

Year in Review



After the Storm
Janet Hookailo,
Caregiver and Artist

“The most important things I have learned over the past years are to ask for help. Picking up my paint brushes again for the first time since my husband’s diagnosis has been a big step in being a caregiver.”

Janet Hookailo,
Caregiver and Artist

There are an estimated 6.5 million Americans living with Alzheimer’s disease (AD). More than 11 million caregivers are unpaid family members and friends. These numbers are expected to increase over the next decades as baby boomers age and medicine keeps us living longer.

DCC Description

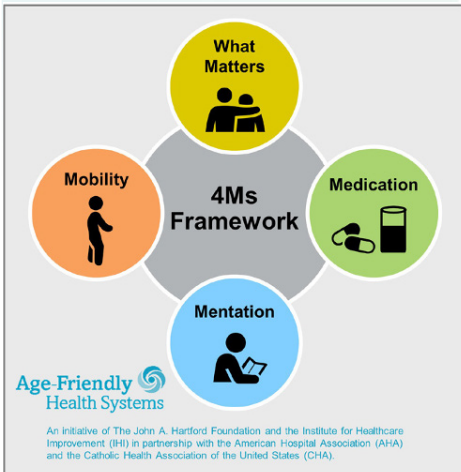
The **Dementia Care Collaborative (DCC)** of Mass General Hospital is committed to improving the experience of patients and families living with Alzheimer’s disease and related dementias. Our goal is to transform the health care experience through education, clinical services, emotional and social support, applied clinical research and experiential programs to reduce caregiver stress.

DCC has four primary initiatives:

- 1) The Dementia Caregiver Support Program (DCSP)**
- 2) The Memory Care Initiative (MCI)**
- 3) Research**
- 4) Community Health and Outreach**

2022

Year in Review



Age-Friendly Health System (AFHS)

DCC New Initiatives

Mass General Hospital, through the efforts of the DCC team, have received the Age-Friendly Health System (AFHS)—Committed to Care Excellence recognition from the Institute for Healthcare Improvement. This designation acknowledges health systems commitment to improving care for older adults and providing the “4Ms” of evidence-based, high-quality care: **What Matters Most; Medication; Mentation; and Mobility.** The development and use of identification cards that state that they are a caregivers or person living with dementia have allowed more access and communication for these people. These cards are translated into 7 languages and distributed throughout the whole hospital.

October 2022 our team worked closely with leaders from the whole Institution to complete the **State mandated Operational Plan** for people living with dementias and their caregivers. This law required education, diagnosis, and disclosure of this diagnosis for this population. It also set the guideposts for progressive actions to improve the quality of life for these patients and their families.

Another ongoing and important initiative has been **collecting data on the rate of dementia** and delirium at Mass General Hospital. This has brought about changes in the Electronic Medical Record, EPIC, and has provided the evidence base for actions to change protocol and policies for patient care.

DCC is pleased to announce an inaugural new program for clinicians and staff at MGH: Schwartz Rounds for Dementia. Started in the Fall of 2022, the **Schwartz Rounds for Dementia** works closely with the non-profit the Schwartz Center for Compassionate Care to foster compassionate care and build community. Extensive staff training and the development of a Planning Committee has produced this unique offering to staff, which offers a safe forum to discuss difficult emotional and social issues that arise in caring for patients. The Rounds are carefully structured to support interdisciplinary Hospital and clinic staff to explore and process their experiences with patients. This Schwartz Rounds for Dementia is the first of its kind; no other Schwartz Rounds has focused solely on caring for persons with dementia and their care partners.

“Please know the difference you all make, to know you’re not in it alone in such an isolated situation.

[The work you do] it matters, it absolutely matters.”

Guidance from experts and from patients and their families

In 2022, DCC held **Patient Family Advisory Council (PFAC)** meetings every other month. The DCC PFAC has integrated and promoted the patient and family voice in the development of programs, services, and initiatives oriented towards persons living with dementia. This PFAC is made up of caregivers and persons living with dementia.

Monthly meeting discussions and feedback have focused on the Emergency Department, visitation at Mass General, and the State's mandated operational plan for dementia and delirium just to name a few topics. Our programs and hospital staff have received valuable insights from the PFAC members' opinions and their caregiving and Hospital

experiences. Several of these insights have translated to improvements in patient care. The DCC also established an **Internal Advisory Board (IAB)** in 2021 and in 2022 this Board continued to assist in providing the highest quality programming to our patients living with dementia and their care partners. The IAB is an interdisciplinary board consisting of MGH Physicians from the Departments of Medicine, Neurology and Psychiatry, Advanced Care Nurse Practitioners, and Social Workers. Their advice has already contributed to the strategy behind MGH's mandated State Operational Hospital plan for patients with dementia and delirium and to the National Age Friendly Health System full recognition and programming.

“We realized that we have learned, with the Dementia Care Collaborative’s support, that we live with the loss and the joys and we must hold both these truths in our mind and heart.”

Joanne Arnaud, Caregiver.
In loving memory of her husband, Dick.



Memory Care Initiative

In 2023, the **Memory Care Initiative** will enter its fourth year. Under the leadership of medical director Christine Ritchie, MD, MPH, Kelsey Anderson-Gandhi, LICSW, and Gabrielle Rex, AGPCNP, have provided essential care and support to over 300 patients, a total of 527 visits, and their families at Bulfinch Medical Group, Newton-Wellesley Primary Care Wellesley Hills, and Primary Care of Wellesley.

If a patient or their loved one communicates concerns about their memory to any of the 40+ primary care providers (PCPs) at these practices, the PCP can place a referral to MCI. During the initial evaluation, the MCI team meets with the patient and their care partner to gather a detailed medical and social history, review medications, and administer a cognitive assessment. For patients without a dementia diagnosis, the priority is to rule out treatable causes of cognitive symptoms before then pursuing further diagnostic workup. If the

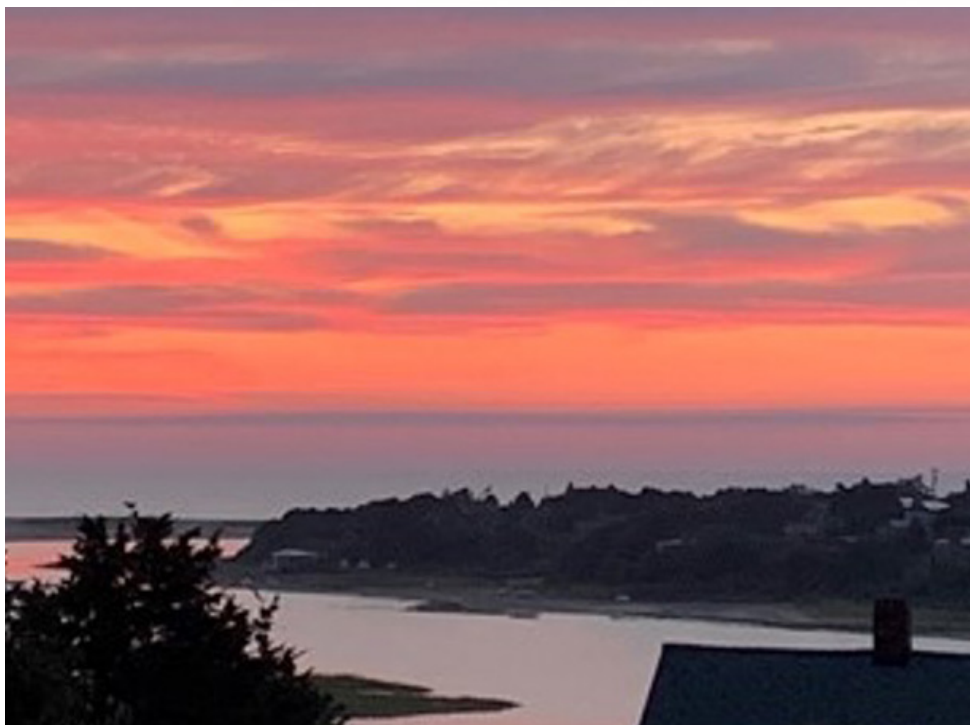
patient has dementia, the team shifts its focus to optimize that person's health and quality of life based on what matters most to them. To that end, the team provides anticipatory guidance, facilitates advance care planning discussions, and offers emotional support and counseling to both the person with dementia and their care partners.

Memory Care clinicians work closely with the patient's primary care team to generate and implement a tailored care plan. As part of the DCC collaboration, all patients and their care partners who are seen in any of the MCI clinics can access DCC Caregiver Support Program services and activities, including Conversations with Caregivers, Fundamental Skills, Support groups, and Health and Resiliency.

MCI was born from a DCC partnership with the UCLA Alzheimer's and Dementia Care (ADC) Program and the John A. Hartford Foundation, as a site of their highly successful dementia co-management model in primary care. In 2022, Kelsey and Gabrielle had the opportunity to take on a national leadership role supporting other similar sites as part of UCLA ADC's National Learning Collaborative. They are specifically focused on helping other health care sites implement an interdisciplinary model of care. They were also invited to speak as experts in a roundtable discussion with the Center for Medicare and Medicaid Innovation, helping inform the development of new care models for patients with dementia. We are also grateful to Deb Basler, CNP, who kindly covered for Gabrielle while she was away on maternity leave.

*“Past the refusal, the anger,
the loss and darkness,
I find the small flicker of
a love that is as steadfast
as the sun”*

Richard Jacobs,
Caregiver and Photographer



Dementia Caregiver Support Program

The **Dementia Caregiver Support Program**, (DCSP) launched in November 2017. The DCSP includes critical offerings: **DCSP Clinical Services** provided by expert dementia-trained licensed Social Workers, Support Groups and Fundamental Skills courses for caregivers, and our expansive educational programming.

The DCSP clinical individualized assessment, emotional support, disease education, assistance with balancing home-life, work and caregiving, and care planning which includes connection to community resources. Referrals come from our partnering clinics in the Neurology Memory Disorder Unit, Geriatric Psychiatry, Geriatric Medicine, and the Memory Care Initiative’s primary care practices. DCSP had a total of 1,146 scheduled visits for 2022.

Additionally, the DCSP is collaborating with Revere Community Health Center and offering a

Caregiver Support Group for their families. Education Programs for persons with dementia and their care partners are the core of the DCC offerings and are virtual and open to the whole community. The **Conversation with Caregivers** monthly lecture series hosts expert speakers to assist in the dementia caregiving journey. **Health and Resiliency** are monthly programs focused on encouraging caregivers to include self-care and healthy activities into their lives. Programs in 2022 have ranged from Chair Yoga and Breathing for Restful Sleep to a Jazz concert and healthy cooking classes all to help people reduce their stress. **Ageless Grace**, a neuro-plasticity movement and music program, is offered weekly. The **Fundamental Skills course** is a four-part series offered every month. An expert facilitator covers communication skills, approaching challenging symptoms, and safety issues.

2022 Education and Support programs

Program/Support Groups*	Number of participants	Number of classes	Average number of participants
Conversations with Caregivers	535	11	49
Health and Resiliency	335	12	28
Ageless Grace	430	40	11
Fundamental Skills	291	36	8
Support Groups	396	36	11

* Not unique individuals

“Your DCSP team has helped me immensely in the last several years since my brother-in-law and husband were diagnosed with dementia. The work you do is incredible. Your social worker has been an angel for me. I really don’t know what I would have done without her. The talks and support have been so helpful.”

Michelle, Caregiver

Research

The **Dementia Care Collaborative** is playing an increasingly expanded role in research. Dr. Ritchie, in partnership with Dr. Ana-Maria Vranceanu, is testing two different programs to support caregivers and persons living with dementia. The first program, called the Mindfulness and Self Compassion Caregiver Support program, which is funded by the National Institute on Aging is testing the value of a curriculum focused on behavioral management strategies, self-compassion, and mindfulness on caregiver well-

being. The second program, which is funded by the Robert Wood Johnson Foundation is developing and testing a multi-sensory (bioexperiential) music, movement and imagery program on the quality of life and interactions of persons with dementia and their caregivers. Increasing recognition of the importance of caregiver resilience in dementia care is leading other scientists to the DCC to assess new interventions to improve the well-being of persons with dementia and their caregivers.

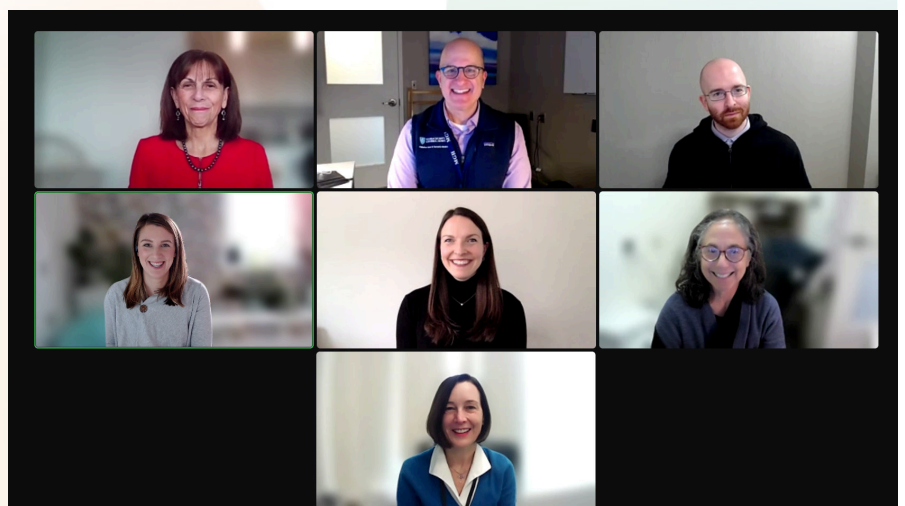
Community Health and Outreach

The **Dementia Care Collaborative** has been fortunate to partner with the Massachusetts Alzheimer's Disease Research Center's Outreach and Recruitment Core to provide dementia education and caregiver support to communities throughout Boston. The DCC has also been working with Eugene Barros and Boston Public

Health Commission to learn more about the findings of the Center for Disease Control's BOLD assessment program, with the goal of using those findings to expand programming and outreach. The DCC continues to work closely with Revere Health Center and is looking for ways in 2023 to offer support for other practices at MGH.

“The DCC support group connection to people who really understand what it's like to be a caregiver to a loved one with dementia.

Tom Lee, Caregiver



Dementia Care Collaborative Staff - 2022

Goals for 2023

The **Dementia Care Collaborative** will continue, in 2023, to offer unique and essential services and educational programs that impact the Hospital, our staff and improve the lives of people living with dementia and their caregivers. We will continue to partner with IHI and other national organizations to create best practice, evidence based, clinical and educational services. Through the Schwartz Rounds for Dementia, a carefully structured interdisciplinary case conference focused on patients with dementia and their care experience, the DCC will continue to expand our education and support to providers. We will conduct a needs assessment of current resources at the Hospital for dementia patients towards improving the patient experience. We will continue our efforts towards serving our

community and patients with respect and equity and engage with community health centers in underserved communities. The MCI team is excited to continue supporting patients at Mass General Brigham and participating in national conversations about best practices for dementia care.

Research is the cornerstone of all of our work and we will implement the newly funded caregiver studies as well as respond to new requests for proposals around caregiving, dementia and delirium. Creation of train the trainer programs and our publications will expand. In 2023, our DCC Team plans to work even harder to offer new initiatives and expand current ones. Engaging you in these efforts is our overall 2023 goal.

Funding Sources and ways to donate

The **Dementia Caregiver Support Program** (DCSP) is funded largely by generous individual donors and foundations, including the Bresky Foundation and the Jack Satter Foundation. We are grateful to these foundations for their financial support in 2022. The Memory Care Initiative is currently funded as a pilot program through Mass General Brigham with plans to extend this program based on its far-reaching impact and success.

WAYS TO LEARN

To learn more about supporting our work:
dementiacaregiversupport@mgh.harvard.edu
www.dementiacarecollaborative.org
617-724-0406

Special thanks

Special thanks to Susan Rowlett, Founder and Director of DCSP. Her commitment and creativity in developing this essential program enhanced our services to caregivers and to our patients. She is missed in our work and we wish her the best in her future endeavors.



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