

A photograph of two women walking in a park. The woman on the left is younger, with dark hair, wearing a blue scarf and a light blue top. The woman on the right is older, with short grey hair and glasses, wearing a light pink jacket over a striped shirt. They are both smiling and looking towards the right. The background is a lush green park with trees.

National Family Caregiver Support Program

Insights from the Caregiving Community

Family caregivers are the backbone of America's long-term care system. According to the National Association of Area Agencies on Aging, more than 65 million Americans are caring for an older adult or someone living with an illness or disability. This translates to nearly 30 percent of the general population. This fact sheet includes information from caregivers based on their own experience.

Advice to Caregivers

From Caregivers to Caregivers

"Find time to focus on you. It can be difficult to find time for yourself while caring for a loved one, but taking breaks to stay active and engage socially can help you maintain your health and continue delivering the best care."

- **Ask for help early and ask for it often.** Caregivers who seek assistance and supports earlier in the process often find the experience to be more manageable than those who don't engage with services until later on in their loved one's decline.
- **Find time for yourself.** We know the caregiving process is physically demanding and emotionally draining. Caregivers who frequently use respite and home health services experience more positive caregiving.
- **Don't go through the caregiving experience alone.** By asking for help as often as needed and making time for yourself, you will have a more positive outlook, experience less stress, experience fewer interruptions in your daily life, have more time to take care of your needs, and be a more effective caregiver to your loved one

Background

Between 2013 and 2018 ACL undertook the first evaluation of the National Family Caregiver Support Program (NFCSP). The two-part evaluation included a process study to understand and document the strategies used to meet NFCSP goals, and an outcome study to understand NFCSP caregiver outcomes including stress reduction and maintenance of the care recipient in the community. The data provided in this fact sheet are drawn from a literature review and sample of caregivers whose care recipient passed away during the course of the outcome evaluation (n=8). This small study gathered information on the service components and needs of bereaved caregivers. The results and conclusions from this study aim at affording local service providers, Area Agencies on Aging (AAAs), State Units on Aging (SUAs), and AoA insights for supporting individuals at all stages of the caring process.

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Managing Bereavement

From Caregivers to Caregivers

“It is never too early to begin estate planning. Talking to your loved one about their wishes can be a difficult step to take, but having a plan in place will reduce the burden on you if the time comes to put it in action.”



- We know from other caregivers the **importance of having a support network** to help you through your grief.
- **Keep family and friends close** and don't hesitate to lean on them when needed. Many caregivers highlight the importance their faith plays in grief management, and the significant role their community plays in supporting them.
- **Plan ahead and get started on estate planning early.** Caregivers report not knowing how to handle the realities of settling their loved one's affairs, such as canceling social security, closing memberships, settling bills, etc.
- Finally, **make an effort to stay active, eat well, and get involved in your local community.** Returning to work, joining a gym, and getting involved in community service and volunteer organizations are all ways to help manage your grief.

HOW DO I FIND HELP IN MY COMMUNITY?



Eldercare Locator is a public service provided by ACL's Administration on Aging. It connects older adults and their families and caregivers with local support resources. Eldercare Locator can be reached at 1-800-677-1116 or eldercare.gov.



The National Respite Locator Service (NRLS) helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs. It is a free service offered by the ARCH National Respite Network. Access the NRLS at archrespite.org/respitelocator.

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