

Family Caregivers

Powerful stories to inspire future change

Results of 2018 Caregiver
Focus Groups conducted
by UConn Center on
Aging with funding by the
Money Follows the
Person Rebalancing
Demonstration



Informal Caregivers Provide More than Love

An estimated **459,000 caregivers** in Connecticut provide a range of supports to family and friends including, but not limited to:

- transportation,
- medication management,
- coordination of health care,
- assistance with medical and nursing tasks, and
- support with activities of daily living

Caregiver Support Ratio

- The caregiver support ratio— the number of caregivers (people age 45-64) per person over the age of 80 - **is expected to drop by more than ½ by 2050.**
- In 2015, the ratio was 6.4 caregivers to 1 individual over age 80.
- By 2050, this ratio is expected to drop to 2.8 to 1.*

Identifying Caregiver Needs

- Connecticut's Long Term Services & Supports Strategic Rebalancing Plan identifies the need to expand and target services for caregivers as a goal.
- Further discussion with State Innovation Model's Consumer Advisory Board led to decision to conduct focus groups with caregivers to identify their needs.

Summer of 2018: UConn Health Center on Aging conducted 2 focus groups with 23 caregivers (19 women, 4 men)

Results:

Finding Information and Applying for Services

- Difficulty with searching for and finding information about services that might help their loved ones was the most frequently discussed topic at the focus groups.
- Finding information that was helpful to their unique situation was challenging.
- Often reported they use word of mouth and ask people they know who have had similar experiences for information. Details were frequently incorrect or lead them to a service that did not help their situation.
- Reported high levels of confusion when applying for services, particularly Medicaid services.

"I felt so alone. I felt like I was all by myself. I felt like I knew nothing. I didn't know where to go. I didn't know. And when I asked for help in places where I felt I should get help, there were no answers. There were a lot of questions by no answers."

"In the end of my dad's life, I had no clue where to go and what to do to try to keep him home because he really wanted to stay in his apartment."

Results: Medical Tasks

- ½ of participants provided support with hands-on caregiving for activities of daily living, like bathing, transferring, dressing and eating. A few participants oversaw medical and/or nursing tasks like managing medications, wound care and monitoring durable medical equipment, like oxygen.
- Caregivers reported:
 - receiving very little training on any tasks and said most learning was “on the job”.
 - More formal training for medical tasks is necessary.
 - They need education about chronic conditions and normal aging processes.

“To make sure they get no bedsores, you move them in bed. You just learn it on your own. No training. I used to watch the CNA. I watched the nurse. I watched whoever and would take notes.”

Caregiver Challenges

- Challenges with Family Members

“We tried to have people come in (to take care of Dad) but my mom she’s got dementia. She would look at them and go “you’re not going to touch him!””

- Financial Challenges

“... you fall into a group in the middle and I was just watching the money fly out of the door. And I knew at some point that this was going to be the end. I could no longer have him go do adult daycare where he was perfectly happy and things like that because I wouldn’t be able to afford it anymore””

Caregiver Challenges Themes

- Caregiver Health Related Challenges

“My mother’s stress level (as a caregiver) and how she dealt with that was difficult. And so I eventually left my work and decided to take them out of [place they lived].”

- Physician and Home Care Worker Challenges

“I had a case where the CNA left her, my mother was bedridden, calls me from the highway and goes “I decided I don’t want to do this job anymore”

Caregiver Stress

"...the pressure on the individual nevertheless to coordinate everything and to deal with all the phases that dementia goes through, and dementia is different for every person"

"It's just the physical and emotional toll is...Beyond description."

"...it really does take a village to adequately deal not only with the person who has the illness but also the caregiver. Because one of the things that I learned is that caregivers will come down with a significant illness within 2 years afterwards."

"There is nothing left over. And you wake up feeling the same and you're tired. You're so tired!"

Conclusions and Recommendations

- Establish designated point persons for caregivers who could help to educate and navigate caregivers about access to services or assist with paperwork. This “navigator” might be a social worker. After hours support is especially needed.
- Provide enhanced education to access points (e.g. primary care physicians, hospital discharge planners, town social service departments) to equip them with up to date and thorough information about available services and supports.
- Improve online access to information on services and supports for caregivers. MyPlaceCT.org is a portal with links to community resources.

Conclusions and Recommendations

- Develop and provide hands-on and virtual training for caregivers on common caregiving tasks such as transferring, wound care, medication management and bed baths.
- Design skill building interventions for caregivers providing complex chronic care, including medical and nursing tasks; develop interventions focusing on specific chronic conditions, medication management and tasks associated with managing those conditions.

Conclusions and Recommendations

- Develop a peer model approach to providing support to caregivers. Learning from others with shared diagnoses in a peer model approach, such as a buddy system, would help caregivers to navigate services and provide support as challenges arise.
- Enhance respite options with flexible budget options. Investigate home sharing and use of friends and neighbors as respite care providers. Expand capacity of nursing facilities, CCRCs, Assisted Living Facilities to provide respite care on a larger scale.
- Develop or select an existing family caregiver assessment tool to utilize across all caregiver support programs and include in all assessments for Medicaid HCBS waiver programs.

Caregiver Reward

- Participants described honoring their family member's wishes, ability to provide care for people at home, having a sense of purpose, feeling gratitude for quality time spent together, and reciprocity of care as rewards they felt for providing care to their family members.

"I promised them that I would do anything I can to keep them in their home. And the positive part of that is I'm bending over backward and I'm driving myself crazy and I'm exhausted and everything else, but the light at the end of the tunnel is they're getting what they wished for, what they wanted...to be safe and happy."