

AARP:

Partnering to Serve People as They Age

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As the world's largest nonprofit, nonpartisan membership organization dedicated to social change and helping people live better as they age, AARP collaborates and partners with other organizations to achieve its purpose. This article describes how AARP uses partnerships to bring prominent attention to the issues that are critical to consumers and the nursing profession in 2 areas: brain health and caregiving. By describing AARP's work with numerous organizations in each of these areas, the article demonstrates how partnering with the right organizations is an effective strategy for bringing about social change and improving the lives of people as they age.

As the world's largest nonprofit, nonpartisan membership organization dedicated to social change and helping people live better as they age, AARP has nearly 38 million members, offices in every state, as well as Puerto Rico, the US Virgin Islands, and the District of Columbia. We also have a vast array of communication channels including *AARP The Magazine*, which last year surpassed *People Magazine* as the most read publication in the United States.

As the CEO and the national volunteer president of AARP, we work together to lead AARP on a mission to disrupt aging. With the population aging at unprecedented rates, we want to challenge outdated attitudes and stereotypes, and spark new solutions that empower people to choose how they want to live as they age. This is not something we can accomplish on our own. In order to succeed, we have to be:

- A strong, powerful, and effective advocate for financial resilience and health security, including strengthening Social Security and Medicare
- A convener that connects like-minded groups and extends our influence to effect change
- A global thought leader that challenges outdated beliefs on aging and sparks new solutions globally
- An influencer that encourages markets to better serve people as they age
- A voice for multicultural audiences, low-income and vulnerable Americans that ensures their concerns are heard among leaders and decision-makers in the public and private sector

Partnerships are at the center of all of these roles. They require that we collaborate with other highly informed and deeply committed organizations and

individuals to bring about social change. For example, in 2007, we partnered with the Robert Wood Johnson Foundation to launch the Center to Champion Nursing in America. Through this partnership, we have brought prominent attention to the issues that are critical to consumers and the nursing profession. Since then, we have partnered with many other organizations to achieve our mission of empowering people to choose how they live as they age.

Two prime examples of the power of such partnerships are our work on brain health and on caregiving.

BRAIN HEALTH

Brain health is an important issue for us at AARP primarily for 2 reasons.

First, as our population ages and people live longer, the sheer number of people living with dementia will increase dramatically. Although Alzheimer's is not caused by age, it becomes more likely with age. More than 6 million people in the United States suffer from

KEY POINTS

- **AARP views partnerships as essential to helping people live better as they age.**
- **AARP engages in partnerships to achieve its 3-pronged strategy to improve brain health by focusing on prevention, care, and cure.**
- **The demands family caregivers face grow as the population ages. Providing them with the support they need requires working effectively with other organizations.**

various types of dementia, including Alzheimer's disease, and those numbers are growing at an alarming rate all around the world. That number is projected to exceed 16 million by 2050, affecting about 1 in 5 Americans age 65 or older. Worldwide, about 50 million people have dementia, a number projected to grow to more than 130 million by 2050.

Second, Alzheimer's and other forms of dementia take a devastating emotional, financial, and physical toll on family caregivers—again, the overwhelming majority of whom are women. Research shows that in 2016, nearly 16 million family members and friends provided more than 18 billion hours of unpaid caregiving assistance to those with Alzheimer's and other types of dementia.

Aware of the broad and devastating impact of these illnesses, researchers have worked hard to find effective treatments. But dementia is a complicated illness. Hundreds of clinical trials have failed, and some advances once thought to be promising have turned into dead ends.¹

Yet, AARP is optimistic that this disease can be defeated. And, we're committed to sparking a lifetime of healthier brains and disrupting dementia. We have developed a 3-pronged strategy to accomplish that goal focused on prevention, care, and cure.

Prevention

AARP has long been committed to raising awareness of dementia-related illnesses and educating people age 50 and older on how to maintain brain health. We want to empower people to live brain-healthy lifestyles based on evidence and behavior change principles.

Care

We seek to support those who suffer from dementia and their caregivers by dispelling myths and busting stigmas to enable better outcomes. This includes inspiring adoption and scaling of evidence-based best practices for people 50 and over, caregivers, the health and long-term care systems, and communities.

Cure

AARP's Brain Health Fund is investing \$60 million in the Dementia Discovery Fund (DDF), which invests in research and development of breakthrough treatments for dementia (see below).

Achieving all parts of this strategy involves partnering with other organizations to achieve our goals. Some examples include:

GLOBAL COUNCIL ON BRAIN HEALTH

Staying sharp mentally is the leading concern of older adults. The Global Council on Brain Health (GCBH), convened by AARP with support from Age UK, the United Kingdom's largest charity dedicated to helping people make the most of their later years. The Council offers the soundest possible advice about how older adults can maintain and enhance their brain health.

GCBH is a collaborative effort. It brings together scientists, health professionals, scholars, and policy experts from across the globe who work in areas of brain health related to human cognition. The Council focuses on brain health that relates to thinking and reasoning ability as people age, including memory, perception, and judgment. The goal is to get beyond the confusing whirl of information in this field and suggest evidence-based steps people can take to improve their cognitive help.

The GCBH collaboration functions as a hub-and-spoke system. The hub consists of about a dozen experts from around the world. This group directs the "spokes," issue specialists who examine priority areas that include physical exercise, mental engagement, diet, sleep, stress levels, socialization, and supplements.

The Council has provided practical advice on brain health through reports on:

- The brain-body connection
- The brain-sleep connection
- The brain and social connectedness
- Cognitively stimulating activities to engage the brain
- Brain food: nourishing your brain health

The Council's launch in October of 2015 built upon earlier collaborations AARP engaged in concerning brain health. In 2001, for example, the Dana Alliance for Brain Initiative and AARP Andrus Foundation produced booklets in English and Spanish entitled, *Staying Sharp: Current Advances in Brain Research*.²

AARP has sent representatives to the G8, G7, and World Health Organizations summits on dementia. In 2014, AARP co-hosted the Changing Global Care for Dementia summit with the Global CEO Initiative on Alzheimer's Disease. The following year, AARP joined the Global Alzheimer's and Dementia Action Alliance.

THE BRAIN HEALTH PARTNERSHIP AND US AGAINST ALZHEIMER'S

The Brain Health Partnership recognizes that while scientists continue to fight to find a cure for Alzheimer's and other types of dementia, we can't simply sit back and wait for that to happen. We need to work together to reduce risk, improve care and help people optimize their brain health as they age. The Brain Health Partnership initiative, under the leadership of US Against Alzheimer's, brings together different stakeholders who all play a part in creating the better future we are all striving for. Together, the Partnership representatives have the insights, experience, and commitment to challenge outdated beliefs on aging and brain health, and spark new solutions globally and develop recommendations that point the way forward.

WOMEN'S BRAIN HEALTH TRUST

Because two-thirds of Americans with Alzheimer's are women, and more than 60% of Alzheimer's and

dementia caregivers are women, AARP plays an active role in the Women's Brain Health Trust, a campaign that helps women see, think, and talk about brain health.

DEMENTIA DISCOVERY FUND

Another important example of AARP's work across national boundaries in the area of brain health is the \$60 million investment we made last year in the DDF. With this commitment, AARP became the single largest investor in the DDF.

The DDF is a London investment fund created in 2015 to provide money to small companies working to achieve a breakthrough that will stop or slow the onset of Alzheimer's disease and other forms of dementia. The DDF is the world's largest venture fund focused solely on finding and developing novel therapies for dementia, including Alzheimer's disease.

By bringing together the world's best minds to accelerate global research efforts, the DDF is helping to kick-start a new approach to dementia research by investing in organizations that are exploring new pathways for treating all types of dementia including Alzheimer's.

This investment in the DDF also provides hope for the future by recognizing that the urgent need to find better treatments will require cooperation among researchers, public health agencies and investors.

CAREGIVING

In the United States today, there are about 40 million unpaid family caregivers and that number is growing. In many cases, people will spend more time—and resources—caring for their aging parents than they did raising their own children.³

This has serious implications for caregiving. We know that at some point in our lives, most of us are either going to be a caregiver or need a caregiver. Although anyone at any age can require caregiving, the vast number of people needing care will be in these older age groups.

Family caregivers face unprecedented demands. And those demands continue to grow. Our research shows that family members do 90% of caregiving, and nearly half perform tasks that were once limited to trained nurses.³

And, as the oldest segment of the population increases rapidly in the coming decades, the ratio of family caregivers to those needing help will decline dramatically—placing even greater demands on fewer family caregivers and creating an urgent need to support them with training, respite, and workplace flexibility. This is a massive undertaking. AARP recognizes that we are in a much stronger position to help them get that support when we combine our brand, reach, and expertise with the assets of other leading organizations. Some examples are cited below.

ALZHEIMER'S ASSOCIATION

In 2018, we launched the Alzheimer's Association & AARP Community Resource Finder,⁴ a database of dementia and aging-related resources that makes it easy for individuals and families to find programs and services in a specific location. The co-branded community resource locator tool includes Alzheimer's and AARP local and online events, housing options, care at home options, and medical and community services, all based on zip code search.

Since 2017, we partnered with the Alzheimer's Association to create a more seamless, relevant experience for callers to the AARP'S Caregiving line (1-877-333-5885) who are interested in more in-depth information about Alzheimer's or dementia. AARP Membership Contact Center representatives identify Alzheimer's/dementia-related calls made on AARP Caregiving line that are more appropriate for the ALZ 24/7 Contact Center to handle, and warm transfer the caller to their hotline.

UNITED WAY WORLDWIDE

In 2017, AARP worked in partnership with United Way Worldwide to apply a user-centered design innovation approach to develop an online caregiving simulator tool that captures the day in the life of millennial working family caregivers at different life stages.⁵ One-fourth of all family caregivers are millennials, many of whom feel isolated and challenged by the physical, emotional, and financial demands of juggling home, work, or school duties. The tool raises empathy and awareness of caregiving in the community and workplace, provides resources on family caregiving, and encourages individuals to support people who are caring for loved ones at home.

ELIZABETH DOLE FOUNDATION

In 2019, AARP partnered with the Elizabeth Dole Foundation and the US Chamber Foundation's Hiring Our Heroes (HOH) program to address the need for improved employment opportunities for military and veteran caregivers. Together, we will convene a national taskforce made up of corporate partners with veteran-focused hiring programs. The taskforce will be charged with identifying challenges to recruiting, hiring, and retaining veteran and civilian caregivers in a corporate work environment, as well as developing best practices for supporting caregivers in the workforce. We will also expand HOH's Corporate Fellowship program and will convene leaders at a national summit on supporting working veteran/military family caregivers.

Also, in 2019, AARP and the Elizabeth Dole Foundation produced a Veteran and Military Family Prepare to Care guide. This guide is designed to help make the job of caregiving more manageable. It includes information on how to have vital conversations with older family members, organize important

documents, assess your loved one's needs and locate important resources.

RURAL WISCONSIN HEALTH COOPERATIVE

For a number of reasons, rural communities are unique, so resources must be unique as well. Although hospitals and health providers are an important way to reach family caregivers, that role is even more important in rural communities. That is why we have partnered with the Rural Wisconsin Health Cooperative (RWHC) to provide rural hospital systems and communities with free, co-branded resources that expand or improve the support for family caregivers while also benefitting providers. RWHC is owned and operated by 42 rural, acute, and general medical-surgical hospitals.

Together, we are developing and will disseminate a “rurally relevant” family caregiver toolkit that we expect to be widely used by both rural health care organizations and family caregivers to improve patient outcomes. RWHC has a strong national reputation, nationwide connections, and knows rural health care. After testing our tools in Wisconsin, we will use RWHC's nationwide network to reach every state in the country.

NATIONAL CAREGIVING SUMMIT

In 2017, AARP convened a national summit, bringing together all of the organizations we work with on family caregiving in order to focus on the areas where we need further progress. Two hundred attendees came together to develop technology, community, and employer solutions for family caregivers and to showcase the ways in which we are working together. Follow-up has been encouraging. More than 40 organizations have continued to connect every other month.

In 2019, we'll hold our second summit and focus on community success stories on caregiving. Partners in the business community and local government will come together to showcase success stories and share our vision for communities and employers that support working family caregivers.

HOME ALONE ALLIANCE

AARP is part of the Home Alone Alliance, which has also included United Hospital Fund, Family Caregiver Alliance, the UC Davis Health Betty Irene Moore School of Nursing, and the US Department of Veterans Affairs. A survey by the Home Alone Alliance in 2019 found that half of family caregivers are performing medical tasks, such as pain management and injections, for which they are not trained.⁶

The survey of almost 2,100 family caregivers was a follow-up to a 2012 AARP Home Alone study that represented the first national look at how caregivers are handling complex medical tasks.

The Alliance also developed a video for caregivers on issues related to special diets. AARP worked with

the US Department of Veterans Affairs on caregiver videos concerning how to manage mobility tasks.

AD COUNCIL CAREGIVING CAMPAIGN

Since 2012, AARP has worked with the Ad Council on a caregiving campaign with public service announcements (PSAs) in English and Spanish. The campaign is designed to raise public awareness of caregivers and provide them with help. The ads drive caregivers to AARP's Caregiving Resource Center, where they are able find articles, tips, and tools. The campaign has included ads targeted to male caregivers, to Latinos, and to African-Americans. Since the campaign began, it has attracted over \$200 million in donated media.

Facebook donated \$100,000 in 2017 to help launch the male caregiving effort. We have engaged in several content partnerships that have enabled us to create caregiving content, share the PSAs and resources with target audiences, and build a relationship with family caregivers who may not have known AARP or our work in this area. These partners have been: Upworthy, a website focusing on viral content; Kaleidoscope, which focuses on reaching community and faith-based influencers to build relationships and drive advocacy and engagement among youth, mothers, and millennials for national brands and issues; and *USA Today*.

NATIONAL POLL ON HEALTHY AGING

AARP works with the University of Michigan Institute for Healthcare Policy Innovation, and Michigan Medicine, the university's academic medical center, on a nationally representative survey of older adults and their caregivers on health issues.

The survey—the University of Michigan National Poll on Healthy Aging—has covered a wide variety of topics. Recent reports showed how older adults view: pets and healthy aging; loneliness and health; health insurance decision-making as retirement approaches; urinary incontinence; genetic testing; opioids; portals to access health information; medical marijuana; overuse of health care; flu vaccines for nursing home staff and residents; dementia caregiving; sleep trouble; dental care; and using doctors and pharmacists to manage drug costs.

The surveys are fielded 2 or 3 times each year to about 2,000 individuals age 50-80.

CONCLUSION

Partnerships have been and will continue to be an integral part of our strategy to help people live better as they age. As the world continues to change, and miraculous innovations in technology and advances in medical science continue to push the boundaries of healthy aging, AARP will be there collaborating with other organizations, innovators, and entrepreneurs to spark new solutions that empower people to live better as they age.

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