When Friends Become Caregivers

How friends and neighbors can tackle challenges they face when stepping in to help another in need.

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By Michael O. Schroeder

As a growing proportion of America goes gray, the demand for caregivers is increasing.

Caregivers help loved ones age in place and assist adults of all ages to manage chronic conditions and deal with physical or mental disabilities. And though most often those duties fall to family, research shows that sometimes it's friends and neighbors who take on the role of caregiver.

“Caregiving in the U.S. 2015,” a report conducted by the nonprofit National Alliance for Caregiving and AARP, found that while 85 percent of caregivers were a relative, 10 percent were friends, 3 percent were neighbors and 2 percent were another non-relative. “There are a lot of people who have no other family, and so their friends, their neighbors are the people they’ll turn to,” says Gail Gibson Hunt, president and CEO of the National Alliance for Caregiving. It might start with something as simple as taking a neighbor to the grocery store or picking up that person's groceries, she says, and then extend to taking that individual to the doctor or advocating for him or her in health-related matters.

“As the population ages, there’s an increasing proportion of adult children who are taking care of their aging parents,” says Melinda Abrams, vice president for delivery system reform at The Commonwealth Fund, a health care and policy foundation. “But as families no longer live in the same community, there’s also an increasing proportion of non-family members, such as friends, neighbors, community members who are volunteering and helping to take care of their elderly, aging and disabled neighbors.”

The Commonwealth Fund examined the makeup of caregivers as part of a 2016 survey of high-need patients. Those included elderly with multiple functional limitations as well as adults with multiple chronic conditions, such as heart failure, stroke or diabetes that require insulin. Of those surveyed, 10 percent received help from friends or neighbors for troubles with activities of daily living, such as getting across the room, dressing or bathing – as compared with 72 percent who said they received help with activities of daily living from a family member or
relative and 17 percent who said a professional, or home health aide, provided assistance. And 14 percent of those high-need patients surveyed said they received help from a friend or neighbor with what are called instrumental activities of daily living, such as cooking and taking medications regularly.

**Offering Support in a Lonely World**

The social isolation many older adults face has sharpened the need for those nearby to take on a caregiving role. “Research shows that there’s a direct correlation between chronic isolation and loneliness and all kind of negative health effects,” says Dallas Jamison, spokeswoman for the National Association of Area Agencies on Aging, which recently launched a campaign in collaboration with AARP to raise awareness about the growing problem of loneliness and isolation affecting older adults. “That could be chronic health conditions, including heart disease, depression and anxiety, dementia – including Alzheimer’s – and even accelerated death.” Given that, she adds, “People may be a bit more sensitive when they see a neighbor who is never with anyone, who seems to be alone all the time.”

Given the potentially involved nature of caregiving, it’s not without pitfalls. To begin to overcome obstacles, a person must first recognize he or she is, in fact, a caregiver – which isn’t always so obvious. “Caregivers don’t self-identify,” Hunt says. The same selfless approach that may lead a person to help out in small and then big ways, can keep people from searching for caregiver support and services that can supplement the assistance they’re providing, experts say.

As with family caregivers, friends and neighbors taking on a caregiving role can access the Elder Care Locator, a public resource through the U.S. Administration on Aging for connecting with services for aging adults, from transportation to adult day care centers for people with Alzheimer’s Disease. The program is administered by the National Association of Area Agencies on Aging and caregivers can go online to get information or call 1-800-677-1116. Area Agencies on Aging will know about caregiver support groups and condition-specific support groups for those being cared for, as well as other services available in a person’s local community, says Patrice Earnest, director of the Elder Care Locator.

**Coordinating Caregiving**

Friends and neighbors seeking to ensure a person they’re caring for gets needed medical treatment will run into a brick wall if they’re trying to access that person’s health information, given laws that protect patient privacy. That can be especially problematic if a friend is listed as an emergency contact, experts say. Fortunately, patients can sign an authorization allowing that information to be released to a person they designate, Hunt says.

More than two-thirds of states have now adopted the Caregiver Advise, Record, Enable, or CARE, Act; this requires hospitals to record the name of a caregiver in a patient’s electronic health record. “Then when the time comes for discharge, that person is involved in discharge
planning, and then lastly they’re given the training in the hospital for how to take care of the person when they come home,” she says. “So it could be that rather than a family member, a friend or neighbor is identified as the caregiver.”

Caregiving is a collaborative affair – and that’s true for how a friend may coordinate with a family caregiver. Often, a family member living out of town may ask a friend or neighbor to check in on his or her loved one. Given that many decisions need to be made on a regular basis and that perceptions of how a person is doing can differ, there can be discord and conflict between caregivers.

So it’s important for all caregivers to listen to one another and preferably discuss concerns – if possible – with the person receiving the care, and always keep that person at the center, experts say. “To the extent possible, stay in close contact with close living relatives to the aging adult or person with disabilities,” Abrams says. Whether by email or phone, keep lines of communication open so you don’t feel that burden of making all the decisions on behalf of the family, she says After all, being a caregiver is a big job – for family and friends alike.

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