

Grappling with the high cost of dying

By Ellen Waldman

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Ann had been hospitalized following a serious illness. Years ago, she made her medical wishes known by completing the Advance Directive and POLST (physician's orders for life-sustaining treatment) forms. She had a longtime relationship with a professional who served as her co-trustee and Power of Attorney (POA), should she not be able to handle her own affairs. And, she had very clear and detailed conversations with the POA describing what she would want at the end of her life. It might appear that this would ensure that Ann was able to have exactly what she imagined for herself. But you also need to know the details of what happens at the actual end-phase of some lives, and the costs associated with them.

Upon discharge from the local hospital, Ann was referred to hospice services for her end-of-life medical needs. She always wanted to be in her own home at this point, and with hospice in place, the medical care was now addressed.

Hospice provides an array of wonderful services. Locally, we have several providers. Asante Hospice (www.asante.org/services/hospice; 541-789-5005), and Providence Hospice (<http://oregon.providence.org/our-services/p/providence-hospice>; 541-732-6500) are two examples. Once meeting the criteria for these Medicare-paid-for services, here is what Ann would receive. This info is from Asante Hospice, but they apply to other hospice providers as well:

Hospice services are available 24 hours a day, and include: a hospice doctor who works with your family doctor; skilled nurses specializing in pain management; home health aides; medical social workers to help with emotional, legal and financial concerns; spiritual support; instruction and supervision for family caregivers; medical equipment, supplies and medications; respite and support services by trained volunteers.

Given that wide range of services, you might think that this covers anything that might be needed at this point. What is not evident at first, is that while the providers will visit a couple of times a week, actual hands-on caregiving is not something they can provide all day long. In Ann's case, she was now totally dependent and bedbound. She needed help with everything: drinking and eating, being turned in bed every four hours, basic cleanliness assistance, and medication administration. Plus, someone there to engage with her in conversations when she was awake and wanted company.

To fill her constant daily care needs not covered by hospice, a licensed and bonded caregiving agency was hired. Ann could never be left alone, so the caregivers were needed for 24 hours a day. Like many people, Ann had not anticipated this, and had adequate funds for only a short amount of time for this level of caregiving. It comes with a higher cost than most people realize: about \$4,000/week for round-the-clock care.

What options were available to fund \$16,000/month of ongoing costs, if she were to remain at home? For Ann, the only way to cover this expense was to look at utilizing the equity in her home. The POA

visited a local lender to discuss the prospects. Some of the lender's suggestions were a home equity line of credit, a reverse mortgage, and a possible refinancing of her home. The short answer to a long search was that none were ideal solutions. Since no one could predict the length of Ann's remaining life, at this rate of spending, she would still fall short of the necessary funds.

After a lot of research, the only choice was to sell her home and move into an adult foster care home, in order to meet her requirements for this level of care. This would cost about one-quarter of what she was currently spending to remain at home. She had never envisioned this outcome for herself, and she was naturally sad. Even with all her up-front planning, these end-of-life costs far exceeded her ability to fund her wishes to remain at home. If this is your anticipated wish as well, consider if it's financially viable for you, now that you have an estimate of the actual costs.