Family Caregivers: The Unrecognized Strength Behind Hospital at Home

"The COVID-19 pandemic, like HIV/AIDS and other epidemics before it, has brought devastation and grief to millions of people. But also, like other epidemics, this one is leading to scientific advances, changes in policy and medical practice, and cultural shifts. Actions taken to meet the COVID-19 crisis can become longer-term opportunities to advance person- and family-centered care.

Hospital at Home (HaH) programs are a case in point. These programs have existed since the 1970s in the United Kingdom, Canada, France, Australia, Israel, and other countries with government-run health systems. Begun in the US in 1995, at Johns Hopkins under the direction of geriatrician Bruce Leff, the model was designed to help older adults avoid potential hazards commonly experienced in the traditional hospital, such as functional decline, inappropriate medications, overuse of tests, and delirium. The solution was to provide hospital-level care in a more comfortable and safer setting—at home.

Numerous studies of HaH programs have documented improvements in care outcomes, lowered readmission rates, and cost savings. The primary barrier to expansion until recently has been a lack of a defined reimbursement package and a medical culture that prioritizes hospital and facility-based care."

From: HealthAffairs | June 3, 2021

How Family Caregiving is Changing

"The number of American family members caring for adult relations is on the rise, according to data from the National Alliance for Caregiving’s (NAC) 2020 Caregiving in the U.S. study.

"When looking at caregivers for adults Is Your Town Friendly to Family Caregivers? A New Survey Will Help

"I felt proud when I did this, proud of the people we work with and how many services we offer," Koet says. “It’s good to review what you’re doing. There are times I thought, ‘Could we do that?’ We get so busy thinking about the seniors we forget..."
only, the prevalence of caregiving has risen from 16.6% in 2015 to 19.2% in 2020 — an increase of over 8 million adults providing care to a family member or friend age 18 or older, primarily driven by a significant increase in the prevalence of caring for a family member or friend who is age 50 or older,” reports C. Grace Whiting, J.D., NAC’s president and CEO.

The assessment — the first of its kind in the nation — asks participants to rank themselves in eight different categories that are considered critical to meeting the needs of a growing senior population. The Caregiver Friendly Communities Assessment provides real-world evidence of the strengths and weaknesses in the caregiving chain — and offers best practices for becoming more caregiver friendly.

From: The Oakland Press | June 10, 2021

UPCOMING EVENTS

Pride of Care Series for LGBTQ Caregivers

June, 2021 | Every Thursday at 11 AM EST| Online

WellMed is hosting a series of hour long virtual sessions focusing on LGBTQ caregivers. The series, Pride of Care, will take place every Thursday in June 2021 at 11 AM EST on Zoom.

Click the red link below to learn more and click HERE to register.

Caregivers Count Webinar: Policy Solutions and Community Resources to Support Family Caregivers

June 15, 2021 | 4 PM EST| Online

There’s no one way to be a caregiver. The Caregivers Count campaign honors the diverse experiences of caregivers and empowers them to recognize themselves as an essential part of our healthcare system. Because many people don’t recognize themselves as “caregivers,” they overlook essential support services that may ease their caregiver experience.

Many people step up to help a loved one who is sick because they believe that is what is expected of them as a family member or friend. However, being a caregiver and assuming that role is so much more than kinship or spending time together; it involves taking on many unplanned or extra actions to support someone who is sick and maintain their quality of life and well-being.

Click the red link below to learn more and click HERE to register.
A Celebration of Service: Welcoming House Committee on Veteran’s Affairs Chairman Mark Takano and Ranking Member Mike Bost

June 16, 2021 | 2 PM EST | Online

Through this virtual welcome reception, the military, veteran, and caregiver communities and all who support them will have the opportunity to connect directly with the congressmen and engage in an important dialogue about the road ahead. We are excited to welcome these key policy leaders for an important discussion around the road ahead for our caregiving community, in 2021 and beyond. Our CEO Steve Schwab will highlight key efforts underway with the new Administration and new opportunities to enhance support for veteran families, caregivers, and survivors.

We Can Do This Covid-19 Vaccine Toolkit Webinars

June 15 - July 8, 2021 | Online

The HHS We Can Do This campaign is a national initiative working hand in hand with trusted leaders and community organizations to continue to build confidence in COVID-19 vaccines and get more people vaccinated. This campaign offers tailored resources and toolkits for stakeholders to use to provide COVID-19 vaccine information to at-risk populations.

The Centers for Medicare & Medicaid Services (CMS) is partnering with the campaign to offer several webinars to walk through each toolkit and its resources and train community organizations, local voices and trusted leaders to use the campaign tools for vaccine outreach efforts to diverse communities.

This week’s webinars are:
- Tuesday, June 15, 1:00-1:30 PM EST: General Populations Toolkit | REGISTER HERE
- Thursday, June 17, 1:00-1:30 PM EST: Rural Toolkit | REGISTER HERE

Elder Abuse in People Living with Dementia: Considerations for Prevention, Detection and Intervention

June 23, 2021 | 2 PM EST | Online

Elder mistreatment is a common phenomenon in our society, particularly among older adults with cognitive impairment and dementia. Yet there is hope. Using practical clinical and legal tools, we can look for high-risk situations and prevent abuse, and we can detect abuse at early stages to stop it from getting worse. This webinar, conducted by physician, Laura Mosqueda, MD, and attorney, Charles P. Sabatino, JD, with years of practical experience in the field, will discuss indicators that should raise concern, provide practical
tips on when and how to intervene, and pay particular attention to the complicated issue of capacity.

Click the red link below to learn more and click HERE to register.

**International Respite (Short Break) Conference**

**June 22-25, 2021 | Online**

ISBA is hosting this international conference for everyone who provides, uses or needs respite or short break services. The conference is also intended for policy makers and program administrators who want to understand the needs of family caregivers and those who use respite or short break services.

Click the red link below to learn more and click HERE to register.

**Living Rare, Living Stronger: NORD Patient and Family Forum**

**June 26-27, 2021 | Online**

Hosted by NORD and featuring the Rare Impact Awards, this event will allow patients, caregivers and advocates to attend panels that will allow them to connect with others in the community and to live their best rare life.

Click the red link below to learn more and click HERE to register.

**Rare Disease Week**

**July 14-22, 2021 | Online**

EveryLife Foundation is hosting Rare Disease Week on Capitol Hill, a week for rare disease members from across the country to come together, meet other advocates, be educated on federal legislative issues and to share their stories with legislators.

Click the red link below to learn more and click HERE to register.
Powerful Tools for Caregivers: Virtual Edition

July 14 - August 25, 2021 | 6 PM EST | Online

The six-week Powerful Tools for Caregivers Program helps people who are caring for an aging loved one. This could be a parent, grandparent, spouse, sibling, neighbor or friend. This virtual, interactive workshop will help caregivers learn techniques to help them take care of themselves while taking care of a loved one, manage stress and understand the complex emotions that often come with caregiving.

The class will help you:
- Find resources
- Learn relaxation techniques
- Manage emotions, including depression, guilt and resentment
- Find confidence in dealing with the demands of caregiving

Click the red link below to learn more and register by calling (833) 262-2200 or email wellnessprograms@aaa1b.org.

CALL FOR SUBMISSIONS

Share Your LGBTQ Caregiving Story

Deadline: June 30, 2021

Caregiving.com is collecting the stories and experiences of LGBTQ caregivers to highlight the important contributions those who are lesbian, gay, bisexual, transgender, queer and questioning have made throughout history. The information gathered will be used to create content for Pride Month and beyond to elevate the stories of LGBTQ caregivers.

Click the red link below to learn more and to share your story.

PATIENT AND CAREGIVER STUDIES

AHEAD Study

Join a trial that aims to help prevent Alzheimer’s disease, funded by the National Institutes of Health (NIH) and Eisai Inc., which is testing an investigational treatment aimed at delaying memory loss before noticeable signs of Alzheimer’s disease begin.

Click the red link below to learn more.
LEAF: Life Enhancing Activities for Family Caregivers

Researchers at UCSF and Northwestern University are testing a program for family caregivers of people with Alzheimer's Disease designed to increase levels of positive emotion, which in turn can help lower stress and support ways of coping with the stresses of caregiving.

Click the red link below to learn more and click HERE to take the pre-screening survey.

LEARN MORE >

Veteran User Experience Research Study

Are you a Veteran? Active duty or Reserves? A caregiver? A family member? The Department of Veterans Affairs wants to make it easier for you to explore, apply for, manage, and track your VA benefits. Teams at the VA want to hear your feedback about improvements they are making to VA websites, mobile applications, and other digital tools -- to ensure that these services are usable and relevant for you.

Click the red link below to learn more and click HERE to register.

LEARN MORE >

IN CASE YOU MISSED IT...

Understanding and Overcoming the Challenges of an Alzheimer's Diagnosis

Knowing the warning signs of Alzheimer’s disease is important for early detection and diagnosis. Family members often are the first to notice the signs, but they may struggle with how to approach their loved one about scheduling a doctor’s appointment. Once they do broach the subject, they may be met with resistance or denial. When receiving an Alzheimer’s diagnosis, the individual and their family may be at a loss for what to do next. As professionals, it is important to help older adults and their families to navigate this diagnosis and its aftermath by providing them with useful information and support. Join
This webinar to learn more about the challenges of an Alzheimer’s diagnosis, how to overcome them and helpful resources to share with those you serve.

WATCH HERE >

When I’m 64: Biden’s New Care Plan

There’s a new president in office, and with him comes a new infrastructure plan, including a plan to improve care infrastructure. But what does the proposed plan entail, and can Washington come together on making it a reality? The podcast got three perspectives. Aisha Adkins is a caregiver and constituency organizer at Caring Across Generations. David Dayen is the Executive Editor of an independent political magazine, The American Prospect. And Terry Fulmer is the President of the John A Hartford Foundation, dedicated to improving the care of older adults.

LISTEN HERE >

RESEARCH & RESOURCES

NEW Centralized Guidebook for Caregivers of Children and Adolescents with Crohn’s Disease

JUST RELEASED!

CIRCLE OF CARE: A GUIDEBOOK FOR CAREGIVERS OF CHILDREN AND ADOLESCENTS MANAGING CROHN’S DISEASE

Download Now

The National Alliance for Caregiving is proud to present a Circle of Care Guidebook for Caregivers of Children and Adolescents Managing Crohn’s Disease, a new resource designed to help caregivers navigate their journey caring for a child or adolescent with Crohn’s disease. The centralized guidebook offers effective information and tools that have helped other caregivers in similar situations. If you or someone you know cares for a child or adolescent living with Crohn’s disease, make sure to check out the guidebook at www.caregiving.org/guidebooks.

You’ll learn about:

- Everyday tips on caring for a child or adolescent with Crohn’s disease;
- Understanding Crohn’s disease from a medical perspective;
- Information on treatment and care coordination;
- Understanding the cost of care and access;
- Empowering your child to manage their Crohn’s disease; and
Caring for yourself and your family.

There is also a section with a comprehensive list of other online and print resources for caregivers, the child living with Crohn's disease, and his or her family that are referenced throughout the guidebook.

Visit www.caregiving.org/guidebooks to learn more and access important resources.

The guidebook was developed with support from The Leona M. and Harry B. Helmsley Charitable Trust.

Navigating the Pandemic: A Survey of U.S. Employers

Employers play a vital societal role by providing employment, work experience, employee benefits, and the ability for workers to save and invest for a secure retirement. This report examines the pandemic's impact on employers across company, their response, and timely opportunities. A strong employee benefits package, including retirement benefits, health insurance, workplace wellness programs, and caregiver support, can create a win-win situation for employers and their employees. Especially now, as our nation is emerging from the pandemic, employers need support from policymakers to continue paving the way for their recovery and to make it as easy as possible to enhance their business practices and expand their benefits offerings.

How to Be a Caregiver

Even if you're not a caregiver now, odds are that you will find yourself in the role someday. In the United States about one in five adults is providing unpaid health or supportive care to someone they love — an aging parent, a family member or child with a disability or a spouse, partner or friend with an illness. We asked experts on caregiving and aging, as well as dozens of people who have been caregivers themselves, for their best advice to help the next generation of caregivers.

Can We Talk About Caregiving? Tips to Support Family Caregivers

Caregivers are an essential part of our healthcare system. Many people, though, don't see themselves as a “caregiver” and, as a result, don't realize the critical role that they play. Here are five tips to help caregivers recognize their role, learn about the resources that can support their specific needs and feel more prepared for the challenges of caregiving.
UsAgainstAlzheimer's has released a new resource for you and your family's brain health. It's never too late to take action on brain health. BrainGuide is a first-of-its-kind platform that empowers people with knowledge and resources to take the best next steps in managing their own or a loved one's brain health.

The BrainGuide memory questionnaire does not provide a diagnosis, but it can help guide you toward information and resources that inform the next best steps you or a loved one can take. No information is recorded or shared with anyone other than the person completing the questionnaire. The BrainGuide memory questionnaire can be completed as a self-administered questionnaire or filled out by a caregiver or someone close to you. Questionnaires are not recorded or shared with anyone other than the individual completing the questionnaire.

Click the red link below to take the memory questionnaire.

TAKE THE QUESTIONNAIRE

FOLLOW US TO STAY CURRENT ON CAREGIVING!