Essential support for informal caregivers providing essential care

Untrained, informal family caregivers usually get the job unexpectedly. Caregivers of all ages are appointed the role by family or friends for a myriad of reasons: medical emergencies, sudden onset of a chronic illness, unanticipated issues related to aging or other scenarios that make it no longer possible for an individual to live at home independently.

Without any formal training, caregivers can feel like they're navigating an obstacle course filled with hazards. Luckily, it doesn't have to be that way. The Caregiver Resource Center (CRC) at Pathlights can help. A point of entry for a broad range of services, the CRC receives funding through AgeOptions, an Area Agency on Aging, to link caregivers to training and education opportunities, emotional and financial support and resources to improve their lives – all free of charge.

According to the Illinois Family Caregiver Coalition, nationwide there are more than 53 million unpaid caregivers (one in five), who provide about 24 hours of care a week. In Illinois, about half of voters aged 50+ have experience as family caregivers and among them, 64% work paying jobs while providing care. Still, caregivers of all ages come to Pathlights for support.

When a granddaughter, who quit her job to become her grandmother's caregiver, needed respite from caregiving to participate in her young child's activities, she obtained it through Pathlights. "In a multi-generational home, there are a lot of implications for a caregiver who lost wages and isn't working," says Catherine Stowers, LCSW, director of caregiver and in-home support services at Pathlights. "We could at least offer that little bit of respite so she could continue to do things with her son, too."

The most sought-after service, respite gives caregivers a break from their day-to-day duties for self-care. They can relax knowing the person they care for is provided with the supervision and companionship of a caregiver from AgeOption's respite registry. Caregiving can take place in-home, at an adult day center or nursing home – the agency will cover room and board at a nursing



facility for a limited time, so caregivers can travel or take a longer break.

Oftentimes, Pathlights is a caregiver's first stop on their journey. They will find a variety of services: information and assistance regarding availability and eligibility requirements of government programs and support; TCARE assessments (a Tailored Caregiver Assessment to identify areas causing distress and recommend personalized interventions like respite and support groups



to prevent burnout); and one-on-one individualized conversations to discuss challenges related to caregiving.

Pathlights' hosts support groups such as "Stress-Busting Program for Family Caregivers" for caregivers of those experiencing memory loss; "Grandparents and Other Relatives Raising

Children" and memory cafes, monthly meet ups for people experiencing memory loss and their caregivers to engage with others in similar situations and participate in music, art therapy and other special programs. In the next few months, Pathlights is launching an "Early-Stage Memory Loss" support group, a program resulting from needs expressed by the community last year at a forum held by the Alzheimer's Association, Orland Park Public Library and Pathlights.

During the pandemic, Stowers witnessed caregivers facing several new challenges. Some caregivers, responsible for paying for



maintenance drugs for those they were caring for, lost their jobs and could no longer afford to buy medications. Pathlights provided a short-term solution: emergency funds to cover the cost of pharmaceuticals for a limited time.

Older adults encountered greater social isolation because family members couldn't visit as often, and doctor appointments and support groups became virtual. While technology was available to bridge the gap, many older adults

"Don't be afraid to ask for help and accept it when someone offers." – Catherine Stowers

weren't equipped to go online right away. With training by Pathlights, they learned how to use the technology they needed to stay connected to the outside world. That program, "TechWise: Technology for Older Adults," is a 6-part instruction series with a curriculum created by Pathlights specifically for adults 60 and over.* Co-hosted with local libraries, these classes aim to increase older adults' comfort with using technology and provide them with tools to help them age more successfully. They offer a place for students to connect, ask questions without feeling awkward, and learn at their own pace.

The challenges didn't stop there. When the work of in-home medical providers like physical therapists, transferred to family caregivers, once again they found themselves providing a highlevel of care they didn't anticipate. Although we're coming out of the pandemic, Stowers expects the demands on caregivers will continue to grow. In the next five years, she estimates caregiving will become more prevalent and the financial, physical and emotional costs will keep rising – making it a top priority to raise awareness about the challenges of caregiving and strengthen the services already available.

She advises caregivers all the time, "Don't be afraid to ask for help and accept it when someone offers." Stowers knows a caregiver who keeps a list of all her caregiving duties in her wallet, from cutting grass to preparing dinner and sitting with her husband. "When people ask, 'Is there anything I can do to help?' she takes out the piece of paper and says, 'If you're willing to do anything on this list, I will gladly accept the help.' There's such power in that," Stowers explains. "Not just her willingness to ask for help but she's so intentional about how she does it. Maybe not everybody is good at cutting grass or a great cook, but there are other ways they can help."

Are you caring for an older relative, spouse, friend, or neighbor? Are you an older adult who is the primary caregiver for a grandchild or other family member under 18? Has someone in your family been diagnosed with Alzheimer's Disease or a related disorder? Our Caregiver Resource Center hosts monthly support groups, convenes experts for engaging events, provides Respite services, counsels on financial assistance, legal issues, and self-care, and in some cases, provides emergency funding. If you are caring for an older adult and are looking for support, call us at 708-361-0219.

*Pathlights' TechWise program is supported in part by federal American Rescue Plan Act (ARPA) funds allocated to the Cook County Department of Public Health.