COMMONWEALTH OF VIRGINIA
DEPARTMENT FOR AGING AND REHABILITATIVE SERVICES

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November 1, 2022

MEMORANDUM

TO: The Honorable Janet D. Howell
Co-Chairwoman, Senate Finance and Appropriations Committee

The Honorable George L. Barker
Co-Chairman, Senate Finance and Appropriations Committee

The Honorable Barry D. Knight
Chairman, House Appropriations Committee

FROM: Kathryn A. Hayfield
Commissioner, Department for Aging and Rehabilitative Services

SUBJECT: Annual Report on Dementia Case Management Program

Pursuant to Item 331 J of the 2022 Appropriation Act, the Department for Aging and Rehabilitative Services (DARS) is pleased to submit the report on the status of the Dementia Care Management Program. This program is built on work undertaken at the University of Virginia's (UVA) Memory and Aging Care Clinic since 2016 through a partnership with DARS. This document provides a brief description of this previous work and information about the program through the first year of funding from July 1, 2021 through June 30, 2022.

If you have any questions about the report, please do not hesitate to contact me.

Sincerely,

Kathryn A. Hayfield

Kathryn A. Hayfield

KH/gw

Enclosure

Report on Dementia Case Management

A Report to the Virginia General Assembly *November 1, 2022*

REPORT MANDATE

2022 Appropriations Act Item 331 J: Out of this appropriation, $262,500 the first year and $262,500 the second year from the general fund shall be provided for an interdisciplinary plan of care and dementia care management for 88 individuals diagnosed with dementia. This service shall be provided through a partnership between the Memory and Aging Care Clinic at the University of Virginia and the Alzheimer's Association. The Department for Aging and Rehabilitative Services shall report the status and provide an update on the results of the dementia case management program to the Chairs of the House Appropriations and Senate Finance and Appropriations Committees by November 1 of each year.

BACKGROUND

During the 2020 Special Session, the General Assembly appropriated funding for a pilot program of dementia case management starting July 1, 2021. In the 2022 Special Session, the General Assembly appropriated additional funding starting July 1, 2022. This funding was appropriated to support the implementation of a program for dementia care management at the University of Virginia's Memory and Aging Care Clinic (UVA MACC) in partnership with the Alzheimer's Association.

KEY ACCOMPLISHMENTS

- Dementia Care Managers (DCMs) support families using an evidence-based program
- 61 persons living with dementia and their caregivers enrolled in first year of program
- DCMs spent 495 hours working directly with families in a total of 1,715 contacts

DARS AND DEMENTIA

DARS' mission is to improve the employment, quality of life, security, and independence of older Virginians, Virginians with disabilities, and their families.

Under the Code of Virginia § 51.5-152, DARS has a number of powers and duties with respect to Alzheimer's disease and related disorders (ADRD). These include evaluating the needs of individuals with ADRD and their caregivers, and identifying the services, resources, and policies that may be needed to address such needs for individuals and their caregivers, and recommending policies, legislation and funding necessary to implement the state plan for meeting the needs of individuals with ADRD and their caregivers.

The most recent plan, the *Dementia State Plan 2020-2024: Building a Dementia-Capable Virginia*, was developed by the Alzheimer's Disease and Related Disorders Commission in consultation with stakeholders and citizens and includes five main goals. Goal Four is to provide access to quality coordinated care for individuals living with dementia in the most integrated setting.

The Dementia Services Coordinator, housed within the Division for Community Living at DARS, supports the Alzheimer's Disease and Related Disorders Commission; disseminates information on systems, services and related activities; and coordinates services and activities of state and local agencies, service providers, advocacy groups, first responders and law enforcement, as well as other entities throughout the state that engage with people with ADRD and their caregivers, specifically the Alzheimer's Association, Area Agencies on Aging and Adult Protective Services.

BRIEF HISTORY

Dementia Case Management began at UVA MACC in 2016 with support from a grant awarded to DARS by the federal Administration for Community Living under the Alzheimer's Disease Initiative—Specialized Supportive Services program. UVA MACC collaborated with the Jefferson Area Board for Aging (JABA), the Area Agency on Aging serving the Charlottesville region, to jointly hire and manage two dementia care managers serving a total caseload of 100 families. Over the nearly three years that the program operated through August 2018, the program served a total of 220 people living with dementia and their caregivers.

The project reported on several measurable outcomes highlighting the benefits of care management. Among both people living with dementia and caregivers, these included: decreased depression, improved quality of life, reduced problematic behavioral symptoms and lower severity of dementia symptoms, and reduced health care utilization. In addition, caregivers reported a reduction in caregiver burden. Overwhelmingly, both people living with dementia and their caregivers felt the program was beneficial, helping prepare them for the future, improving clinical care and treatment, improving access to community resources and reducing stress.

These results help explain why dementia case management has maintained a high profile in Virginia's Dementia State Plan since the first plan in 2011. The Alzheimer's Disease and Related Disorders Commission has consistently advocated for state funding to support dementia case management with an ultimate goal of having these services available across the Commonwealth. Since the DARS-supported grant projects ended in 2018, UVA's two dementia care managers have continued to serve about 100 families annually with the support of additional grant funding from the Administration for Community Living and the Department of Defense. Under the former funding project, UVA successfully incorporated the evidence-based Benjamin Rose Institute Care Consultation (BRICC) program. Through the Covid-19 pandemic, dementia care management continued to be provided virtually, with similar outcomes in terms of depression, quality of life, symptom management and health care utilization.

IMPLEMENTATION

Partnership with the Alzheimer's Association

As directed in the budget language, UVA MACC has partnered with the Alzheimer's Association to carry out the project. This was accomplished through negotiating a Memorandum of Understanding (MOU).

The Association identified a DCM to join the UVA MACC team, who was trained to use necessary systems including the BRICC program, and other systems including the electronic health record and data collection systems. The two existing DCMs devoted significant time and energy to providing specific peer training relevant to the program for the new DCM.

With the establishment of the MOU and the onboarding of the new DCM taking longer than anticipated, the launch of the pilot program was delayed until October 20, 2021. This is comparable to the initial introduction of the care coordination program in 2016, which had a lead of three months from hiring the DCMs to opening the program up to participants.

How the program works

Most participants are first offered information about the program by their health care team at the UVA MACC, at diagnostic visits or follow-up care visits. They are given a brief description of the program, and if they are interested, their contact information is shared with the program coordinator. The coordinator then follows up with a call to the family to provide further information, and enroll the individual living with dementia together with a primary caregiver willing to meet regularly with their assigned DCM.

Once enrolled, the individual and caregiver are asked to complete a comprehensive set of questionnaires addressing depression, anxiety, quality of life, healthcare utilization, dementia-related behaviors and caregiver reactions, and others. Caregivers are additionally asked to complete measures of caregiver stress and burden, dementia knowledge and self-efficacy. These questionnaires are used to inform the person-centered care plans developed by the DCMs in consultation with the individual and caregiver, as well as to gauge the effectiveness of the program.

The assigned DCM then contacts the individual and the caregiver. The degree of interaction with the person living with dementia will depend on their own preferences as well as the stage of the disease process, with people early in the disease process more likely to engage regularly with the DCM. DCMs use the BRI CC program to guide their interactions including structured assessment conversations in the first few weeks of participation to help formulate the care plan. Over the twelve months after enrolling, participants are contacted at least once a month by their DCM, with additional contacts determined by the individual and caregiver needs.

At the end of the 12-month enrollment period, a second set of questionnaires is sent to the caregiver to complete. This includes the same questionnaires completed at enrollment and the Satisfaction with Care Survey. Six months later, an abbreviated set of questionnaires is sent to the caregiver to complete.

How the DCM helps

One of the primary goals of the DCM program involves coordinating care around their dementia diagnosis, with an emphasis on providing person-focused support, education and guidance as they navigate healthcare and community providers. An equally important, but less obvious role involves providing validation and emotional support at a time in life where things can be particularly overwhelming. DCMs validate the participants' emotional experience, while also providing disease-specific education and helping them to identify supports and strategies that would be beneficial for their unique needs. DCMs have the flexibility to meet the participants where they are physically and emotionally, and allow space for building a sense of rapport, safety and trust early in the relationship.

Most of the program's interventions can be organized into seven main categories: 1) care coordination, 2) education on diagnosis and dementia progression, 3) guidance and education on community resources, 4) guidance and education on financial resources, 5) guidance and support for long term care planning, 6) emotional support, and 7) behavioral management and safety strategies.

While the goals and anticipated outcomes of care are unique for each individual living with dementia and their primary caregiver, DCMs can broadly anticipate helping to prepare individuals for the challenges associated with living with dementia, reduce the need for unplanned medical treatment, decrease the emotional and physical burden of living with dementia, and improve emotional outcomes for individuals and caregivers.

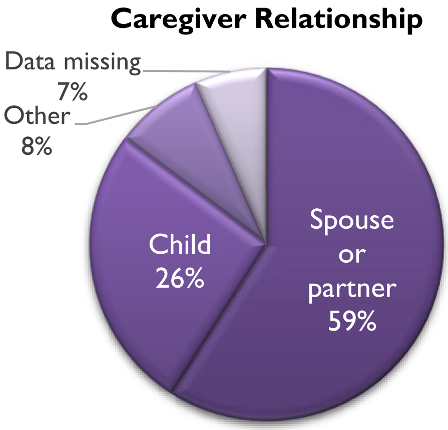
DCMs use a variety of means to maintain contact with the participants including phone, email, videoconferencing and in-person visits. Typically, DCMS will also accompany participants while they are in the MACC for follow-up care visits, providing another set of ears in often emotional and sometimes overwhelming appointments. Clinic visits usually entail meeting with a number of members of the care team that can include neurologists, neuropsychologists, nurse practitioners, social workers and others.

Program enrollment

Through the end of June 2022, the program enrolled 61 individuals living with dementia and their primary caregivers. Demographic information about the participants is in Table

Table 1: Participant Demographics

	Individual Living with Dementia (61 persons)	Primary Caregiver (61 persons)
Female	49%	67%
Black/African-American	18%	18%
Hispanic/Latino	2%	2%
Veterans	11%	10%
Age Range		
60-69	20%	30%
70-79	31%	20%
80-89	36%	20%
Married	59%	82%



1. Caregivers are often younger than the person living with dementia and generally female. By relationship, 59% of caregivers were the spouse of the person living with dementia, followed by 18% who were adult daughters.

Services provided

Care coordination is provided in a variety of settings, including during participant's visits to the clinic and DCM visits to the participants' home, and through phone calls, emails and telehealth visits. At a minimum, DCMs contact each participant once a month, with an average of three contacts per month. DCMs record the time spent assisting participants as direct hours and indirect hours (see Table 2). Direct hours are actual time spent with the participants including at clinic visits, in-person home visits, phone calls, telehealth visits, and emails. Indirect hours are time spent working on tasks for the participants such as leaving or answering voicemails, locating resources, communicating with providers about specific patient needs, travel to and from visits, and time spent documenting interactions with participants.

Table 2. SFY 2022 DCM Outputs

Total Service Hours	1,178
Direct	495
Indirect	683
Total Contacts	1,715

Program Outcomes

As of June 30, 2022, none of the participants had completed the 12-month questionnaires, so it is not possible to quantify the changes experienced by the participants. The steady accumulation of this data after October 20, 2022 (the one-year anniversary of the first enrollees), will provide evidence of any changes in the outcomes of interest, such as depression, anxiety, and caregiver self-efficacy.

However, the DCMs report a decline in healthcare utilization for enrolled participants. They reported a reduction in the need for in-person appointments at MACC and emergency room visits as they are available to problem solve, answer questions, help caregivers navigate the health system, and help caregivers implement behavioral intervention strategies.

DCMs have also been able to facilitate positive changes for participants that allow the individual living with dementia to remain in the home longer. Examples of such changes include the following:

- Creating a safe environment (i.e., making suggestions to make the home safer and help with fall prevention) while finding community volunteers and grants to make the home more accessible (i.e., installing ramps and shower bars, fixing mold issues, helping with roof repair, and finding

and delivering durable medical equipment);
- Connecting families with local individuals and home health agencies to provide respite;
- Addressing cognitive changes with the treatment team, as needed, rather than the participants needing to wait for the standard yearly follow up visit;
- Providing education and emotional support;
- Connecting families to community-based services for free durable medical equipment or other adaptive devices (e.g., bathtub chairs, disposable briefs, wedges to make shifting someone in the bed easier on a caregiver's back, etc.);
- Helping connect caregivers to support groups, therapists, or other mental health support to combat caregiver fatigue/burnout;
- Ensuring caregivers are aware of their local community support agencies, including their Area Agency on Aging, Department of Social Services, Senior Centers, and others.

Letters of support and testimonials provided by families receiving care coordination through this program are included in the appendix to further illustrate the positive impact care coordination has on families.

Lessons from the first year

As the initial contracting and onboarding process took longer than anticipated, enrollment in the program began on October 20, 2021. Despite these challenges, the team was able to provide services to more than the minimum number of participating families (50) in the shortened delivery period.

During the past year, the program team has faced several challenges in providing care coordination. DCMs have found that a change of primary caregiver makes continuity and provision of care more challenging. Similarly, changes in the status of the individual living with dementia, including moving to a higher level of care, worsening health conditions, or dying, have significant impacts on caregivers, as well as the level of care coordination DCMs can provide. DCMs have also found that caregiver health status and access to resources plays a large role in the caregiver’s ability to provide care for their loved one.

Over the last year, COVID has continued to create challenges in care provision. Isolation resulting from COVID has played a significant negative role in caregiver burden, as caregivers have struggled to find respite providers, home health aides, and other activities to improve quality of life.

The DCMs and program coordinator have learned from caregivers that they are concerned about losing care coordination after 12 months. Participants are so satisfied with the program that they have requested services to be extended beyond a year. The program team has been discussing whether the program can have a greater impact by limiting participation to 12 months, allowing more people to access services, or by extending services to current participants and thereby limiting the number of additional participants.

Program reception

Since its inception, the Dementia Care Management program has received an overwhelmingly positive response from participants, the MACC clinical team, and community partners. The team has found that the great majority of participants receiving care in MACC are interested in care coordination. As such, the team has had to be strategic in how the program is advertised to ensure a manageable waitlist, even while making the program available to as many participants as possible. To date, demand for services has far outstripped the capacity of existing DCMs.

APPENDIX

Letters of support for Dementia Care Management from participating families (redacted to protect the writers' identity)

A. To Whom It May Concern,

My husband was diagnosed with Frontal Temporal Dementia x years ago at the age of xx. When he was diagnosed by a Neurologist the doctor referred us to UVA memory group. What a blessing this referral was for us. The group is amazing, knowledgeable and very caring. One of the biggest blessings was to be assigned a caregiver to help us with this horrific, confusing and terrifying disease.

I truly don't know what I would have done without the help, guidance, care and support we have received from this part of the group! Anytime I had questions, concerns or fears all I had to do was reach out and I had help, guidance and genuine care about everything. Finances have been a struggle but I was always being sent information on where I could reach out for assistance. When my husband was still working and his employer wanted him to resign too early I received guidance on what to do to help him stay at his job as long as he could. Liz has always reached out to me to see if I needed anything, to let me vent, to send information for help with my depression and fears. She helped me get set up with a family counselor who opened the eyes of my family and friends on ways to support us.

Recently my husband's disease had advanced to a point where I am unable to care for him. I work a full time job and have a daughter in college. I have to work and nights of little sleep took a toll on me physically and mentally. Reaching out to our care coordinator I got the help and guidance I needed. Hospice was called in and they were an added assistance.

Long before this happened she discussed with me that I should start looking for a memory care facility early and get put on the list so things would go much easier when the time came to admit him. She even gave me recommendations that had been given to her from other family members. Wow! When it was time all was ready and the transition was smooth, amazing and our care coordinator still reached out to make sure all went well. The facility is more than I could have ever asked for and without the help she gave me everything would have been insurmountable and I truly doubt I would not have the results for both myself and my husband that we received.

I believe that if you talked to anyone who worked with a caregiver/support person like I have you would jump at the chance to provide that for anyone including your own family member.

I can't thank you enough for making this available to us.

Best regards,

B. To Whom it may concern,

I am writing to tell you what a blessing it was to have a care coordinator for [my husband]. He had Alzheimer's for many years and I was his caregiver. Before having a care coordinator, I felt like I was on my own to figure out how to care for him. Once he had nightmares of blood and death of babies which was brought on by a new medicine he was given. He never had experienced anything like that before. I called the doctor's phone number and got someone who was not a doctor. I told him I needed to ask the doctor what to do. He took the message. I told him I was going to discontinue the medication. I didn't know what that might do to [my husband]. I really worried. Four days later I got a call from the doctor. Since we got our care coordinator things improved. She visited the home, treated my husband with respect and care, and always included him in the conversation. At the same time, she checked on me about how things were going and offered suggestions that might help for any new problem. (such as his not wanting to bathe, incontinence, violent behavior) She relieved a lot of the stress. When a medication question came up or something important, I was able to call Liz and she would check it out with the right person and get back to me with the answer in about a half hour instead of 4 days. Getting help was suggested and I was able to take [my husband] to an adult day care for a few hours 3 days a week. They even had a monthly meeting for caregivers of loved ones who had Alzheimer's. I would never have known about these things if not for Liz. The care coordinator program helped me keep [my husband] out of a memory care facility until just a few weeks before he passed away. As more people are diagnosed with dementia, this care coordination program is more essential than ever. I hope it will be continued so that in the future others can be helped as we were.

Sincerely,