Family Caregivers Feel the Pandemic's Weight

"Most older Americans who need help with the so-called activities of daily living — bathing, dressing, eating, using a toilet — don't receive any kind of paid care, at home or in care facilities. They rely on unpaid family caregivers.

Now, early research is showing how those caregivers struggled through 2020, as the pandemic made an already stressful job tougher.

A study recently published in The Gerontologist, comparing 576 family caregivers to nearly 3,000 non-caregivers, found significantly higher rates of anxiety, depression and disturbed sleep among the caregivers (average age, 59), most of whom were caring for people over 65.

The caregivers also reported less social interaction and more worries about finances and food, even after controlling for factors like income and employment.

'The pandemic has exacerbated things,' said Scott Beach, a social psychologist at the University of Pittsburgh and lead author of the study. 'It impacted everybody, but it impacted caregivers more.'"

From: The New York Times | May 21, 2021

How to be a Better Long-Distance Caregiver

"More than 1 in 10 caregivers look after family or friends from a distance, which can make the task much more difficult and expensive. A 2016 AARP survey found that caregivers in general incur an average of about $7,000 a year in out-of-pocket expenses. Long-distance caregivers — those who live at least an hour away from the care recipient — incur about $12,000 on average, according to the survey.

In Pandemic, Geriatrician Finds Herself Juggling Needs of Several Elderly Loved Ones

"This has been a year like none other for Dr. Rebecca Elon, who has dedicated her professional life to helping older adults.

It’s taught her what families go through when caring for someone with serious illness as nothing has before. 'Reading about caregiving of this kind was one thing. Experiencing it was entirely

From: The New York Times | May 21, 2021
Long-distance caregivers are more likely than local caregivers to hire help, take unpaid time off work and pay for travel, Goyer says.

Yet many distant caregivers worry they’re not doing enough and that a preventable crisis will develop because they weren’t on hand to spot the red flags.

'As caregivers, guilt is our constant companion,' Goyer says. 'When you’re a long-distance caregiver, it’s even more so.'

From: AP | May 24, 2021

WERE IT NOT FOR THE CHALLENGES SHE’S FACED DURING THE CORONAVIRUS PANDEMIC, ELON MIGHT NOT HAVE LEARNED FIRSTHAND HOW EXHAUSTING END-OF-LIFE CARE CAN BE, PHYSICALLY AND EMOTIONALLY — SOMETHING SHE UNDERSTOOD ONLY ABSTRACTLY PREVIOUSLY AS A GERIATRICIAN.

And she might not have been struck by what she called the deepest lesson of this pandemic: that caregiving is a manifestation of love and that love means being present with someone even when suffering seems overwhelming.

From: The Washington Post | May 17, 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.

The Virtual National Health Equity Summit

June 7-10, 2021 | Online

A summit hosted by Global Healthcare, LLC. to discuss health equity, the challenges faced by diverse communities, and possible solutions moving forward.

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

LGBTQ Week of Action: New, Lower Costs on Marketplace Health
Insurance Plans

June 7-11, 2021 | Online

You may be eligible for more savings and lower costs on health coverage through the Health Insurance Marketplace due to the American Rescue Plan Act of 2021.

What's new:
- More people than ever before qualify for tax credits that lower the cost of health coverage, even those who weren't eligible in the past.
- Most people currently enrolled in a Marketplace plan will qualify for more tax credits.
- Health insurance premiums after these new savings will go down.
- 4 out of 5 customers can find a plan for $10 or less per month.

Enroll or change plans with the 2021 Special Enrollment Period through August 15.

Fill out and submit your application on HealthCare.gov (or CuidadoDeSalud.gov for Spanish speakers) by August 15, 2021. After you submit your application, you have 30 days to enroll in a plan. Coverage starts the first day of the month after you enroll. For example, if you enroll any time in May, your coverage starts June 1.

For more information about the Special Enrollment Period, visit HealthCare.gov.

Click the red link below to learn more.

Maintaining Balance: Online Yoga for Caregivers

June 8, 2021 / 1 PM EST

The Elizabeth Dole Foundation and Yoga4Caregivers has teamed up to provide self-care and mindfulness through the practice of yoga to military caregivers.

RARE Drug Development Symposium

June 9-11, 2021 | Online
The RARE Drug Development Symposium is a two-day interactive event in partnership with The Penn Medicine Orphan Disease Center that focuses on educating both beginners and advanced participants on the drug development process.

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

**LEARN MORE >**

**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.

**LEARN MORE >**

**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.

**LEARN MORE >**

**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.

**LEARN MORE >**
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.

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.
State Strategies to Reduce Costs and Provide Quality Care for Older Adults and People with Disabilities Webinar

Improving long-term services and supports (LTSS) has long been a priority for state legislatures. Not only do these services provide daily assistance to millions of older adults and people with disabilities, but they are also primarily paid for by Medicaid, which takes up a substantial portion of states’ budgets. This webinar explored state strategies to both reduce costs and provide quality care for older adults and people with disabilities.

RELATED REPORT

Caregiving in the LGBT Community

What would you do if doctors said you weren’t allowed in your partner’s hospital room, or if you saw your loved one being discriminated against and denied care? Listen to the April 22 recording to hear Christopher MacLellan talk about the hurdles he had to overcome as a caregiver to his late partner Richard Schiffer; and Amy Whelan, Senior Staff Attorney at NCLR, and Joey Costello, Assistant Director of Care Management at SAGE, talk about how the caregiving journey of lesbian, gay, bisexual and transgender (LGBT) people is made that much harder by discrimination.

LISTEN HERE

It’s Not A Burden: The Humor and Heartache of Raising Elderly Parents

A documentary created by Emmy Award nominee Michelle Boyaner, this film offers a look at the relationships between aging parents and their adult children who care for them, examining the challenges they face and the solutions they discover along the way.

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

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.

The Economic Impact of Supporting Working Family Caregivers

This report by AARP explores the possible economic benefits of employers and governments providing greater support to working family caregivers age 50-plus, allowing them to remain in the workforce and to remain more active participants in the labor force. The report estimates that if supports were increased, the potential economic contribution could increase by $1.7 trillion (5.5%) in 2030 and by $4.1 trillion (6.6%) in 2050.
Fidelity Investments 2021 American Caregivers Study

Across the country, an estimated 53M Americans provide unpaid care for loved ones.1 This includes those providing care for children, aging parents or partners, including those with a disability or experiencing illness. As the ranks of those giving and receiving care continues to grow, planning and financial needs will demand attention and support. Fidelity’s research shares insights about awareness and management of the costs of caregiving, both emotional and financial; best practices around planning and managing care responsibilities; and lessons to be shared with future caregivers.

Brain Guide By UsAgainstAlzheimer's

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!