

Aging Happens: New CARE Act could help family caregivers

By Ellen Waldman

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If you have ever provided help to a loved one, you have joined the ranks of what are called family caregivers. In the past, this might have meant offering transportation or providing a few meals. Now, after being discharged from a hospital stay, the family caregiver is expected to handle even fairly complex medical tasks.

As of Jan. 1, 2016, and Oregon now has implemented the CARE Act (Caregiver Advise, Record, Enable), developed by AARP. Also known as HB 3378, it was unanimously passed by the Oregon Senate on May 27, 2015. The goal is to better integrate and provide support to family caregivers after a loved one returns home from hospitalization.

I recently spoke with Jon Bartholomew, government relations director for AARP Oregon (503-513-7370; jbartholomew@aarp.org). He explained how this act helps make family members an integral part of the care team. This helps the patient, the family and ultimately reduces the need for hospital re-admissions. This last point is crucial. If you are re-admitted to the hospital within 30 days for the same condition, there is the possibility that your medical insurance might not cover this second admission. This Act goes beyond the monetary considerations though, and goes straight to the heart of what regular folks are expected to do for their family member. Here's a quote from an article about this act:

"Family caregivers are the backbone of providing long-term supports and services in Oregon," said Jon Bartholomew. "More than 460,000 unpaid caregivers in the state help care for aging parents, spouses and other loved ones so they can remain at home — as opposed to costly institutions. These family caregivers provide unpaid care valued at a staggering \$5.5 BILLION annually."

In fact, almost half of the 42 million family caregivers in America have performed medical or nursing tasks for their loved ones that were once provided only by medical professionals. Now, people will be better prepared and able to provide safe care for family members once they return home.

The new CARE Act, which aims to care for the family caregiver, requires hospitals to do the following:

1. Record a family caregiver's name when admitted into a hospital or rehab facility, and notify them when their loved one is discharged, either back home or to another facility; and
2. Provide a written explanation and give instructions of the medical tasks that the family caregiver will perform at home, such as managing multiple medications; injections; providing wound care; managing special diets; and operating monitors or other specialized medical equipment.

Still, these questions remain: Can a family member manage all this on their own? And, if so, what is the impact on their own well-being? There are no sure answers yet.

Here's what happened to a couple in Ashland recently. The wife had been caring for her husband for a long time, especially after recent hospitalizations, and realized she needed some time off. She looked for respite care, the new lingo being a "short break." Her idea was for him to go to a local facility for three

days a week, so she could recoup in her own home. This proved to be a very difficult search. In fact, finding any place for a short break is harder than it used to be.

Leaving money aside for a moment (even though this stops many people in their tracks), the only day-care respite solution we had in Ashland, Lifespan Respite, is now offered only in Medford. They closed this program primarily due to lack of attendance. There are some assisted living facilities, such as Brookdale/Ashland, which currently seems to have an overnight respite service available. Frankly, it depends on what the current company owners feel they can provide. There has just not been a reliable, ongoing resource for overnight respite care here for many years.

This need for caregiver respite has led to another round of conversations that Jon Bartholomew is having with stakeholders around the state. He is focusing on assessing the needs and the resources in each local area. We are particularly lean on what's out there for family caregivers. The hope is that with more research and planning for this need, we will come up with some new options.

In the meantime, my suggestion to family caregivers is to take incremental breaks when they can: daily, weekly and monthly. Caregivers are the linchpins holding everything together for their families, and they need all the help they can get. Let's hope that answers come sooner than later.