Enhancing Lives
Connecting People
Increasing Understanding

2022

IMPACT REPORT
Dear Friends,

The Dementia Action Alliance (DAA) has been able to provide many services, supports, resources, and activities over the years, but 2022 was an especially eventful year, even for us! DAA’s 2022 Impact Report provides details about the many efforts DAA accomplished in 2022 with the help of its many wonderful volunteers.

The collaborative development of *Pathways to Well-Being with Dementia: A Manual of Help, Hope and Inspiration* was a dream project come true. Dementia is such a complex condition that is widely misunderstood, even by physicians. But there is very little information about how to live with and manage the symptoms of dementia – especially from first-hand lived experiences. Without this vital information, each individual and their support partners are left to figure it out themselves - an almost impossible task. Proactive information, resources, and support are having a significant positive impact on the health and well-being of people who are living with dementia and for those who care about them.

DAA has always believed that more can be done together. *Pathways* is an excellent example of this belief! The book includes insights, expertise, information grounded in science, and inspiration from 48 contributing authors, including people living with dementia, care partners and leading dementia specialists. Beth Baker, a renowned healthcare journalist, rounded out the dream team as the book’s writer/editor.

If you hear clinicians and other healthcare professionals say, “Nothing can be done,” about living with dementia, please let them know about *Pathways*. It’s a free, downloadable publication. When people living with dementia and their support partners know there are indeed proactive things they can do to help support health and well-being, they undergo a transformation. Apathy becomes determination. Disablement becomes enablement. Hope becomes real! Help us get the word out. Thank you.

*Karen Love*
The Dementia Action Alliance (DAA) is a national non-profit education and advocacy organization that has, for the past 26 years, worked tirelessly to empower, engage, and support people living with dementia and those who care about them and to increase understanding about living with dementia.

We are creating a better society in which to live with dementia!

DAA provides hope, help, and support to individuals living with dementia and care partners and educates about how to live proactively with and manage symptoms of dementia. DAA is a 501(c)(3) charitable organization incorporated in the Commonwealth of Virginia.

Our Goals -

- Enhance lives and well-being through interactive and engaging programs, discussions, and other supports and services.

- Provide resources and support about the benefits of having a proactive attitude about living with dementia.

- Champion full inclusion of individuals living with dementia, so their experiences and knowledge inform a truer and better understanding about living with dementia. Nothing About Us Without Us!

- Educate clinicians, healthcare providers, care partners, researchers, policymakers, and others about living with dementia so that symptoms are better understood and supported.

- Recognize dementia as a chronic disability requiring accommodation and supports for changing cognitive abilities.

- Increase awareness about the damaging effects stigma and misperceptions about living with dementia cause.

- Advocate for humanistic (person-centered) practices that optimize well-being.
2022 Accomplishments

Goal 1 – ENHANCING LIVES

- Provided over 240 diverse and interactive virtual engagement programs offered five days a week, such as For Love and Art, Music Beat and Trivia, and Stories in the Moment among many others to over 1800 participants.

  “This program is the favorite part of my day. I really look forward to it!” noted one participant.

- Launched a Helping Hands Volunteer Committee to serve as a pathway for people living with dementia who are interested in helping others.

  “The Helping Hands Committee work gave me my purpose back. Helping people is part of normal life and helping others makes me feel better,” is one Committee member’s experience.

Goal 2 – CONNECTING PEOPLE

- Provided 150 discussion programs as a pathway to connect and engage with others living with dementia. Three programs each week are hosted by DAA Board and Advisory Board members living with dementia – Dementia Discussions; Faith, Hope, Love; and Drop in with DAA.

- Connected and engaged with over 900 people living with dementia regularly through two DAA managed Facebooks groups – Arts & Dementia and Memory Warriors.

- Hosted DAA’s 3rd national conference in September 2022 in Indianapolis, IN - Living Well with Dementia – bringing together a diverse gathering of people committed to making a better society in which to live with dementia.

  “DAA’s conferences have to be experienced. They are wonderful and life changing events,” noted a conference attendee.
Goal 3 – INCREASING UNDERSTANDING

To improve understanding about the lived experience and norms of people from diverse communities living with dementia, DAA partnered with the Global Council on Alzheimer’s Disease to develop a paper and podcast series to learn from people living with dementia and their care partners from the Black/African American and LGBTQ+ communities.

Papers: https://daanow.org/discovery-center/diversity/books/
Podcast series: https://daanow.org/calling-all-voices/
Working with colleagues at AgingME (GWEP), DAA developed two educational videos to increase awareness about two important topics -

- **Advance Care Planning** – a video about end-of-life considerations and planning for people living with dementia with AgingME Director, Dr. Susan Wehry and others. [https://www.youtube.com/watch?v=QCiiI6eZxZA&ab_channel=AgingMEGWEP](https://www.youtube.com/watch?v=QCiiI6eZxZA&ab_channel=AgingMEGWEP)

- **Cooking Strategies for People Living with Dementia** – a video featuring four individuals living proactively with dementia who discuss strategies they have found to help them be successful cooks living with dementia. [https://www.youtube.com/watch?v=VBO7WDihUvI&fbclid=IwAR3pn1OVe8Xi_-1EI98vho3jKlf7H_s6iKxRfDAFUOWCNHpjTtCfrb9dOH0&ab_channel=AgingMEGWEP](https://www.youtube.com/watch?v=VBO7WDihUvI&fbclid=IwAR3pn1OVe8Xi_-1EI98vho3jKlf7H_s6iKxRfDAFUOWCNHpjTtCfrb9dOH0&ab_channel=AgingMEGWEP)

---

**Goal 4 – PROVIDING TRUSTED RESOURCES**

Completely redesigned DAA’s website to enhance usability and expand the platform to be able to provide more resources and information ~ [https://daanow.org/](https://daanow.org/).

So often people hear from their physicians when being diagnosed with dementia, “there is nothing than can be done”. This is not the case but there are few resources describing what people can do. Working with 48 contributing authors living with dementia, care partners, and leading dementia specialists, DAA developed a 428-page comprehensive, easy-to-read book detailing what can be done. *Pathways to Well-Being with Dementia: A Manual of Help, Hope and Inspiration* is a free downloadable publication. [https://daanow.org/pathways-to-well-being-with-dementia/](https://daanow.org/pathways-to-well-being-with-dementia/)

“This is the most beneficial information about living with Dementia my husband and I have ever found,” noted a person living with dementia.
Developed a comprehensive and carefully curated online Discovery Center with several hundred helpful resources divided into easy-to-navigate categories, including Arts, Care Partnering, Living Well with Dementia, and Diversity among other categories. The Discovery Center had over 1,000 visitors in the last five months of 2022. https://daanow.org/discovery-center/

Working with people living with dementia, DAA developed a catalog of beneficial technologies for people living with dementia and care partners. https://daanow.org/discovery-center/technologies/daa-technology-catalog/
Along with its partner, The Eden Alternative, DAA developed the first of its kind practice guide of dementia support and care standards for nursing homes, *Raising the Bar*. [https://daanow.org/store/](https://daanow.org/store/)

---

**Goal 5 – INCREASING IMPACT**

With its partner, the Jewish Family & Children’s Service of Greater Boston, DAA won a $25,000 Maude Award for its collaborative “Living Well with Dementia at the Café” initiative. This initiative helps memory cafés foster a leadership and empowerment model with participants living with dementia.
Worked with Eisai on its “Hope with Alzheimer’s” video project featuring Mark Timmons, a DAA Advisory Board Member, to increase societal awareness about living well with dementia.

Worked with the Mayo Clinic on its development of an online platform for information about financial and legal considerations for people living with dementia.
Dementia Action Alliance Advisory Board Members
Living with Dementia

Cynthia Huling Hummel, DMin
Lives with Alzheimer’s in New York

Chuck McClatchey
Lives with Alzheimer’s in Nevada

Barney Nelson
Lives with Lewy Body dementia in Oregon

Nancy Nelson
Lives with MCI in Nevada

Steve Schneider
Lives with Young-onset MCI in New York

Mark Timmons
Lives with mixed dementia in Massachusetts
Dementia Action Alliance Board of Directors

Jan Bays, PT – Board Chair
Director of Program Development & Education – Jill’s House

Jennifer Carson, PhD
Director, Dementia Engagement, Education & Research Program, School of Public Health,
University of Nevada, Reno

Sandy Douglass – Board Vice Chair
Principal, Douglass Consulting

Craig Fowler - Treasurer
CEO – JoyGage

Karen Love – Co-Founder
DAA CEO

Jackie Pinkowitz, MEd – Co-Founder
DAA Chair Emeritus

Lon Pinkowitz
Dementia Advocate

John Richard (JR) Pagan
Dementia Advocate

Laurie Scherrer
Dementia Advocate and Educator

Regina E. 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