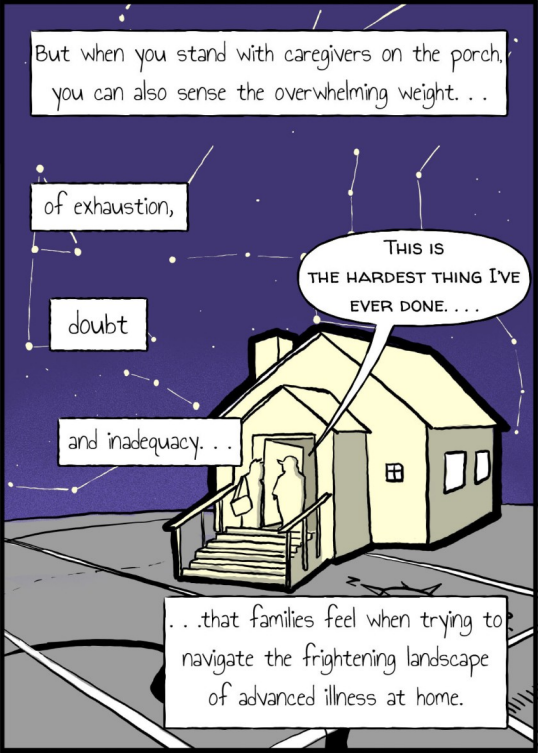
of exhaustion,

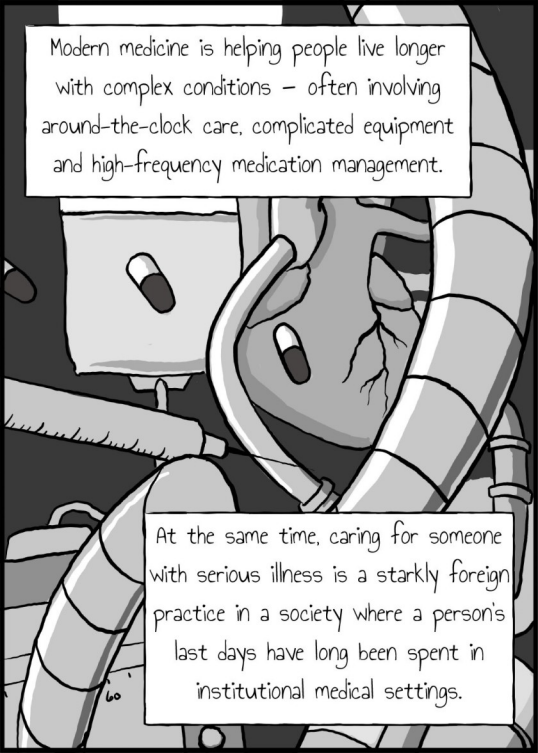
doubt

and inadequacy. . .

THIS IS
THE HARDEST THING I'VE
EVER DONE. . . .

. . . that families feel when trying to
navigate the frightening landscape
of advanced illness at home.





Modern medicine is helping people live longer with complex conditions – often involving around-the-clock care, complicated equipment and high-frequency medication management.


At the same time, caring for someone with serious illness is a starkly foreign practice in a society where a person's last days have long been spent in institutional medical settings.

Even the natural physical decline of ordinary dying is an unfamiliar process to many of us.



SHE WON'T EAT ANYTHING AT ALL. I'M DOING EVERYTHING I CAN, BUT SHE'S SO WEAK SHE CAN BARELY SIT UP. I CAN'T EVEN WALK HER TO THE BATHROOM ANYMORE.

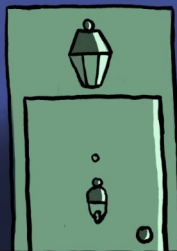
When isolation, lost sleep and financial strain are added to the grief of losing a loved one, the results are devastating.

A person wearing a yellow hoodie is shown from the chest up, looking out from a doorway of a shop. The shop has a yellow roof and red walls. The background consists of stylized, layered shapes in shades of red, orange, and blue, suggesting a sunset or a hazy sky. The person's expression is one of concern or distress.

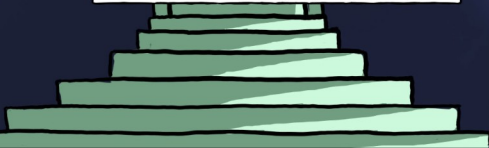
I HAD TO CLOSE
OUR SHOP WHILE I CARE
FOR HIM. I HAVE NO IDEA
HOW WE'LL PAY THE NEXT
ROUND OF BILLS.

The distress is so universal that I've actually started carving out time at the doorstep after each visit.

I try to provide comfort and resources where I can.

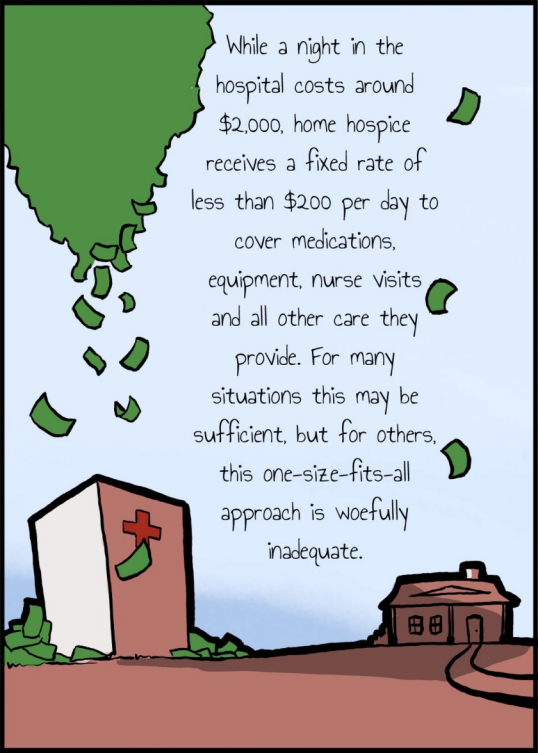


Unfortunately, I'm usually left wishing there was more help to offer.



For those in their last months, home hospice provides expertise, equipment and help with symptoms such as pain or shortness of breath, but hospice only visits a handful of times each week. The remainder of 24/7 caregiving falls squarely on the shoulders of family members.





While a night in the hospital costs around \$2,000, home hospice receives a fixed rate of less than \$200 per day to cover medications, equipment, nurse visits and all other care they provide. For many situations this may be sufficient, but for others, this one-size-fits-all approach is woefully inadequate.

Inpatient care at a hospice facility provides skilled around-the-clock support, but insurance restrictions limit this care to crisis situations, usually in the last few days of life. Less than 2% of hospice care is delivered in a hospice facility, and in many areas, inpatient hospice units are not available.



The U.S. spends more each year per capita on healthcare than any other country. As much as 25% of total Medicare costs occur in the last year of life, but our health system devotes little to caregiving needs at home.

\$4,965

\$4,974


\$5,447

\$5,986

\$10,586



Outside of Medicaid or veteran benefits, few health insurers cover daily home support. For families trying to hire help, the \$20 per hour cost of a health aide adds up quickly . . . meaning it's often an option only for the wealthiest.

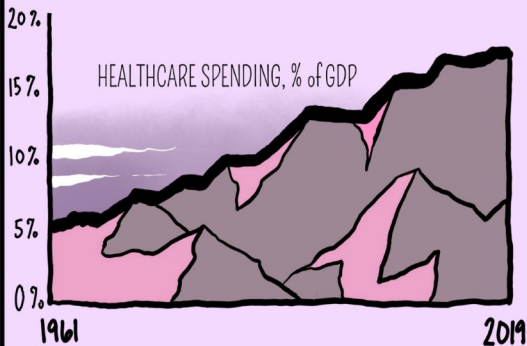


For those who may still have many months to live, the burdens of care can cripple a family.

Many are trying to determine how we can save costs in medicine, but when we send people home to crisis, we're not necessarily saving costs; often we're simply shifting them from hospitals and insurers onto the backs of struggling families – families that will lose wages, spend their savings and risk their own health to provide care.

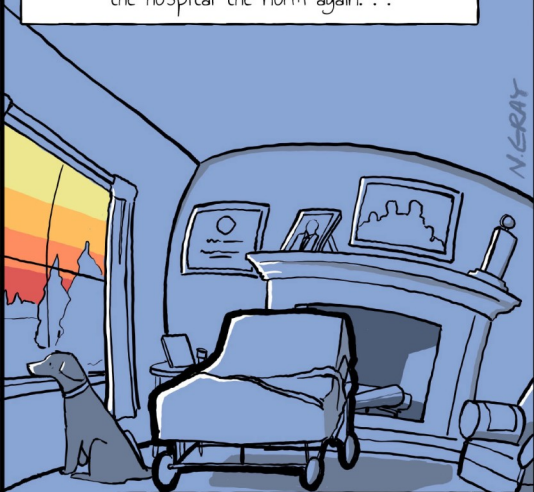


Addressing this challenge will mean having difficult conversations about where we spend our healthcare dollars. In a system where new cancer drugs cost on average \$100,000 a year per patient, we can't expect end-of-life care at home to happen on a shoestring budget in order to offset escalating costs elsewhere.



SOURCE: CENTER FOR MEDICARE & MEDICAID SERVICES

Many of us will have our last days extended by hospitals, devices and drugs, but ALL of us will still die. If we're going to make dying outside the hospital the norm again. . .



then we must invest more in helping people live well at home till the end.