

Dementia Action Alliance

2020

IMPACT REPORT

Powered by People with Purpose





...from DAA's Co-Founder & Executive Director

Rarely does a whole population experience a difficulty together. 2020 was such a time. While COVID-19 caused much pain and many challenges, it also created opportunities for the best in people to shine through. This was the case for DAA's Advisory Board members living with dementia, DAA Board members, and DAA partners. By April 2020, they were focusing on ways to enhance the lives of people living with dementia around the country. Two new weekly virtual discussions were quickly launched, *Faith, Hope & Love* and *Drop-In with Dr. Susan*, followed by the launch of a virtual engagement program five days a week with a variety of sessions, such as *Laughter for Health and Happiness* hosted by Deborah Shouse and Ron Zoglin.

Laughter has been the common thread that has helped many of us deal with the fear, pain, and challenges caused by COVID-19. It turns out laughter is physiologically good for well-being. According to the Mayo Clinic, laughter can soothe tension, improve your immune system, relieve pain, improve mood, and bring people together. We can personally attest to the beneficial effects of laughter!

There is an abundance of research about the positive effects of laughter. In addition to laughter, there are other proactive ways people diagnosed with dementia can support their well-being, such as eating nutritiously, staying well hydrated with water, getting restorative sleep, reducing stress, being physically and socially active, doing things that are fun, interesting, and have purpose. Research shows that following these healthy lifestyle habits not only contribute to well-being but actually help manage the symptoms of dementia. While these proactive principles are well known, they are not yet widely applied by the medical community to benefit people who are living with dementia. DAA is working to change this.

DAA will celebrate its 25th anniversary in July 2021. We are using this special occasion to partner with other advocates to launch a 25-month initiative to impact societal change to enhance the well-being of people living with dementia and their care partners across the country. Expect lots of laughter!

Karen Love





**The Dementia Action Alliance (DAA)
is a diverse coalition of passionate people
creating a better society in which to live with dementia.**

We provide hope, help, and support to individuals living with dementia and care partners with information about how to live proactively with this chronic condition. We offer programs, services and peer supports including three weekly online discussion groups, two monthly podcasts, an online Resources Center, a national Speakers Bureau, and other services. All our efforts and activities are shaped and informed by individuals living with dementia. DAA is a 501(c)(3) charitable organization incorporated in the Commonwealth of Virginia.

Our Goals

1. Foster hope and well-being through the power of proactive practices, grounded in science.
2. Champion full inclusion of individuals living with dementia so their experiences and knowledge inform a truer, stronger understanding about living with dementia.
Nothing About Us Without Us!
3. Educate about the negative and damaging effects stigma and misperceptions about dementia have on the well-being of individuals living with dementia and their care partners.
4. Recognize dementia as a disability requiring accommodations and support for changing abilities.
5. Advocate for person- and relationship-centered practices to optimize well-being.
6. Identify beneficial technologies and innovations that enhance the quality of life and well-being of individuals living with dementia and care partners.
7. Increase DAA's visibility and positive impact.



FOSTER HOPE AND WELL-BEING

- Hosted 128 interactive virtual discussions for people living with dementia (PLWD) to connect through their shared experiences for inspiration, friendship, support, and fun. DAA's virtual discussions often include PLWD outside the U.S.
- Provided special online drop-in discussions hosted by PLWD and DAA Board members on Thanksgiving and Christmas — often challenging days for PLWD.
- Piloted a two-month project to test the effectiveness and PLWD participant interest of using Zoom to participate in diverse, interactive engagement sessions. The project proved to be very successful. It received much feedback along the lines of, "You are saving my life," that DAA established it as a regular program five days a week.



CHAMPION *NOTHING ABOUT US WITHOUT US*

- Served as advisors on two National Academy of Sciences, Engineering and Medicine dementia-focused projects to provide insightful perspectives and experiences of PLWD.
- Provided over fifty hours of targeted feedback to technology companies and universities requesting user experience about technologies designed to support PLWD and their care partners.
- Hosted two compelling podcasts — *This Dementia Life* and *Professional Insights* — every month hosted by PLWD with over two dozen invited guest speakers.



**Jennifer Carson, PhD
Director Dementia Engagement,
Education & Research Programs
University of Nevada Reno**



**John V. Tucker
Disability Rights Attorney**



**Katurah Hartley, BPharm
Project Manager Healthy Brains
Cleveland Clinic Lou Ruvo Center
for Brain Health**

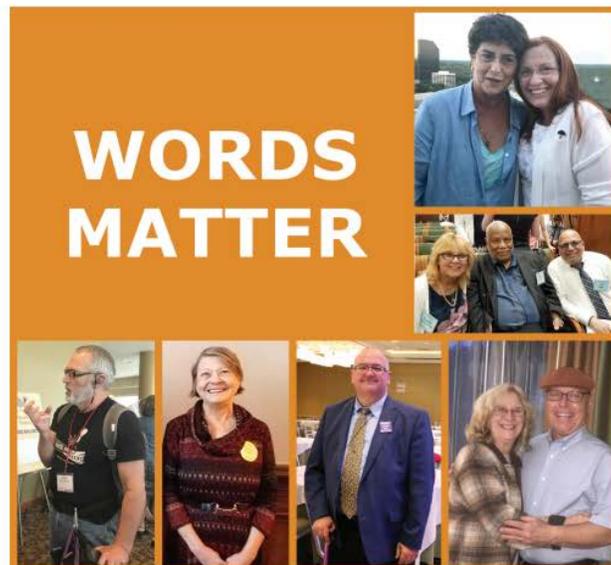
MOVE FROM STIGMA TO UNDERSTANDING

- DAA's Speaker Bureau provided over 80 hours of presentations by speakers living with dementia to several thousand audience members.



Mike Belleville from DAA's Speaker's Bureau presenting with Alton Brown from the Food Network for Brighthouse Financial.

- Published the 2nd edition of DAA's widely cited *Words Matter* publication.





Dementia Action Alliance Advisory Board Members Living with Dementia

Mike Belleville

Lives with Lewy body dementia in Rhode Island

Paulan Gordon

Lives with vascular dementia in Ohio

Cynthia Huling Hummel

Lives with Alzheimer's dementia in New York

Chuck McClatchey

Lives with Alzheimer's dementia in Nevada

Terrie Montgomery

Lives with Alzheimer's dementia in Georgia

Barney Nelson

Lives with Lewy body dementia in Oregon

Laurie Scherrer

Lives with frontotemporal and Alzheimer's dementia in Alabama

Mark Timmons

Lives with vascular and frontotemporal dementia in Massachusetts

Brian Van Buren

Lives with Alzheimer's dementia in North Carolina





Dementia Action Alliance Board of Directors

Jan Bays, PT – Treasurer
Director of Program Development & Education – Jill's House

Jayne Clairmont
CEO – Alzheimer's Expertise

Sandy Douglass – Vice Chair
CEO – Douglass Consulting

Craig Fowler
CEO – JoyGage

Paula Gordon
Dementia Advocate and Educator

Karen Love – Co-Founder
DAA Executive Director

Chris Perna
Former CEO & President – The Eden Alternative

Jackie Pinkowitz, MEd – Co-Founder
Chair

Laurie Scherrer
Dementia Advocate and Educator

Lon Pinkowitz
Senior Vice President – FuturAge

Regina Sofer, DM, MPA – Secretary
Principal – The Sofer Consulting Group

Susan Wehry, MD
Chief of Geriatrics, University of New England College of Osteopathic Medicine



Dementia Action Alliance
2305 Avinity Court
Charlottesville, VA 22902
www.daanow.org