



There's More Than One Path The Joys and Stresses of Caregiving (In the midst of COVID- 19)

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Thank you!

- To anyone who has the courage to be a caregiver (family and professional).
- Nebraska Caregiver Coalition
- Jina Ragland – AARP - ASD Advocacy and Outreach
- Mollie George (for her work on the coalition and in locating valuable resources for this talk)
- Jessie Cook for being our Zoom expert!

Holy People Doing Holy Work





Some Observations in the Midst of COVID-19

- Of all the people who are always ready for the unexpected...
The CAREGIVER!!!
- Drawing from the rural experience – availability of services
(Or lack of services)
- The value of the moment
Each person, each day, each moment has value
- Physical distance does not mean social distance (Dr. Kelly McArthur)





Caregiver Statistics – What We Do Know

“65.7 million caregivers provide support to someone who is ill, disabled or aged.”

“52 million caregivers care for adults 18 and older with a disability or illness”- caregiving is not limited to aging adults.

“43 million caregivers support someone 50 and older and 14.9 million care for someone with Alzheimer’s disease or other dementia.”

Source: Family Caregiving Alliance – National Center on Caregiving – November 2012; updated February 2015





Dementia Caregiving – Fast Stats

- 5.8 million Americans living with Alzheimer's dementia
- 83% of care provided to elders is from unpaid sources – family, friends and others
- 18.5 billion hours of care (\$234 billion) by family and other unpaid caregivers

Alzheimer's Association, Facts and Figures, 2019

If You've Seen One Caregiver...

- People caring for children with special needs
- People caring for adult children
- People caring for an aging spouse, parent or relative
- People who do this informally and those who do it formally





Caregiver Statistics – What We Don't Know

- Most current data is from 2015. Expect new data will be available sometime this summer.
- How many people are caring for loved ones due to the Covid-19 situation because other options are not available?
- How many people are providing extra care for a loved one because the usual options (adult day services, senior centers, child care, day care) are closed indefinitely?





What COVID-19 is Making Apparent

- Caregivers may or may not be available or interested in providing support.
- Smaller families may make it difficult to provide relief for others – especially with physical distancing in place.
- Usual sources of support – may not be available (senior centers, adult day programs, etc.).





Pre-COVID-19 Discoveries Joys and Stresses





How are Caregivers Impacted?

- **Emotional Challenges** – (seeing decline in person, patience, understanding on multiple levels, change, emotional aspect of caregiving)
- **Caring for the person** (communication on various levels, making them, things, life – ok)
- **Memory Issues** (forgetfulness, no longer be recognized)
- **Time** (not having enough, balancing act, 24 hour care)



Caring for People with Dementia: Caregivers' Experiences, AARP – 2018
Alzheimer's Association – Facts and Figures, 2018



Is Caregiving Really that bad?

What caregivers tell us:

Caregiving is viewed by some as stressful and burdensome

Others know it is stressful, but they also see the gains and rewards.

Factors contributing to feelings of burden of caregivers of elderly persons with senile dementia were studied. The amount of burden of caregivers was found to be less when more visits were paid to the dementia patient by other relatives. Severity of behavioral problems was not associated with higher levels of burden. The results suggest the importance of providing support to caregivers as a critical step in the community care of elderly persons with dementia.

Relatives of the Impaired Elderly: Correlates of Feelings of Burden¹

Steven H. Zarit, PhD,² Karen E. Reever, MPA/MSG,³
Julie Bach-Peterson, MSG⁴

Senile dementia, which affects 5 to 10% of the older population, results in cognitive impairments and memory loss that generally leave the afflicted person in need of supportive care. While placement is often made into nursing homes or other protective settings, the majority of the older population have senile dementia. Kay et al. (1964) found severe mental deterioration to be present in 4.9% of their older British community sample and mild mental deterioration to be present in an additional 5.2% of those 65 and over. Approximately 90% of the organi-



Positive Aspects of Caregiving

What does **THIS** mean?

Positive aspect of caregiving (PAC) has been defined as “the gains or satisfaction feelings resulting from the caregiving experience.”

“Dependency feeling, fulfillment, bring family members closer together, companionship and more meaningful life and spiritual/moral remuneration.”

Abdollahpour, I., Nedjat, S., & Salimi, Y. (2018). Positive Aspects of Caregiving and Caregiver Burden: A study of caregivers of patients with dementia. *Journal of Geriatric Dementia*.





Caregiving Competency

Helping caregivers to appreciate their strengths and see they are competent in providing care can be beneficial with respect to well-being and satisfaction with life.

Highlighting competency can also be an approach used by professionals when working with caregivers. A focus on the positive.

Quinn, C., et al (2019). Influence of Positive and Negative Dimensions of Dementia Caregiving on Caregiver Well-Being and Satisfaction with Life: Findings from the Ideal Study. *American Journal of Geriatric Psychiatry*.





How To Make Life Livable In Uncertain Times



What to Focus On – Things Beyond Ourselves

- **Cross-sectional study of caregivers (N=87) supporting US Military personnel (N=73) injured in combat**
- Attempt to understand protective factors in caregiving – resilience (“...how an individual reacts and adapts to a serious challenge or event and the ability to bounce back after stress.”)
- Predictors of resilience:
 - Spiritual growth – strength from a higher source
 - Problem orientation or attitude toward problems.

Source: Dreer, L.E., et al, 2019. Resilience Among Caregivers of Injured Service Members: Finding the Strengths in Caregiving. *Archives of Physical Medicine and Rehabilitation*, 100, S76-84.





Support of Dementia in Rural Areas

- Rural areas: limited access to health services and resources – not just geographically but available people to serve+
- More of a family oriented attitude toward caregiving along with assuming responsibility for care along with marital vows.
- What helps:
 - Informal support – workplace, church, neighbors, friends & family)
 - Religious coping
- What is still needed:
 - Financial support – AAAs
 - When available – encouraging service usage

Source: Gibson, A., et al (2019). Providing Care for Persons with Dementia in Rural Communities: Informal Caregivers' Perceptions of Supports and Services. Journal of Gerontological Social Work, 62, 630-648.





Ways to Address Problems



Caregiving in the Age of COVID-19

- **How can I keep my loved one connected?**
 - Television may be an issue if the news is always on (not just for the person we are caring for but even ourselves)
 - If your stressed, the person you are caring for will be stressed
 - Routine, routine, routine – for all ages.





Use of Technology

- Does the person have the skill-set to use the technology?
- Is the person or the caregiver able to use the technology?
- Is the technology up to date enough that there won't be issues?
- Charging and use – making sure it is ready to go.
- Connectivity – Wi-Fi, broadband, etc.
- Does it cause agitation or concern or does it bring joy? Not a 24/7 solution.

Source: AARP (2018) – Tech Solutions that Make life Easier for Dementia Care



Low-Tech (From Wi-Fi to Hi-Fi)



Source: Ekra, D. (2020). Systematic Use of Song and Music in Dementia Care: Health Care Providers' Experiences. Journal of Multidisciplinary Health care

Low-Tech Options - Homemade

The screenshot shows the Education.com website's worksheet generator for word searches. The page title is "Word Search Reading worksheet generator". Under the "Options" tab, there is a section "Enter word search content" with a note "30 by 30 is about as big as makes sense help". A text box for "Title" contains "Caregiver Word Search". Below this is a "Words" section with a scrollable list of terms: Parents, Children, Grandchildren, Spring, Games, Dancing, Omaha, Lincoln, Norfolk, Scottsbluff, Hastings, Capitol, Sandhills, and Cranes. To the right, a "Preview Worksheet" section shows a 30x30 grid of letters for the "Caregiver Word Search". Below the grid is an "ANSWER KEY" table with the following words and their locations:

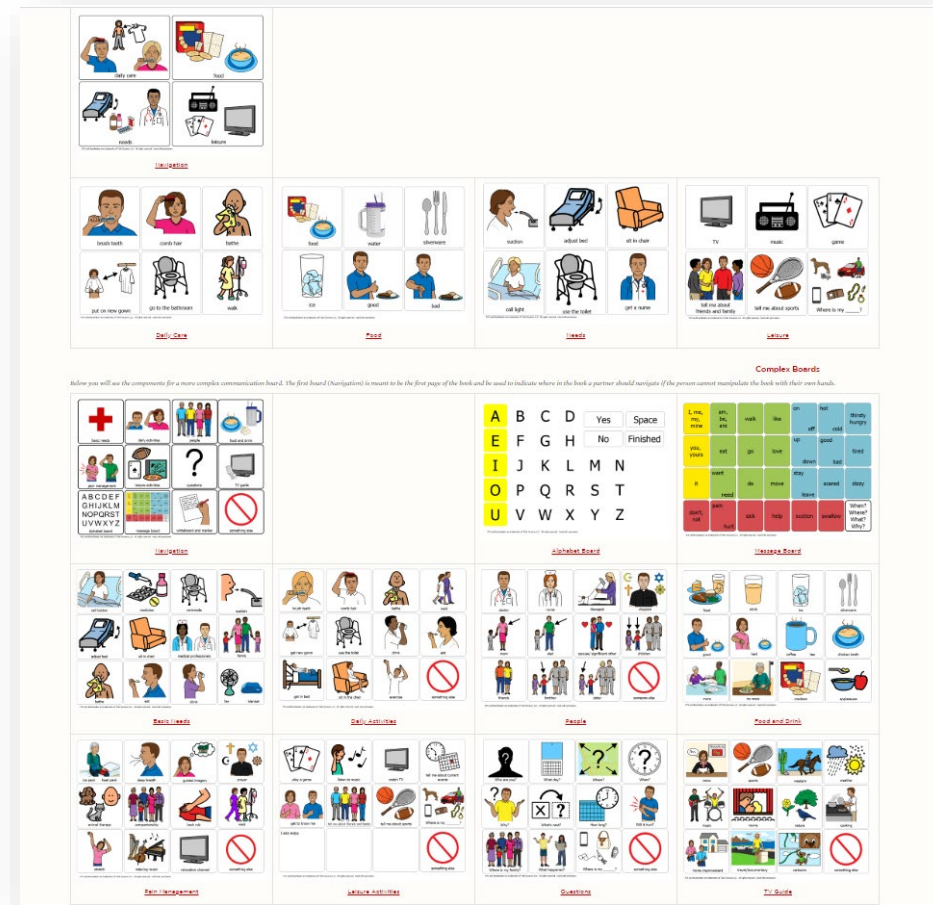
Word	Row	Column
Grandchildren	1	1
Comhuskers	1	11
Parents	1	21
Poetry	1	31
Omaha	1	41
Aging	1	51
Scottsbluff	2	1
Nebraska	2	11
Capitol	2	21
Children	2	31
Wife	2	41
Hastings	3	1
Dancing	3	11
Capitol	3	21
Lincoln	3	31
Home	3	41
Sandhills	4	1
Hastings	4	11
Cranes	4	21
Songs	4	31
Games	4	41
Love	4	51

<https://www.education.com/>

Ask a neighbor, child,
grandchild or someone else
for help in making a word
search with words that
mean something

(UNL Graduate Student – Lauryl McClintick in collaboration with Bryan Health and Dr. Kristy Weissling)

<https://cehs.unl.edu/aac/aac-icu-0/>



Still Open for Business

- Area Agencies on Aging

<https://nebaaaa.org/>

- Eldercare Locator

<https://eldercare.acl.gov/Public/Index.aspx>

- Aging, Disability and Resource Center

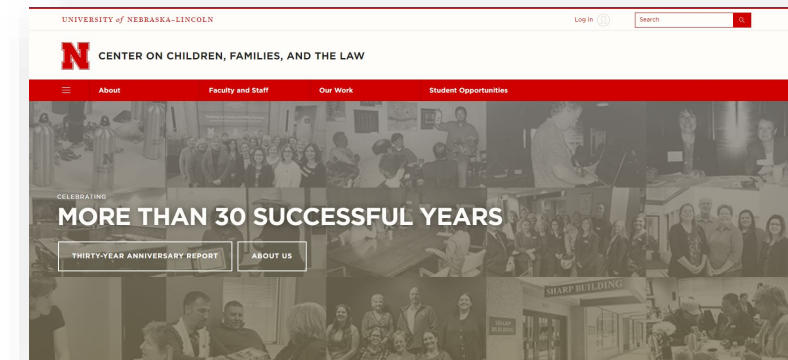
<https://nebraska.arounja.org/>

- Center on Children, Families and the Law

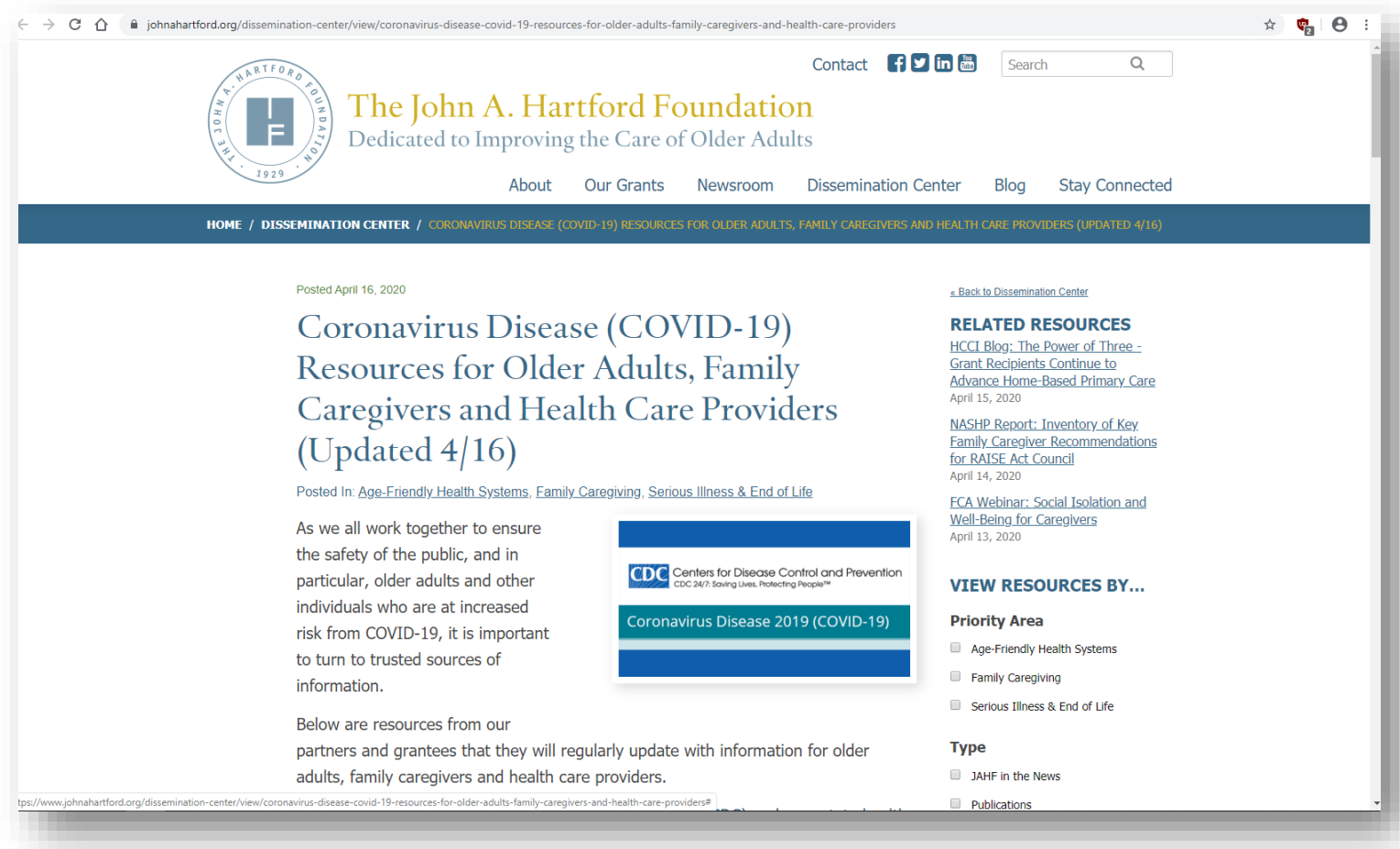
<http://ccfl.unl.edu/>

- AARP Community Connections

<https://aarpcommunityconnections.org/>



Programming for Caregivers and Providers



Programming for Organizations to Consider



The screenshot shows the Family Caregiver Alliance (FCA) website. The header includes the FCA logo, the text 'FAMILY CAREGIVER ALLIANCE® National Center on Caregiving', a search bar, a 'DONATE' button, and social media icons for Facebook, YouTube, Twitter, and LinkedIn. The navigation menu includes 'About FCA', 'Caregiver Education', 'Policy & Advocacy', 'Caregiver Connect', 'Press', and 'Contact Us'. The main content area is titled '12 Remote-Delivery Programs for Organizations That Support Dementia Caregivers' and includes a 'Printer-friendly version' link. The text describes the challenges faced by caregivers during the coronavirus outbreak and lists 12 programs. A sidebar on the right contains a 'Get Involved' section with links to subscribe to newsletters, join an online support group, and share a caregiver story. Below this is an 'Education and Events Calendar' for April 2020, showing dates 1 through 30. At the bottom of the sidebar is a 'Smart Patients Caregivers Community' section with a 'JOIN' button and a 'Learn more' link. The footer of the page includes the text 'CAREGIVER STORIES'.

← → ↻ 🏠 📍 caregiver.org/12-remote-delivery-programs-organizations-support-dementia-caregivers ☆ 📱 🗂

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National Center on Caregiving

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Home

12 Remote-Delivery Programs for Organizations That Support Dementia Caregivers

Printer-friendly version

As the coronavirus outbreak spreads, friend and family caregivers of those living with dementia are navigating new challenges and stressors. Even as they continue managing their usual care-related responsibilities, many now receive less assistance from others, have access to fewer services, and in some cases must care for and supervise other dependent family members who must remain at home. Moreover, essential guidelines for physical distancing and transmission-risk reduction are upending many aspects of their daily lives and the lives of those they provide care to.

Subject to the same health and safety guidelines, the organizations that provide support and services to caregivers are scrambling to ensure that they can continue to help those who need assistance, while maintaining caregiver safety and well-being. Services that were previously delivered in-person are now paused, and the need for distance-friendly, high-quality programs is surging.

12 programs made for these times

To help organizations meet this unprecedented challenge, the experts at Benjamin Rose Institute on Aging and Family Caregiver Alliance have compiled a list of top dementia caregiving programs that can be delivered remotely (by telephone or online). These programs are vetted, proven and ready for implementation—complete with program details and contact information of program developers.

Get Involved

- ▶ Subscribe to FCA newsletters
- ▶ Join an online support group
- ▶ Share your caregiver story

Education and Events Calendar

« April 2020 »

S	M	T	W	T	F	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

Smart Patients Caregivers Community
In partnership with Family Caregiver Alliance

enter your email **JOIN** [Learn more](#)

CAREGIVER STORIES

Free Continuing Education

meinstead.com/news/home-instead-program-offer-free-ceus

TYPE SIZE

Home Instead
SENIOR CARE
to us, it's personal.

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ARCHIVE View by Month
 ▼

Home Instead Senior Care Program Offers Free Continuing Education Credits (CEUs)

[Home](#) | [News and Media](#) | Home-Instead-Program-Offer-Free-CEUs

The Home Instead Senior Care® network, the world's largest provider of non-medical in-home care for seniors, is now offering free continuing education credits (CEUs) in conjunction with the organization's Family Caregiver Support Webinar Series program.

Caring for Your Parents: Education for the Family Caregiver(SM) is a family caregiver support series that addresses senior resistance to care and features a variety of topics such as choosing an in-home care provider, the signs of aging, long distance caregiving and communicating with aging parents. The program has been adapted for [CEU accreditation in cooperation with the American Society on Aging \(ASA\)](#).

The CEU courses are offered compliments of Home Instead Senior Care so there is no cost for the CEU. The first webinar, titled Recognizing the Signs of Aging and Need for Care, will be held October 27; a second webinar, Challenges of Communication between Older Adults and their Children, will





Keeping Connected ... When Restrictions Apply

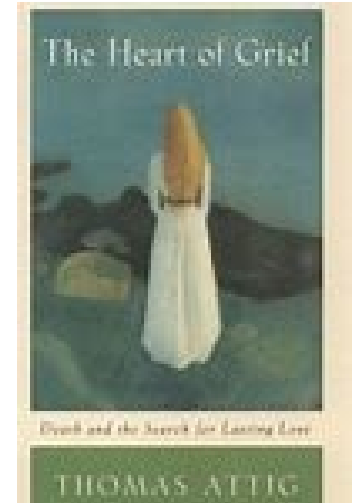
- Send pictures – perhaps older ones for people with dementia
- Send a care package
- Call often
- Pray with the person each morning
- Show the staff your appreciation
- Deliver extra items for staff

<https://www.guideposts.org/caregiving/family-caregiving/advice-for-caregivers/6-ways-to-help-your-loved-one-with-alzheimers-when-visits-are-restricted>



Things to Cherish

- You just have to laugh (Deb Welk!)
- Recognize when you have done something well
- Being in the moment



"Their absence frustrates us constantly. We have lived as if they would always be with us. Our pain and anguish derive in part from reminders of how we took their presence for granted..." From Thomas Attig's book, *The Heart of Grief: Death and the Search for Lasting Love* (Oxford University Press).



Post COVID-19

- Technology Companies – Entrepreneurs
- Amazon model that goes to rural areas
- Better Broadband Support for everyone
- Rethinking service delivery – from hospital to home



Post COVID-19 – Next Steps – Post-Mortem

- Post-mortem – what did you learn?
- Who do you still need in your life? It is ok to ask for help.
- Legal assistance (private or through the ElderAccess Line)
- Caregiving and supportive services – Area Agencies on Aging along with other providers.



Make time for
quiet
moments, as
God whispers
and the world
is loud.

Unknown



healthyspirituality.org



