



# ON FIRST ANNIVERSARY OF THE CARE EXECUTIVE ORDER, SUPPORT FOR FAMILY CAREGIVERS IS GROWING, BUT CONTINUED PROGRESS IS NEEDED

On April 18, 2023, the Biden Administration announced an Executive Order to recognize the more than 48 million family caregivers across America as a national priority and support their rapidly growing needs. The order aims to better include and support family caregivers through federal programs. AARP advocated for and applauded this historic Executive Order that helped lead to:

- Medicare testing a new model to improve the quality of life for people with dementia and help them live in their homes and communities. The model will reduce strain on unpaid caregivers through caregiver education and support and respite services.
- CMS engaging hospitals on how they will work with family caregivers during a loved one's participation in the Hospital at Home program in Medicare and Medicaid, which allows hospitals to treat some patients in their homes.
- CMS reaffirming the responsibilities of hospitals to engage caregivers as active partners in planning for discharge from the hospital and care after discharge.
- All Veterans Affairs Medical Centers having Veteran Directed Care (VDC), which helps Veterans live at home by receiving home and community-based services, by the end of Fiscal Year 2024. Veterans in VDC may hire family, friends, and/or neighbors to provide services.

## The Roles and Struggles of Family Caregivers Today

As the backbone of our long-term care system, family caregivers help older adults, people with disabilities, and veterans live independently in their homes where they want to be. Caregiving touches nearly every family – across all ages, races, ethnicities, and segments of our population.

Family caregivers provide \$600 billion annually in unpaid labor to their loved ones. This includes assisting with daily activities such as eating, bathing, dressing, meal preparation, finding and coordinating care, managing medications, transportation to medical and other appointments, performing complex medical/nursing tasks, supporting their loved one through care transitions such as from hospital to home, managing finances, and so much more. The physical, emotional, and financial challenges caregivers face cannot be overstated, as exemplified by a poll released by AARP last year on family caregivers.

- Over half (56%) of family caregivers advocate with care providers, community services, or government agencies on behalf of their loved one. Nearly one-third of individuals coordinating care, however, find it difficult to do so.
- Family caregivers spend, on average, 26% of their income on caregiving expenses, or over \$7,200 annually.

- Sixty percent of unpaid family caregivers also have jobs. To accommodate their caregiving responsibilities, a significant number are adjusting their work schedules, switching from full to part-time, taking a leave of absence, or giving up their jobs entirely to accommodate their caregiving responsibilities, according to recent AARP [research](#). This is particularly true for female family caregivers, who account for three in five caregivers.
- In just one state, AARP [found](#) that close to three-quarters (72%) of women caregivers changed their work schedule, more than a quarter (27%) took temporary leave, almost a quarter (22%) went from full to part-time, and 20% stopped working.

However, family caregiver needs are so vast that greater federal support is needed to help America's caregivers who serve loved ones, often in an unpaid capacity at the expense of their own health and financial well-being.

AARP members care deeply about this issue and took over 870,000 actions in support of helping family caregivers since the Executive Order in 2023, such as mailing their federal and state representatives in support of solutions that save caregivers time and money and provide them with more support. Members also shared thousands of poignant, heartbreaking, and even humorous personal stories about their caregiving experiences through AARP's [I Am a Caregiver campaign](#).

## As a result of AARP's recent advocacy, here is an overview of additional progress at the federal level in the past year.

### New Steps Through Medicare

- Under a [recent CMS rule](#), Medicare can pay health care professionals solely to train family caregivers, who are often unprepared to care for their loved ones.
- Family caregivers are included in Medicare's new [principal illness navigation services](#), which help patients with high-risk health conditions understand their medical condition or diagnosis and guides them through the health care system.
- Within the [Medicare Shared Saving Program](#), an accountable care organization (ACO) can receive advanced investment payments to help improve the quality of care for more people with Medicare. The program also provides an opportunity for health care providers in rural and underserved areas to form an ACO. [Patient caregiver supports](#) are explicitly included as a potential use of funds.

### New Steps Through Medicaid

- CMS [reported](#) that 29 states are investing in efforts totaling \$1.3 billion (under Medicaid home and community-based services and American Rescue Plan Act resources) that offer family caregivers training, respite, resources, counseling and/or support groups, and other services.

### New Steps in Hospital Settings and Elsewhere

- A funding opportunity for the [AmeriCorps Senior Companion Program](#) now prioritizes family caregivers.
- As part of the National Strategy to Support Family Caregivers, [new funding](#) from the Administration for Community Living will allow organizations to develop, test, and disseminate new approaches to support family caregivers through some current programs.

## Strong Bipartisan Support in Congress

AARP is also working closely with Congress to advance bipartisan legislation that will directly respond to the challenges family caregivers face each day.

- The **Credit for Caring Act** (S. 3702/H.R. 7165) would create an up to \$5,000 tax credit to help eligible working family caregivers offset some of the cost of caregiving expenses.
- The **Connecting Caregivers to Medicare Act** (S. 3766/H.R. 7274) would require CMS to promote the 1-800-MEDICARE helpline to make it easier for family caregivers to get the information they need to help their loved ones make the most of their Medicare coverage.
- The **Alleviating Barriers for Caregivers (ABC) Act** (S. 3109/H.R. 8018) would help reduce red tape for family caregivers by requiring the Centers for Medicare & Medicaid Services (CMS) and the Social Security Administration to take actions to simplify and streamline policies and procedures that improve customer service for family caregivers and individuals covered by or filing for Medicare, Medicaid, CHIP, and Social Security.
- The **Lowering Costs for Caregivers Act** (S. 3254/ H.R. 7222) would allow flexible spending accounts, health savings accounts, health reimbursement accounts, and Archer medical savings account funds to be applied to medical expenses for a parent or spouse's parent.

To learn more about AARP's advocacy for family caregivers, please reference our **[caregiving resource guide](#)**, **[state and federal advocacy guides](#)**, and **[www.aarp.org/careforcaregivers](http://www.aarp.org/careforcaregivers)**.