

2021

Year in Review



Life with Dementia
Sinikka Nogelo,
Painter and Caregiver

“We have been walking in the dark and now we have you as a beacon of light.”

The Massachusetts General Hospital **Dementia Care Collaborative (DCC)** is committed to improving the experience of patients and families living with Alzheimer’s disease and related dementias by changing the way our healthcare system understands and treats these individuals. Our goal is to transform the health care experience for this population through education, clinical services, emotional and social support, applied clinical research and experiential programs to reduce caregiver stress.

DCC has four primary initiatives:

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

2021

Year in Review

In the past year, DCC has expanded its scope and impact to become fully integrated into Mass General's 'four pillars' that are central to its mission:

- 1) Patient Care
- 2) Research
- 3) Education
- 4) Community Health



Dementia Care Collaborative Staff - 2021

MGH's deep commitment to diversity, equity and inclusion spans the four pillars. The DCC seeks to create and maintain a welcoming and respectful environment for all; recruiting, retaining, and promoting diverse talent; diversifying researchers, research participants and our research agenda; training providers on the delivery of culturally attuned care; diversifying our patient population; and strengthening community engagement. 2021 has seen growth in these areas throughout MGH and at the DCC.

This year MGH was honorably recognized as an Age-Friendly Health System (AFHS) by

the National Institute for Healthcare Improvement. MGH treats all older people with dignity by keeping the AHFS "4Ms Model" in mind: **What Matters, Mentation, Medications, and Mobility.**

In 2021, DCC recruited caregivers and patients living with dementia to our new Patient Family Advisory Council (PFAC). The DCC PFAC integrates, elevates, and promotes the patient and family voice in the development of programs, services, and initiatives.

The DCC also established an Internal Advisory Board (IAB) to assist in expanding 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, Nurses and Social Workers. Their advice has already contributed to developing a new no-restraint policy and adding a flag (with consent of the patient or their proxy) to the medical record that indicates the patient has memory impairment.

"Thanks so much for this great service to the caregivers and consequently those with dementia!"

Memory Care Initiative

On January 30, 2022, the **Memory Care Initiative**, MCI, will mark two years since meeting its first patient at Bulfinch Medical Group. MCI was born of 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. These partnerships facilitated robust clinical training and implementation assistance to the MGH team.

In 2021, through the disruption of the COVID-19 pandemic, the MCI team of Kelsey Anderson-Gandhi, LCSW, and Gabrielle Rex, AGPCNP, under the leadership of medical director Christine Ritchie, MD, MPH, provided essential care and support to 199 patients and their families at Bulfinch Medical Group, Newton-Wellesley Physicians - 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 partner.

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 have access to participate in DCC Caregiver Support Program services and activities, including Conversations with Caregivers, Fundamental Skills, Support groups, and Health and Resiliency.

“The support, empathy, and practical advice of the CGSP’s programs are critical to us as we navigate this difficult journey together.”

Joanne, caregiver,
and her husband, Dick.



Dementia Caregiver Support Program

The **Dementia Caregiver Support Program**, CGSP, that launched in November 2017, has expanded to include patients living with dementia, their families, care-partners and professionals from across the community, within and beyond MGH. The CGSP's main offerings include clinical services provided by expert dementia-trained licensed Social Workers, Support Groups for caregivers and our expansive educational programming.

The CGSP's Social Workers understand that caring for an aging parent, spouse or friend can be daunting and overwhelming and they seek to ease the load through guidance and support. They provide 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. The clinical services were provided to 980 patients and their families in 2021.

CGSP Support Groups for caregivers are offered as a vital extension of our individualized clinical service. In 2021 the Support Group program expanded from 2 daytime support groups to include an evening support group. Additionally, the CGSP is collaborating with the Revere Community Health Center to re-launch a support group that was disrupted by the pandemic.

Education Programs for persons with dementia and their care partners are at the heart of the DCC programming and open to the whole community. These were all run virtually

in 2021. The **Conversation with Caregivers** lecture series offered 12 monthly, evening sessions with a total of 775 participants. **Health and Resiliency Tuesdays** is a monthly evening program focused on encouraging caregivers to include self-care and healthy activities into their lives. Programs have ranged from modified Tai Chi and Breathing for Restful Sleep to a Jazz concert, and a healthy cooking demonstration. **Ageless Grace**, a neuroplasticity movement and music program, is offered weekly. The **Fundamental Skills course** is a three-part series offered virtually every month. An expert facilitator covers communication skills, approaching challenging symptoms, and safety issues. Due to the amount of interaction between participants and the facilitator, this course is limited to 15 students per course.

2021 Education and Support programs

Program/Support Groups*	Number of participants	Number of classes	Average number of participants
Conversations with Caregivers	775	12	66
Health and Resiliency	370	13	28
Ageless Grace	954	84	12
Fundamental Skills	382	40	10
Support Groups	280	29	10

* Not unique individuals

Research

The **Dementia Care Collaborative** partners with researchers at MGH and BWH to offer studies that may be of value to persons with dementia and their care partners. The DCC also partners with the Mongan Institute Center for Aging and Serious Illness (CASI) that participates in numerous national studies to improve care and quality of life for persons with dementia.

In 2021, the DCC was involved in a National Institutes of Health-funded multisite study to evaluate the impact of early dementia palliative care for those with moderate to severe dementia; participated in several studies (in partnership with the Icahn Mt Sinai School of Medicine and the University of California San Francisco) to better understand the dementia care needs among those who are homebound; advised on a study evaluating dementia screening strategies in primary care practices, and helped lead a qualitative study to better understand challenges experienced by persons with dementia and their care partners. The DCC, in partnership with CASI submitted two grants in 2021 for funding, both focused on improving quality of life for care partners of those living with dementia.



"It's so reassuring, you can't imagine. I just feel so lucky to have this support."

Community Health and Outreach

In 2021, Dr. Ritchie began co-leading the Outreach, Recruitment and Engagement (ORE) Core of the Massachusetts Alzheimer's Disease Research Center (MADRC). The focus of the ORE Core is to outreach to the community about dementia and dementia care, recruit persons with dementia and/or their care partners into research studies and engage community partners in conversations

about dementia care. Enriched partnership between the DCC and the ORE Core will increase opportunities for persons with dementia and their care partners to participate in research, a key activity for improving care and health outcomes.

One of the DCC's goals is to better address the dementia care needs of patients served by our community health centers in Revere, Chelsea,

and Charlestown. To that end, we have begun working with the director of the Revere Community Health Center, Dr. Roger Pasinski, to better understand the dementia care needs with the Revere community. Dr. Pasinski has agreed to serve as a member of the IAB and will work with the DCC to conduct our first community-focused dementia care needs assessment.

Goals for 2022

In 2022, the **Dementia Care Collaborative** is looking forward to a year of continued patient and family participation to expand our unique programs and services. DCC staff will initiate the Satter Rounds, a carefully structured interdisciplinary case conference focused on patients with dementia and their care experience, with the goal of increasing dementia awareness and improving outcomes. We will assess the current resources at the Hospital for dementia patients and begin offering educational opportunities and training to staff.

We will continue our efforts towards serving our community and patients with respect and equity and engage with community health centers in underserved communities. We will expand our research and our impact on national elder care through dissemination of our activities, train the trainer programs and our publications. 2022 will be a year of challenges and hopefully many successes. We look forward to DCC offering new initiatives and expanding current ones with your guidance.

Funding Sources and ways to donate

The Dementia Caregiver Support Program 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 increased financial support in 2021. 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
 617-724-0406

“Caregiving has made me stronger and has made me realize that love, good health, forgiveness and grace are really what matters in this life.”

Bernice, caregiver, and her father

