National Caregiver Support Collaborative | USAging Leaders in Aging Well at Home | FCA Family Caregiver Alliance | Innovations in Family Caregiver Services and Support

Family Caregivers and Planning for Long-Term Services & Supports

Introduction

An estimated 63 million Americans provide care for an older adult or someone living with illness or disability.[1] Family caregivers provide a wide range of services, such as transportation, food preparation, housekeeping and personal care, enabling care recipients to live at home or in the setting of their choice with dignity and independence. Without supportive services, nearly 62 percent of caregivers have suggested that the individual they care for would be living in a nursing home.[2] Additionally, there are at least 2.4 million children being raised by grandparents or other relative caregivers, serving as a safety net and providing care when children's parents are unable.[3]

This Action Guide is part of a series to help Aging Network organizations develop innovative caregiver services and supports that meet the needs of a growing population of caregivers.

> A ***family caregiver*** is an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation. This includes any grandparent or relative adult who has primary responsibility for grandchildren or other children who cannot remain with their parents.[4]

The resources included in this Action Guide are designed to increase an organization's capacity to identify and support family caregivers in planning for Long-Term Services and Supports (LTSS). The availability of LTSS varies across regions, but the examples in this guide include replicable ideas and resources that can help fill gaps in your community.

As defined by AARP, "***long-term services and supports"*** consist of a broad range of day-to-day help needed by people with long-term conditions, disabilities or frailty. This can include personal care (bathing, dressing, toileting); complex care (medications, wound care); help with housekeeping, transportation, paying bills and meals; and other ongoing social services. LTSS may be provided in the home, in assisted living and other supportive housing settings, in nursing facilities and in integrated settings, such as those that provide both health care and supportive services."[5]

Outreach to Family Caregivers to Engage in LTSS Planning

A challenge of connecting with family caregivers is that many people don't identify as family caregivers. This may be especially true in communities where the expectation is that "this is just what you do for family." Many people don't seek out support services until the care needs are more complex or they are in crisis. In some communities, it is also considered bad luck to talk about illness and death. Many families find these topics uncomfortable or

Innovations in Family Caregiver Services and Supports is a project of USAging, funded by the Administration for Community Living as part of its National Caregiver Support Collaborative.

challenging to discuss. However, planning and accessing resources early can help reduce stress and financial burden and is well worth the effort.

Action Steps

1. Consider different caregiver outreach strategies, tools and resources.

- Help identify family caregivers by asking if they care for or help someone with common tasks like transportation to appointments, preparation of meals, handling bills and medication management listed in Family Caregiving Alliance's Self-Screening Checklist.
- Consider specific points of entry where providers may be more likely to connect with family caregivers, such as hospitals, doctors' offices, faith-based organizations or places of worship.
- Launch a media or social media campaign like the ones highlighted in the National Academy for State Health Policy's Family Caregiver RAISE Awareness & Outreach Roadmap to help family members and friends identify as caregivers.

2. Explore innovative caregiver outreach program examples.

Program Name: Caring for Caregivers Model (C4C)
Organization: RUSH University Medical Center (Chicago, IL)
Program Description: The Caring for Caregivers (C4C) model provides a structured and sustainable approach to support family/friend caregivers of older adults in a variety of settings. The model is rooted in the 4Ms of an Age-Friendly Health System and assists with compliance with the CARE ACT. Reductions in caregiver burden, depression, and anxiety have been demonstrated. C4C is listed as a proven, effective dementia care model for caregivers on Best Programs for Caregiving. RUSH University Medical Center received a grant from The John A. Hartford Foundation to share this model with Age-Friendly Health Systems and Area Agencies on Aging nationwide.
Learn More: RUSH Caring for Caregivers

Program Name: Caring Together, Living Better
Organization: AgeOptions (Oak Park, IL)
Program Description: Caring Together, Living Better is a faith-based train-the-trainer curriculum designed to meet the spiritual and supportive needs of African American and Latino family caregivers. It partners with churches and community organizations and includes workshops on chronic disease management and support groups for caregivers.
Learn More: AgeOptions Caring Together, Living Better

Additional Resources

- AC Care Alliance: Care Navigators work with program participants to identify and address needs, provide trusted resources and encourage skills to empower persons needing advanced illness care and their caregivers.
- African American Alzheimer's Caregiver Training and Support Project 2 (ACTS2)This is a free faith-integrated skills-building and support services to caregivers of loved ones with dementia.
- ALTER: ALTER creates dementia-friendly congregations within the African American community.
- Cuidando con Respeto (Caring with Respect): This program has been adopted by Amazing Place in faith-based communities in Houston with Latino Families.

Advance Care Planning

Advance care planning is the process of preparing for future decisions about care if/when someone becomes seriously ill or unable to communicate their wishes. Having meaningful conversations with loved ones and

caregivers is the most important part of advance care planning. These conversations can be ongoing and revisited as life circumstances or preferences change. Many people also choose to put their preferences in writing by completing legal documents called *advance directives* that can be shared with health care systems.

Advance directives are usually a combination of documents that address treatment preferences and appointment of a health care agent to carry out those preferences. Increasingly, advance directives address serious illnesses that can happen farther from end of life, such as planning for dementia.

Action Steps

1. Explore advance care planning program examples and resources.

Program Name: Honoring Choices® Indiana
Organization: Aging & In-Home Services of Northeast Indiana (Fort Wayne, IN)
Program Description: Honoring Choices® Indiana is an initiative committed to promoting and sustaining advance care planning across the state to ensure individuals' future health care preferences are discussed, documented and honored. Partners include hospitals, health systems, community groups, educators and faith-based organizations. Honoring Choices® Indiana is part of a 13-state network that shares information, resources and best practices.
Learn More: Aging and In-Home Services of Northeast Indiana

Program Name: Wills for Seniors
Organization: Jefferson Area Board of Aging (Charlottesville, VA)
Program Description: Jefferson Area Board of Aging partners with university law students supervised by seasoned attorneys and volunteer notaries to host clinics where older adults and caregivers can meet to prepare customized legal documents, including advance medical directives.
Learn More: Jefferson Area Board for Aging

2. Use resources and staff training to guide caregivers and care recipients in the creation of an advance care plan.

- Advance Care Planning: Advance Directives for Health Care, from the National Institute on Aging, has information and access to a free 72-page conversation guide with worksheets and tools to help families plan. The guide can be downloaded or ordered.
- PREPARE for Your Care has two programs: one for an individual to have a voice in their own medical care, and another to help other people make medical planning and decisions.
- Five Wishes is legally valid in nearly every state and covers personal, spiritual, medical and legal wishes all in one document. It is written in plain language making it easy to understand and complete.
- My Advance Care Plan & Guide for Native Americans from National Indigenous Elder Justice, created by the Center of Rural Health and the University of North Dakota in partnership with the National Indigenous Elder Justice Initiative.
- Advance Care Planning Tools and Resource List, developed by the Coalition for Compassionate Care of California, includes a list of different tools that can be used to create programs or develop materials.
- The Conversation Project, provided by the Institute for Healthcare Improvement, has free conversation guides.

Financial Planning

Many families may incorrectly assume that Medicare covers facility-based long-term services and supports, such as nursing homes, skilled nursing facilities or rehabilitation centers. In fact, most long-term services and supports that occurs in a facility is paid for by the individual; Medicaid (for those who qualify or spenddown); Veterans Affairs (VA) benefits; through long-term-care insurance, which is expensive and oftentimes challenging to acquire. Given the costs and health insurance restrictions, most long-term services and supports happen at home with the support

of family caregivers. For the caregiver, it may be compelling to reduce their work hours, decline promotions, quit their job or retire early to provide care—but before doing so, caregivers should understand the financial impact on their own finances and retirement.

Financial planning for long-term services and supports is complex and can evolve over the caregiving journey. Aging Network staff don't need to be experts, but they can serve as a trusted source for information, sharing resources, tools and materials that already exist. The resources in this section can be shared with caregivers to help guide these important decisions.

Action Steps

1. Explore financial planning program examples and resources.

- The Financial Caregiving Hub from WISER is a clearinghouse of resources, tools and other helpful information for caregivers and their care recipients to help manage the financial impact of caregiving. It includes *WISER's Financial Steps for Caregivers*, a guide looking at the financial challenges facing today's family caregiver and providing information, tips and resources to help caregivers keep their own finances on track while caring for someone else.
- Family Caregiver Alliance's What Every Caregiver Needs to Know about Money covers how to talk about money with family members and financial considerations for caregiving (including a caregiver's own health care coverage and retirement). Family Caregiver Alliance has a tip sheet for holding family meetings.
- Alzheimer's Association's Financial and Legal Planning for Caregivers webpage includes information on planning for care costs, paying for care, insurance, health care appeals for people with Alzheimer's and other dementias, Social Security disability, Medicare, Medicare Part D benefits, Medicaid, tax deductions and credits, planning ahead for legal matters and legal documents.
- The Alzheimer's Association also has a free financial course geared towards caregivers focused on finances available at Alzheimer's Association Managing Money: A Caregiver's Guide to Finances.
- AARP's Financial and Legal web page for caregivers includes topics on insurance, fraud and finances, and financial workbooks for caregivers in multiple languages.
- Some AARP local branches offer financial workshops online or in person geared towards family caregivers. Visit AARP's website to see if your local branch has a workshop.
- The U.S. Department of Veterans Affairs (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC) provides a monthly stipend to Primary Family Caregivers of eligible veterans, in addition to other caregiver support benefits. Caregivers who are enrolled in PCAFC also can access Legal and Financial Planning Services. Eligible caregivers will have access to paralegals, licensed attorneys and certified financial counselors. Additionally, the VA may reimburse for mileage and other travel expenses to and from approved health care appointments for eligible veterans.
- National Council on Aging (NCOA)'s Benefits Checkup is a comprehensive online tool to connect older adults and people with disabilities to benefits assistance.

Professional Care Options

Many caregivers use a combination of informal supports, such as family and friends, and formal supports to care for a loved one. Family caregivers may need assistance identifying formal services available, including home care, adult day services, respite, care management, medical homecare, chore services and skilled nursing facilities for short-term or permanent stays. This section shares program examples and materials that other communities have developed to help guide families through a range of care options.

Action Steps

1. Explore innovative program examples and resources.

Program Name: Making the Link
Organization: Aging and Disability Resources and Health Care Providers Council of Pierce County (Pierce County, WA)
Program Description: Making the Link is an annual outreach and education event for all types of front-line health care professionals that showcases the community's range of LTSS. It aims to educate these professionals about how to help older adults and their caregivers link to LTSS.
Learn More: Pierce County Aging & Disability Resources

Resource Name: Options for Long Term Care
Organization: Senior Resources of West Michigan
Resource Description: "Options for Long Term Care" was developed for older adults and family caregivers who requested printed information on aging and disability resources. Senior Resource counselors use the information to educate people about in-home and out-of-home care options, payment choices and eligibility requirements.
Learn More: Senior Resources Options for Long Term Care

2. Highlight resources to assist families with vetting services or hiring in-home support.

- A resource for finding private geriatric care managers is available through Aging Life Care Association.
- Family Caregiver Alliance's Caring at Home web page includes tips for hiring in-home help through an agency. The Out of Home Care web page includes information on residential care options. The Services by State tool helps family caregivers locate public, nonprofit and private programs and services nearest to their care recipient.
- The VA has programs that can assist caregivers, such as the Homemaker and Home Health Aide program, Veteran Directed Care, Respite Care and Adult Day Health Care.

Additional Resources

- Medicare Compare at Medicare.gov
- Hand in Hand, the Domestic Employers Network
- The National Alliance for Care at Home
- ARCH National Respite Network and Resource Center

Palliative Care

Palliative care is a medical specialty focused on improving quality of life for seriously ill patients and their families and caregivers, through symptom management, communication and fostering patient autonomy using a holistic, patient-centered approach. Palliative care can be delivered alongside other treatments and is appropriate for seriously ill individuals of any age, regardless of prognosis. Palliative care is often confused with hospice, but hospice is a service subset of palliative care only offered to people with a prognosis of 6 months or less.

Hospice is available through every insurance, but patients must apply and be approved to receive the benefit. While palliative care is available in most U.S. hospitals and is increasingly available in physician offices, clinics and patients' homes, all types of palliative care are not yet available in every community. In some regions, there may be few palliative care clinics or home-based services, and the services that do exist may only be available to certain patients based on insurance coverage and diagnosis. Also, because there are no specific standards for palliative care from Medicare or other regulators, the types of support offered by palliative care services vary dramatically. Some programs offer intentional support to family caregivers, including education and emotional support, in addition to referrals, while others do not. For these reasons, it is important to develop an accurate understanding of the palliative care services that are available in your region, including eligibility criteria, services offered and staff qualifications.

Action Steps

1. Find palliative care programs in your area and explore program examples.

Start by developing a list of palliative care services in your area, including settings where they operate, eligibility criteria, services offered, any insurance coverage requirements and so on. A good starting point could be investigating the services listed in the Palliative Care Provider Directory. Additionally, most nonprofit hospitals with more than 50 beds offer inpatient palliative care. Leaders of these hospital-based programs are likely to be aware of palliative care clinics and home-based services in the area. It is also useful to check on the palliative services offered through local VA health centers, as well as programs sponsored by integrated delivery systems such as Kaiser. Most cancer centers offer supportive (palliative care) clinics.

Program Name: Sharp HealthCare's Transitions program
Organization: Sharp HealthCare
Program Description: In-home palliative care to individuals with serious illness and their loved ones. One pillar of the program is "professional care for the caregiver," along with in-home disease management, helping the patient and caregiver know what to expect as illness progresses and support in advance care planning.
Learn More:

- Sharp Transitions Advanced Illness Management Program
- Sharp Transitions Program Guidelines: Chronic Illness Management

Program Name: Arizona Supportive Care
Organization: Hospice of the Valley
Program Description: A team of physicians, nurses, nursing assistants, chaplains and social workers provide compassionate, specialized support, not just to patients, but also to overwhelmed family caregivers. The program focuses on explaining medications and disease progression, coordinating care with specialists, referring to community resources and assisting with medical directives.
Learn More: Arizona Supportive Care

2. Use resources and tools to provide education to family caregivers about palliative care.

- This video by the Alameda County (AC) Care Alliance describes palliative care and highlights the difference between palliative care and hospice: Palliative Care Myths and Facts.
- Understanding Palliative/Supportive Care: What Every Caregiver Should Know, developed by the Family Caregiver Alliance, provides important information about palliative care, including what it is, payment and access. A related guide by FCA is all about Advanced Illness: Holding On and Letting Go.
- Introducing Palliative Care, by the Coalition for Compassionate Care of California, is a video series that helps case managers and clinicians become more comfortable describing palliative care services.

Conclusion

The caregiving journey is often complex, but as a provider you can play a pivotal role in empowering caregivers and ensuring they have the resources, guidance and support they need. Within your agency capacity, we invite you to use the information in this guide to offer practical resources and referrals, educate caregivers on available options and provide ongoing assistance to help ease the emotional and logistical burdens that accompany caregiving responsibilities.

Acknowledgements

USAging would like to thank the Caregiving Action Guide Workgroup comprised of Ames Simmons, Duke University School of Law; Anita Kong, San Francisco VA Health Care System; Diane Mariani, RUSH University Medical Center; Jasmine Ng, Family Caregiver Alliance; Jessica Zitter, Reel Medicine Media; Kathleen Kerr, Transforming Care Partners; Kylie Madhav, SAGE; Lara Hinz, WISER; Larissa Atkins, Senior Services of Southeastern Virginia; Marda Quon Stothers, FCA Board Member, Former Caregiver and Deacon; Michelle Tapia, San Francisco VA Health Care System; Rachel Neely, ADvancing States; Rita Choula, AARP Public Policy Institute; Sarah Adams, Trellis; with support from Family Caregiver Alliance staff Christina Irving, Kathleen Kelly, Jenna Shankman and Leah Eskenazi, for their major contributions that helped shaped this Action Guide.

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This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $4,400,000 with 75 percentage funded by ACL/HHS and $1,476,288 and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, ACL/HHS, or the U.S. Government.