

# Collaborative Care Coordination

**A model of person-centered collaborative care coordination for  
people living with dementia and their care partners**

A replication manual based on Virginia's Dementia Specialized Supportive  
Services Program of Care Coordination

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COLLABORATIVE CARE COORDINATION



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# Introduction

The Virginia Dementia Specialized Supportive Services Project was developed with the support of the Administration for Community Living's Alzheimer's Disease Initiative—Specialized Supportive Services (ADI-SSS) Program in 2015. The ADI-SSS Program was implemented in 2014 with funding from the Affordable Care Act's Prevention and Public Health Fund in order to support initiatives designed to meet gaps in long-term services and supports (LTSS) for people living with Alzheimer's disease and related dementias (ADRD) and their caregivers. In particular, the program aimed to provide services to support people living alone with dementia in the community, to provide person- and family- centered care to individuals living with moderate to severe impairment and their caregivers, and to offer behavioral symptom management training and expert consultation to caregivers.

In 2011, Virginia published its first Dementia State Plan: Virginia's Response to the Needs of Individuals with Dementia and Their Caregivers. The Plan enumerated five goals to improve Virginia's readiness to support the growing numbers of people living with ADRD. Goal Four of the Plan was to "Provide access to quality coordinated care for individuals with dementia in the most integrated setting". Recognizing that professional care coordination is necessary for helping families navigate the complex web of medical services and to learn about available long-term services and supports, this goal was reaffirmed in the 2015 Dementia State Plan.

Evidence supports the use of care coordination in interdisciplinary memory disorder or assessment clinics to provide better outcomes for people living with dementia and their caregivers. To help meet Goal Four, Virginia first identified and surveyed interdisciplinary memory assessment centers within the state and in neighboring states. Next, the Department of Aging and Rehabilitative Services (DARS) partnered with the University of Virginia Health System's Memory and Aging Care Clinic, one of the identified assessment centers serving people living with dementia from across

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Virginia and surrounding states, and with the Jefferson Area Board for Aging, the Area Agency on Aging serving Charlottesville and surrounding counties, to pilot an embedded care coordination program that could serve as a collaborative model for the rest of the state and elsewhere.

This guide is intended to help agencies and organizations to successfully implement this model. The appendices include all materials and measures developed for this program by the partners.

Some of the referenced programs, systems or documents are specific to Virginia, but many of these will have counterparts in other states that can be substituted where applicable.

# Partner Organizations

## **Virginia Department for Aging and Rehabilitative Services**

Office of Aging Services

1610 Forest Avenue, Suite 100

Henrico, VA 23229

Contact: George Worthington, M.S., Dementia Services Coordinator

[george.worthington@dars.virginia.gov](mailto:george.worthington@dars.virginia.gov)

## **University of Virginia Health System**

Memory and Aging Care Clinic

Primary Care Center, Fourth Floor

1221 Lee Street

Charlottesville, VA 22908

Contact: Dr Scott Sperling, PsyD, Assistant Professor

[sas7yr@hscmail.mcc.virginia.edu](mailto:sas7yr@hscmail.mcc.virginia.edu)

## **Jefferson Area Board for Aging**

674 Hillsdale Drive, Suite 9

Charlottesville, VA 22901

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# Program Overview and Outcomes

## Program Overview

Virginia's Dementia Care Coordination program was designed to help meet Goal 4 of Virginia's Dementia State Plan, to provide access to quality coordinated care for individuals with dementia in the most integrated setting, by creating a best practice model for the entire state. The pilot program, which ran from September 2015 to August 2018, limited enrollment to those living with a recent diagnosis of cognitive impairment and dementia, focusing on those with Alzheimer's disease or related dementias (ADRD) who are living alone, those with Mild Cognitive Impairment (MCI) and at high risk of developing ADRD, and those with moderate dementia, as well as their caregivers. The project was led by Virginia's Department for Aging and Rehabilitative Services (DARS), which houses the state's Dementia Services Coordinator. The DARS planned the project with two partners, the University of Virginia Health System's Memory and Aging Care Clinic (MACC) based in Charlottesville, and the Jefferson Area Board for Aging (JABA), the Area Agency on Aging serving Charlottesville and five surrounding counties.

The MACC already possessed many of the elements of a coordinated care system, such as supporting an active on-site interdisciplinary team providing medical and behavioral treatments for people living with ADRD and conducting numerous clinical trials for the treatment of ADRD. It also maintained close ties with the community through educational programs for the Alzheimer's Association. Since its beginnings in 1997, the MACC had assessed over 2,000 patients, with most new patients coming from rural counties surrounding Charlottesville.

JABA brought many additional elements to the development of an improved system of coordinated care. The Information and Referral Program serves as JABA's front door for individuals seeking services and basic information. A team of dedicated

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Options Counselors provide a deeper level of person-centered support, helping individuals define their personal goals for long-term care as well as locate and engage community services in order to support individuals as they age in a place of their choosing.

Together, these partners provided the expertise to collaboratively hire, train and supervise Dementia Care Coordinators (DCCs) who were embedded in the MACC yet able to harness the resources of JABA to support people living with ADRD in the community. For the pilot, each partner hired one DCC with a background in health, social work or nursing professions and experience in aging, medical or mental health spheres. Once hired, DCCs were provided with supplemental training on dementia and caregiving related topics, behavioral and psychological symptoms of dementia and best practice management methods, available services and providers within the aging network and the UVA Health System. DCCs were also certified as Options Counselors under Virginia standards based on current national models, and used the statewide No Wrong Door tool to facilitate referrals and to manage the tracking of individual specific interventions and care. All activities of the DCCs were documented in the individual's electronic health record.

DCCs provided person-centered care coordination such as helping individuals and their care partners navigate the health system, learn about dementia and related disorders and examine and choose supports and services. As part of the protocol, DCCs visited participating individuals at their home, providing opportunities for a strong bond of trust and rapport to be developed. As intended, the DCC became the first point of contact for participating individuals' memory care.

## Program Outcomes

The Care Coordination program was evaluated using a number of measures to gauge the impact of the program on the individual living with dementia and their primary caregiver. DCCs administered measures in the following domains: functioning (ADLs/IADLs), mood, neurocognitive and behavioral symptoms, healthcare utilization, quality of life, and program satisfaction. In addition, caregivers were asked about caregiver burden and self-care.

Benefits associated with this program included:

- Reduced symptoms of depression in both caregivers and individuals living with dementia
- Improvement in caregiver's quality of life
- Reduction in reported behavioral and psychological symptoms of dementia suggesting improved caregiver efficacy
- Reduction in unplanned healthcare utilization
- Reduction in caregiver burden and improvement in having caregiver's basic needs met
- Feeling better prepared for the future.



# Prerequisites

## Staff required

### Manager/Supervisor

The Manager/Supervisor should have experience managing and supporting options counselors, case managers or similar serving older members of the community or those living with a disability, and should be able to provide weekly or biweekly individual supervision to DCCs as well as oversee their training.

### Dementia Care Coordinators

DCCs should have a background in health, social work or nursing with experience in aging, medical or mental health. DCCs should have a minimum of a bachelor's degree in a human services field with at least two years of experience working in case management or social work, preferably with an older population. An advanced degree in social work, psychology or nursing is preferred.

Staffing levels will depend on the number of individuals and care partners to be served. Dedicated DCCs should serve a maximum of 75 individuals living with dementia. DCCs require training and ongoing supervision and support. Training can be largely autonomous, as many of the suggested training materials are available on-line. Hands on training may be needed for documentation and systems, while shadowing opportunities and peer training are essential for furthering understanding of the process of Options Counseling, home visits, and administration of required measures.

In this model, DCCs received weekly supervision, typically of one hour duration, as well as attended weekly clinic meetings at the health system and monthly Options Counseling staff meetings at the AAA.



# Choosing the Model

## Is Collaborative Care Coordination an appropriate model for your agency?

### Who will you serve?

Care coordination has been shown to improve outcomes for people living with dementia and their caregivers. While this model was piloted with people with a recent diagnosis of Mild Cognitive Impairment or Alzheimer's disease or a related disorder, in practice this allowed for the enrollment of people ranging from only limited cognitive impairment to those in the moderate stages of dementia who had not received a diagnosis sooner in the disease process. This model of Care Coordination is applicable and should be made available to people at any stage of the disease process while they continue to live in the community. Care Coordination should continue to be offered as long as the individual is receiving follow-up care at the memory assessment center; however the DCC's involvement is likely to be limited to coordinating appointments and helping navigate the health system following a transition into a residential care facility.

#### **Lessons Learned**

The level of trust developed between the individual and caregiver and the DCC meant in practice that caregivers continued to turn to DCCs with care issues even after the individual living with dementia had moved into residential care. DCCs can usefully educate caregivers about other potential advocates such as the long-term care ombudsman or adult protective services at the time of placement.

## **Will Collaborative Care Coordination help meet the needs of people in your community?**

Care Coordination is intended to help smooth the path for people living with dementia and their caregivers by providing education and emotional support, referrals to services and supports available in the community, and assistance with navigating the complex web of medical and community services. Care Coordination demonstrably improves outcomes and may help delay residential placement. Used in combination with other evidence-based programs such as Virginia's FAMILIES program, a variant of the New York University Caregiver Intervention, the impact of care coordination on caregiver stress and burden is likely to be even higher. In the pilot program conducted at UVA and JABA, outcomes included a reduction in depression for both caregivers and participants, reduced caregiver burden and stress, and a greater understanding of the disease process and planning for future needs.

This model should be readily translatable into communities large and small. The crucial elements are having the DCCs be an integral part of the memory assessment clinic, and having the training in options counseling that allows them to work in a person-centered way to help achieve the goals of the individual living with dementia and the care partner.

### **Choosing appropriate partners**

This model of Care Coordination involved a contractual relationship between the participating health system and Area Agency on Aging. For future replication, it is recommended that one agency assume control of the program in order to have a unified experience for both staff and participants. In order to maximize the benefits of the collaborative model, there should be close integration of the DCCs in both the memory clinic and the AAA. DCCs were able to take advantage of training opportunities at the AAA and maintain those links through regular attendance at



relevant staff meetings at the AAA (such as those for options counselors). This helped to continually expose the DCCs to the importance of person-centered interactions, provide training opportunities surrounding home visits and related issues, and expand their knowledge of supports and services available in the community.

Conversely, the addition of the DCCs to regular options counseling meetings can help improve the knowledge and understanding of issues related to dementia by agency staff, all of whom are likely to encounter individuals living with dementia or people caring for someone living with dementia as they work in the community.

In addition to the training provided by the AAA in options counseling and Virginia's No Wrong Door tool (a proprietary web-based system of case management, information and referrals), DCCs received in-person training in areas such as available programming for individuals living with dementia or their care partners from the local chapter of the Alzheimer's Association.

The majority of training materials used in this model are freely available on-line, allowing the DCCs to undergo training autonomously.

#### **Lessons Learned**

A unique feature of the current model was having one DCC employed by the health system and one DCC employed by the local Area Agency on Aging. Although the partners conducted joint interviews to hire the DCCs, they had different salary and benefit structures that negatively affected team cohesion. Additionally, the DCCs initially experienced different levels of support and supervision as a result of this split.

After the project had run for nine months and the program experienced turnover among the DCCs, the model was modified to have both DCCs under the daily supervision of one person, in this case a manager from the Area Agency on Aging. This manager was responsible for the day-to-day supervision of the DCCs,

conducted their performance reviews and helped ensure that there was little difference in the working experience of either DCC.

Overall, our experience suggests that the program would benefit from DCCs being employed by the health system, with supervision and training being provided contractually by the external partner to enable integration of the DCCs in both the health system and the community based organization.

## **Does the program fit the abilities of your staff?**

### Program manager/supervisor

The person who provides supervision to the DCCs should plan on spending at least 25% of their time during the first six months of the program on:

- Hiring and supporting the training of DCCs
- Providing regular individual supervision to the DCCs
- Conducting team meetings (at least biweekly)
- Review referral and tracking spreadsheets
- Randomly check notes and client files to ensure fidelity and thorough documentation
- Work with team to identify trends and monitor improvement opportunities

The program manager should:

- Help facilitate relationships between the DCCs and community partners who may provide referrals to the Care Coordination Program
- Help facilitate relationships between the DCCs and community partners to whom the DCCs may provide referrals for the individuals and families in the Program
- Have a high level of expertise in handling the challenges of Alzheimer's disease and related disorders, and the challenges of providing care for someone living with these diseases

- Have knowledge of available resources to meet the needs of individuals and caregivers
- Understand how to use data reports and analysis to evaluate the program, DCC performance and outcome measures.

### **Lessons Learned**

Once trained, the DCCs should need minimal daily supervision, but regular supervision is essential for DCCs with a bachelor's degree and/or limited experience in providing services and supports to an older population. In this model, DCCs were offered weekly in-person or telephonic supervision. DCCs reported strong satisfaction and benefit from having regular individual supervision with a manager. This allowed the DCCs to process the often emotionally-charged work with individuals and families, and helped continue their training and development through staffing of particular cases.

### Dementia Care Coordinators (DCCs)

The choice of DCCs will determine the experience of care coordination for individuals served and their care partners.

#### *Qualifications:*

- background in health, social work or nursing with experience in aging, medical or mental health.
- minimum of a bachelor's degree in a human services field
- at least two years of experience working in case management or social work, preferably with an older population
- advanced degree in social work, psychology or nursing preferred

#### *Skills:*

- knowledge of aging issues including the impact of illness and disability,
- knowledge of the impact of dementia on individuals and care partners,

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- ability to understand social, health and resource issues and their impact upon the lives and well-being of the older population
- understanding of casework principles, person-centered planning principles and consumer direction
- strong active listening skills,
- ability to build strong working relationships with individuals, caregivers, staff, volunteers, community agencies and the general public
- knowledge of Medicare and Medicaid and long-term care insurance desirable

A sample job description can be found in the *Materials* section.

### **Does the program fit your Agency's Service Delivery Culture?**

Work by the DCCs is comparable to that of a social worker embedded in a clinic or assessment center, although the DCCs work more intensively and remain engaged for a longer period with individuals and families. Contact with the individuals and families is regular and frequent, with monthly check-in calls, ad-hoc contact initiated by the individuals or families, and at least one home visit each year. In addition, DCCs should be available to attend the individual's appointments within the memory clinic or neurologist.

Home visits are typically not part of the repertoire of services offered by health systems, and illustrate an area where collaboration with a community partner with expertise in services utilizing home visits can be of value for training the DCCs. In this model, home visits were arranged shortly after the individual enrolled in the Program and were seen as an opportunity not only for the DCC to learn about the individual's and family's circumstances, but also as an opportunity to develop the strong rapport and trust with the individual and family that underlie the Care Coordination relationship going forward.

## Does the program fit your budget?

A sample budget for this program can be found in the *Materials* section.

The following items should be considered in any budget:

- Cost of hiring and training DCC
- Salary/fringe for each DCC hired (caseload target of 50-75 individuals per DCC)
- Cost of travel for home visits
- Cost of program manager's time
- Cost of equipment, office space, etc.
- Cost of marketing the program taking into account special characteristics of the populations served



# Planning

## Design the outreach campaign

This project relied on direct provider referrals, but marketing materials were produced including a rack card and flyer (these are reproduced in the *Materials* section). In addition, the program was announced via a press release and through the partners' social media. Additional presentations were made to potential referral sources such as Area Agencies on Aging, chapters of the Alzheimer's Association, and primary care providers.

### Lessons Learned

One of the goals of this program was to enroll individuals living alone with dementia. In practice, this population proved difficult to access unless they were already receiving follow-up care for cognitive impairment. If possible, agencies should undertake promotion efforts in alignment with local organizations or programs such as the Alzheimer's Association, congregate meals, community centers, or faith-based organizations.

## Data collection and management

Collecting useful data is essential for program evaluation. Data collection and management will depend on your agency's needs and established procedures. Measures used in this program are available in the appendix. Satisfaction surveys developed for this model and completed annually by both the individual and their care partner from the first enrollment anniversary onward are included in the *Materials* section.

### Databases/EHR/spreadsheets

DCCs should be trained on your agency's established documentation system and use this for all program-related documentation. DCCs in our model maintained

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comprehensive documentation of all interactions with the individual or those involved in their care in the individual's Electronic Health Record, and used Virginia's No Wrong Door Tool to document referrals to community-based services and supports.

### **Process indicators**

Process indicators provide early and ongoing indications of the program's strengths and weaknesses. These can include

- documenting marketing activities
- number of referrals received and their source
- referral outcomes (enrolled, uninterested, not eligible)
- reasons why individuals did not enroll
- attrition reasons and rates
- time spent providing direct and indirect services
- number of contacts with individuals and care partners

## **Staffing overview**

### **Average caseload per DCC**

Maximum caseload per DCC should be 75 individuals together with their primary caregiver, if any. The intensive, complex and time-consuming nature of effectively coordinating care for individuals living with dementia, providing education and support, and accessing community supports and services argue against a higher caseload.



**Lessons Learned**

The original plan for this model was to have 100 families per DCC. As recruitment progressed, it became clear that the DCCs would not be able to provide effective care coordination for this population. Additionally, the DCCs in this program were tasked with organizing and providing regular cycles of a ten-week education program (the Effective Strategies Program) for people with subjective cognitive impairment and caregivers that required a commitment of at least 8 hours per week. As such, the maximum caseload was set at 50, a level that is likely not to be cost-effective for replication purposes.

**Training****Site-specific Training**

DCCs should undergo standard orientation and training at the participating agency(ies). This should include an introduction to relevant programs provided by the agency, shadowing staff members as appropriate and any other standard orientation typically provided to agency employees. This would include training in HIPAA and process related to personal health information.

Training of the DCCs is undertaken jointly if possible. The included trainings have been identified as relevant and necessary for ensuring the DCCs are able to fully engage with the individuals living with dementia, utilize Virginia's statewide No Wrong Door (NWD) tool, and provide care coordination and management services such as options counseling to identify individual participants' goals and needs.

**Training in the model**

Prior to enrolling and working with individuals and families, DCCs were trained in multiple areas including:

- Alzheimer's disease and related disorders

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- Options Counseling
- Person-centered care
- Home visit safety
- Medicare and Medicaid
- Protocol administration
- Documentation procedures (use of No Wrong Door tool)

A list of the specific training materials can be found in the *Materials* section.

Other potentially useful trainings include:

- Motivational interviewing
- Caregiver support group facilitation
- Care transitions (Coleman model)
- Overview of Chronic Disease Self-Management Education program

# Practice

## Delivering Collaborative Care Coordination in your community

The Care Coordination Program (CCP) ensures the delivery of coordinated care by the DCCs to individuals living with dementia and their families. The CCP has several facets, including but not limited to:

- Options counseling
- Education on dementia
- Information and referrals to community-based organizations
- Behavioral symptom management training and expert consultation
- Eligibility assistance
- Assisting individuals with funding to attend an Adult Care Center
- Assist with coordination of medical care

The broad aim of the CCP is to help individuals living with dementia remain in their homes or in community settings for as long as possible.

### Options counseling

Having completed the training detailed above, the DCCs can offer counseling to individuals living with dementia and their caregivers, when applicable, on options regarding care and other issues ranging from meeting basic needs such as housing and nutrition to higher-level needs such as socialization activities and respite care. Through the collaborative, person-centered process of options counseling, the DCCs can help the individual and their caregivers to identify goals, and help direct them to the resources that will enable them to achieve these goals. A timeframe should be set for achieving each goal in order to provide a framework for the process. Sometimes developing a written action plan that enumerates the individual's identified goals, specifies who will be responsible for the required action, and in

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what time frame the indicated course of action is to be completed, can be helpful to ensure action is taken.

The DCC may assist with directly helping to achieve goals, but the overarching aim should be to help empower the individual and their caregivers to be their own advocates in achieving the identified goals within the agreed timeframe.

DCCs will understand that options counseling is a process, and should check in regularly (this could be weekly or even every few days at the start of the process) with the individual, to provide assistance and encouragement with helping the individual to achieve the identified goals.

### **Education on dementia**

The DCCs should make educational opportunities available to the individuals they are working with. DCCs will be able to provide information regarding the diagnosis, the different diseases that lead to dementia and strategies for managing activities of daily living (ADLs), and more generally living at home at both the current stage of their disease and as the disease progresses.

Key components of this education are to normalize the individual's experience and to help both the individual and the caregiver understand that what they are experiencing is a disease, not something that is due to any failure or lack of trying by the individual.

DCCs will understand and help reinforce individual and caregiver understanding that an early diagnosis can help facilitate the most appropriate treatment, if any, and enable the individual to be involved with planning for their own future.

### **Information and referrals to community-based organizations**

The DCCs will have a thorough knowledge of community-based organizations that can assist the individual with meeting the goals that were identified through options counseling. It must be recognized that not every request will require the full process

of options counseling. Participating individuals and/or their caregivers should be encouraged to contact the DCC with requests for information and/or referrals to organizations that will enable them to remain in the community.

## Preparation

DCCs should gather factsheets and other information covering subjects likely to be of interest and benefit to the individuals and care partners they work with. A list of resources available on the internet that can be easily accessed is also useful. These will be provided to the individual and/or care partner as needed, either as printed materials or as links via email. Suggested topics include:

- Financial and Legal Planning
- Home Safety
- Driving Safety
- Healthy Living
- Medical Issues
- Bathing
- Communication
- Caring for the Care Partner
- Behavioral Symptoms
- Wandering

Other useful resources such as the National Institute on Aging's *Caring for a Person with Alzheimer's Disease* should be kept on hand.

DCCs should attempt to obtain materials that are culturally relevant to the individuals they are serving. For example, materials in Spanish or those created for the LGBT population.

### Care Coordination Guide

Each enrolled individual should be provided with a binder containing a Care Coordination Guide. Using a binder enables families to keep paperwork relevant to their memory care such as After Visit Summaries, medication lists, appointment letters etc.

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The actual Care Coordination guide should at a minimum contain (a sample guide is in the *Materials* section):

- Contact details for their Care Coordinator
- A description of the Care Coordination Program,
- A description of the clinic or interdisciplinary team that will provide follow-up care and treatment for the individual,
- A checklist of subjects that the family should begin to think about such as advance planning, driving, and respite care options
- Contact information for the local Area Agency on Aging or Senior Services provider
- Contact information for the local chapter of the Alzheimer's Association and the 24/7 helpline
- Information on useful disease-specific websites
- Space to write in other useful supports or services

Resources will change so it is important that the DCC provide the most up-to-date publications and resources on a range of matters (e.g., understanding particular forms of dementia, home and safety issues, medical management issues, and caregiver issues).

DCC should source materials that are most relevant to people with dementia and their caregivers. Information on other resources available in the community should be sourced at the first instance from the local AAA or from Senior Navigator (Virginia Navigator). DCCs should become familiar with referral processes and eligibility requirements of local programs.

### **Intake**

In this model, the bulk of referrals to the program came directly from practitioners in UVA's Memory and Aging Care Clinic, a clinic specializing in the diagnosis, treatment and care of individuals with a neurodegenerative

disease. DCCs were housed within the Clinic, and were thus typically available to meet with families following a diagnostic appointment.

## Eligibility

For the purposes of this demonstration project, individuals were required to be residents of Virginia and have a recent diagnosis of Mild Cognitive Impairment or of a neurodegenerative disease such as Alzheimer's disease. This was intended to ensure a somewhat homogenous group of participants in terms of disease process. Eligibility for any program would depend on the requirements of the managing organization and are likely to revolve around what diagnoses are deemed appropriate (e.g., a diagnosis of a neurodegenerative condition excluding MCI), but should not be overly exclusive. Making the program available to all individuals living in the community who receive a diagnosis of Alzheimer's disease or a related disorder should be the goal.

### Lesson Learned

Individuals who were enrolled with a diagnosis of MCI tended to be less engaged with the program unless they transitioned to a diagnosis of Alzheimer's disease or a related disorder. Although there was some utility in having built trust and rapport already with this individual, and they may have been better prepared to receive their new diagnosis as a result, a referral to the clinic social worker rather than to the Care Coordination Program would likely have been a better use of the DCCs scarce time. Similarly, although some families remained engaged following a residential placement, the Care Coordinators ability to connect the individual and family with available resources was more limited; these needs may have been better met by the facility social worker and/or a long-term care ombudsman.

## **Enrollment**

Care coordinators should meet with potential participants as soon as is practicable after the diagnosis is received. Potential participants were typically referred to the program by members of the care team. In this program, DCCs often met with the family the same day, although some families preferred to have the DCC call them at a later date. On meeting the individual and caregivers, DCCs succinctly described the program and answered questions. While a few potential participants asked to have some information about the program that they could take with them to consider in their own time, the vast majority of individuals and families introduced to the program in person recognized the potential utility of having a care coordinator to help them navigate the complex web of services and supports. People were less likely to eventually enroll if they were introduced to the program later via telephone or email.

- Provide Care Coordination Guide: DCCs should review the Care Coordination Guide and ask whether there is any specific information that is not already included that they would like immediately (e.g., some information regarding a topic on the checklist). If there is, DCCs should add that information to the Care Coordination Guide before the individual leaves. Having a library of materials covering the subjects on the checklist will
- Schedule home visit

## **Home Visit/Assessment**

DCCs should arrange to visit the individual and their caregivers at their home as soon as is practicable following enrollment, but no later than six weeks from enrollment. The home visit provides the best opportunity for the DCC to build rapport and trust with the individual and caregivers. In return,



DCCs typically gain valuable insight into the individual's circumstances and potential needs. Any evaluation measures can also be completed at this time, and written consent can be acquired from the individual and/or caregiver to enable the DCC to make referrals on their behalf. The Virginia Authorization to Use and Exchange Information form, used by Departments of Social Services, Area Agencies on Aging, Community Services Boards and Centers for independent Living among others, was used in this program. To guide the overall conversation and gather relevant information, DCCs used the Virginia Uniform Assessment Instrument.

- Depending on the number of measures the enrolled individual and caregiver are asked to complete, the home visit can last from 1.5 to 3 hours, with two hours the norm.
- Follow-up home visits should be completed annually or more often if a significant change in the individual's or caregiver's circumstances has occurred.
- If the family refuses a home visit, the DCC should explain why a home visit can be beneficial for the individual and caregiver. If the family still refuses, the DCC may meet the individual and caregiver in a place of their choosing to complete the evaluation measures and have a fuller discussion about the individual and caregiver goals and needs.
- Home visits typically generate several hours of follow-up work and documentation, so DCCs should avoid scheduling more than two in any week.
- Times available for home visits should follow agency guidelines (for example, DCCs in this program were not permitted to schedule home visits at the weekend or after 5pm). However, when practicable, DCCs should try to accommodate caregivers who are juggling other commitments such as work or childcare.

## Monthly Contact

DCCs should plan on contacting every individual or caregiver on their caseload each month that they are enrolled in care coordination. While the call is not scripted, a checklist of topics to ask about will be helpful. Typically, the DCC should ask about any changes noticeable over the past month, paying particular attention to:

- falls
- medication compliance
- changes in memory
- sleep patterns
- appetite
- exercise
- socialization

When appropriate, the DCC should consult with the interdisciplinary care team and/or make a follow-up appointment for the individual at the memory assessment center. Other outcomes would be to schedule an appointment with the individual's primary care physician or provide referrals for other services or supports and follow up as necessary.

## Attendance at memory/neurology appointments

Memory care appointments can be lengthy and stressful for both the individual living with dementia and their care partner/s. Typically practitioners will provide a large amount of information and ask many questions, and this can be overwhelming. Having the DCC, with whom the individual and care partner has built rapport and trust, participate in the

appointment can help alleviate some of the stress and reduce the burden on the individuals and care partner to understand and remember all that is said.

DCCs should plan on attending all appointments at the memory assessment center with enrolled individuals. In addition to helping support and advocate for the individual and caregiver, attending appointments helps keep the DCC aligned with the care team. The DCC can help ensure that the individual and caregiver have a full understanding of the process, paying special attention to any changes in treatment or recommendations from the care team. If the individual and caregiver are overwhelmed, the DCC can review any pertinent information with them at a later date.

In this model, DCCs typically reviewed the After-Visit Summary with enrolled individuals and their caregiver at the end of the appointment. Having been present at appointments, DCCs were able to answer any follow-up questions from individuals or caregivers. Although this part of the program was not explicitly evaluated, anecdotal reports from individuals and caregivers suggest this was an important and valued service.

## Disengagement

Disengagement from the program may be initiated by either the individual and caregiver or the DCC. In the pilot program, disengagement

- occurred automatically if the enrolled individual moved out of state
- was deemed to have occurred if the DCC was unable to make contact with the individual or family over three monthly calls and a follow-up letter prompted no response
- could be initiated by the individual or caregiver for any reason.

If the individual or family informed the DCC that they would like to withdraw from the program, the DCC should try to find out the reason,

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attempt to address the reason if possible, and offer to resume care coordination services at any point in the future.

### Evaluation

Program evaluation is an integral part of the process of ensuring that the service provided is useful and beneficial to the individual and family. This protocol required that measures be completed shortly after enrollment (typically at the first home visit), and annually thereafter. Measures examined satisfaction with the program, mood, behavioral symptoms, ability to perform activities of daily living, quality of life and caregiving burden and self-care.

This program used the following measures (all measures available in the *Materials* section):

- Care Coordination Program Satisfaction Survey (Participant)\*
- Care Coordination Program Satisfaction Survey (Care Partner)\*
- Center for Epidemiologic Studies in Depression Scale Revised (CESD-R)
- Neuropsychiatric Inventory Short Form (NPI-Q)
- Lawton Instrument Activities of Daily Living (IADL) Scale
- Katz Index of Independence in Activities of Daily Living
- Quality of Life- Alzheimer's Disease (QOL-AD)
- Revised Memory and Behavior Checklist
- Stanford Health Care Utilization Questionnaire
- Shortened Zarit Revised Burden Interview (Care partner only)
- Caregiver Well-Being Scale (Care partner only)

\*Measures created for this program

# Materials

Materials needed to replicate the Collaborative Coordinated Care model described in this manual are included here:

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Materials F. Satisfaction Survey for Individuals Living with Dementia and Caregivers.....	58
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Materials A. Sample Job Description and Qualifications for Dementia Care  
Coordinator

## Sample job description, qualifications for Dementia Care Coordinator (DCC)

**Education:** BA degree required and minimum two years of social work or case management experience in the field of human services. Advanced degree in social work, psychology or nursing preferred.

**Knowledge:** Knowledge of aging issues including impact of illness and disability. Knowledge of the impact of dementia for individuals and their caregivers. Ability to understand current economic, social, health and resource issues and their impact upon the life and wellbeing of the elderly population. Knowledge of casework principles. Knowledge of individual, group, and organizational behaviors. Knowledge of person-centered planning principles and consumer direction.

**Skills & Abilities:** Ability to communicate effectively orally and in writing. Ability to work autonomously and as a team member, and to establish and sustain interpersonal relationships. Ability to understand and interpret local and governmental policies and procedures as applied to service provision. Ability to build excellent working relationships with individuals, caregivers, staff, volunteers, community agencies and the general public. Comfort working in a healthcare setting. Ability to adapt to changes in work roles and expectations in order to accomplish client/depart. goals. Valid driver's license and ability to travel to the extent of designated counties and other areas for delivery of services, meetings, and trainings. Ability to use computer to access the Internet, use applications including MS Office Word, Excel and Outlook, and web-based data management systems to document services.

**Physical Capacity Requirement:** Employee is expected to be able to routinely lift 10 pounds, climb stairs, sit, stand, stoop/bend, reach, perform repetitive hand motions, fingering, grasping, and walking. It also requires talking: expressing or exchanging ideas by means of the spoken word; those activities where detailed or important spoken instructions must be conveyed to other individuals accurately, loudly, or quickly; and hearing: perceiving the nature of sounds at normal speaking levels with or without correction, and having the ability to receive detailed information through oral communication, and making fine discriminations in sound. This work is described as sedentary to light duty.

Materials B. Program Sample Annual Budget



## Program Sample Annual Budget

<u>Item</u>	<u>Amount</u>
Salary/fringe 2 care coordinators: (\$50,000/yr)	\$143,000
Salary/fringe 1 half-time supervisor:	\$43,000
Supplies/materials/printing costs:	\$3,000 (includes promotional materials)
Postage:	\$300
Training:	\$500
Equipment/computer:	\$2,000
Mileage reimbursement:	\$6,000 (depends on size service area)
Administration/support costs:	\$15,000
<b>Total estimated annual budget:</b>	<b>\$212,800</b>

## Materials C. Sample Marketing Materials

# Care Coordination Program

A research study for dementia



The Care Coordination Program is offered through the University of Virginia's Memory and Aging Care Clinic (MACC) in partnership with the Jefferson Area Board for Aging (JABA). The goal is to improve the quality of care for participants with Mild Cognitive Impairment (MCI) or dementia living in Virginia. Participants are linked with a care coordinator who provides individualized long-term support services. Care coordinators aim to provide emotional support, education about memory loss and dementia, and access to UVA and community resources. Support is also offered to care partners.

**434-817-5222**  
**[www.jabacares.org](http://www.jabacares.org)**



## Care Coordination Program

### Who is Eligible?

- Any person living in Virginia who has received a diagnosis of Mild Cognitive Impairment (MCI) or dementia in the previous six months.
- Any care partner of an individual enrolled in the program

### What the Program Aims to Offer

- Coordination of health care services
- Education about memory loss and dementia
- Emotional support
- Coping strategies
- Assistance with long-term care planning

### Possible Benefits include

- Easier coordination of clinical care
- Better understanding of memory loss and dementia
- Reduced stress
- Improved mood
- Improved quality of life

### Contact Us

If you have questions about the Care Coordination Program, please call

This study is part of the Virginia Dementia Specialized Supportive Services Project and is funded by the Administration for Community Living (ACL) through the Virginia Department of Aging and Rehabilitative Services (DARS).

434-817-5222  
[www.jabacares.org](http://www.jabacares.org)





## Care Coordination Program

The University of Virginia Memory and Aging Care Clinic (MACC) is excited to host a pilot program for patients who have been recently diagnosed with cognitive deficits or dementia.

This program provides patients and their care partners with a Care Coordinator. Patients will be provided support and services that fit their individual needs.

The goal of this program is to improve the quality of memory care.

This program is funded by the Administration for Community Living.

The potential benefits of participating in this program will be evaluated.

### What the program offers:

- Coordination of health care services
- Education about memory loss
- Emotional support
- Coping strategies
- Assistance with long-term care planning

### Possible benefits include:

- Easier coordination of clinical care
- Better understanding of memory loss
- Reduced stress
- Improved mood
- Improved quality of life

**To determine if you are eligible or to learn more, call or email**

Materials D. List of Materials Used for Dementia Care Coordinator  
Training

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**List of training webinars and materials for Dementia Care Coordinators**

The list is presented in the order recommended for the Dementia Care Coordinator to review, beginning with general dementia knowledge, then approach to care when working with patients (i.e. Options Counseling), and finally resources for patients, caregivers, and professionals.

TOPIC	SOURCE
<b>DEMMENTIA KNOWLEDGE</b>	
<b>Virginia Alzheimer's Commission AlzPossible Initiative</b>	
<b>BASICS</b>	
<i>Overview of Dementia</i>	<a href="http://alzpossible.org/alzheimers-disease-and-related-dementia-the-basics/">http://alzpossible.org/alzheimers-disease-and-related-dementia-the-basics/</a>
<i>General Dementia Knowledge</i>	<a href="http://alzpossible.org/general-dementia-knowledge/">http://alzpossible.org/general-dementia-knowledge/</a>
<b>Alzheimer's Association: Training and Education Center</b>	
<i>The Basics: Memory Loss, Dementia and Alzheimer's Disease</i>	<a href="http://training.alz.org/products/1016/the-basics-memory-loss-dementia-and-alzheimers-disease">http://training.alz.org/products/1016/the-basics-memory-loss-dementia-and-alzheimers-disease</a>
<i>Know the 10 Signs: Early Detection Matters</i>	<a href="http://training.alz.org/products/1014/know-the-10-signs-early-detection-matters">http://training.alz.org/products/1014/know-the-10-signs-early-detection-matters</a>
<b>Virginia Alzheimer's Commission AlzPossible Initiative</b>	
<b>BASICS</b>	
<i>Differentiating Depression and Dementia</i>	<a href="http://alzpossible.org/differentiating-depression-and-dementia/">http://alzpossible.org/differentiating-depression-and-dementia/</a>
<i>Vascular and Mixed Dementias</i>	<a href="http://alzpossible.org/vascular-and-mixed-dementias/">http://alzpossible.org/vascular-and-mixed-dementias/</a>
<i>Dementia with Lewy Bodies</i>	<a href="http://alzpossible.org/lewy-body-dementia/">http://alzpossible.org/lewy-body-dementia/</a>
<i>Parkinson's Disease Dementia</i>	<a href="http://alzpossible.org/parkinsons-disease-dementia/">http://alzpossible.org/parkinsons-disease-dementia/</a>

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<b>OPTIONS COUNSELING</b>	
<b>Options Counseling (OC) Training</b>	
<i>Module 1</i>	<a href="https://vcuppd.github.io/ocss-customer-site/#top">https://vcuppd.github.io/ocss-customer-site/#top</a>
<i>Module 2</i>	<a href="https://vcuppd.github.io/ocss-customer-site/#top">https://vcuppd.github.io/ocss-customer-site/#top</a>
<i>Module 3</i>	<a href="https://vcuppd.github.io/ocss-customer-site/#top">https://vcuppd.github.io/ocss-customer-site/#top</a>
<i>Module 4</i>	<a href="https://vcuppd.github.io/ocss-customer-site/#top">https://vcuppd.github.io/ocss-customer-site/#top</a>
<i>Annual Options Counseling Refresher</i>	<a href="https://vcuppd.github.io/ocss-customer-site/#top">https://vcuppd.github.io/ocss-customer-site/#top</a>
<i>Dementia Capability for Options Counselors</i>	<a href="https://www.surveymonkey.com/r/DARSdementiatrainingOC">https://www.surveymonkey.com/r/DARSdementiatrainingOC</a>
<i>Person Centered Planning: Structures for Options Counselors</i>	<a href="https://slideplayer.com/slide/10531340/">https://slideplayer.com/slide/10531340/</a>
<b>Virginia Alzheimer's Commission AlzPossible Initiative</b>	
<b>Individual: Person-centered Principles</b>	
<i>Culture Change</i>	<a href="http://alzpossible.org/culture-change/">http://alzpossible.org/culture-change/</a>
<i>Person Centered Care and Culture Change in an Adult Day Setting</i>	<a href="http://alzpossible.org/person-centered-care-and-culture-change-in-an-adult-day-setting/">http://alzpossible.org/person-centered-care-and-culture-change-in-an-adult-day-setting/</a>
<i>Aging in Place: A Hallmark of Person-Centered Care</i>	<a href="http://alzpossible.org/aging-in-place/">http://alzpossible.org/aging-in-place/</a>
<b>Additional resources</b>	
Pioneer Network	<a href="http://www.pioneernetwork.net/">http://www.pioneernetwork.net/</a>



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RESOURCES FOR INDIVIDUALS LIVING WITH DEMENTIA	
<i>Living with Alzheimer's for People with Alzheimer's</i>	<a href="http://training.alz.org/products/1018/living-with-alzheimers-for-people-with-alzheimers">http://training.alz.org/products/1018/living-with-alzheimers-for-people-with-alzheimers</a>
<i>Living with Alzheimer's for Younger-Onset Alzheimer's</i>	<a href="http://training.alz.org/products/1025/living-with-alzheimers-for-younger-onset-alzheimers">http://training.alz.org/products/1025/living-with-alzheimers-for-younger-onset-alzheimers</a>
<i>Healthy Living for your Brain and Body: Tips from the Latest Research</i>	<a href="http://training.alz.org/products/4038/healthy-living-for-your-brain-and-body-tips-from-the-latest-research">http://training.alz.org/products/4038/healthy-living-for-your-brain-and-body-tips-from-the-latest-research</a>
<b>Virginia Alzheimer's Commission AlzPossible Initiative</b>	
<b>Nutrition and Exercise: Heart Disease, Stroke, Nutrition, Exercise</b>	
<i>Diet and Exercise - Living Well to Care for and Preserve Cognition</i>	<a href="http://alzpossible.org/healthy-diet-and-exercise/">http://alzpossible.org/healthy-diet-and-exercise/</a>
<i>Falls and the Individual with Alzheimer's Disease</i>	<a href="http://alzpossible.org/falls/">http://alzpossible.org/falls/</a>
<b>Communication: Communication Tools, Challenges, Opportunities</b>	
<i>Effective Communication with Physicians (2009)</i>	<a href="http://alzpossible.org/communication-with-your-doctor-2/">http://alzpossible.org/communication-with-your-doctor-2/</a>
<b>Additional resources</b>	
Alzheimer Society of Canada	<a href="http://alzheimercanada.ca/en/Home/We-can-help/Resources/For-health-care-professionals/culture-change-towards-person-centred-care">http://alzheimercanada.ca/en/Home/We-can-help/Resources/For-health-care-professionals/culture-change-towards-person-centred-care</a>
Alzheimer's Association	<a href="http://www.alz.org">www.alz.org</a>
Senior Navigator	<a href="http://www.seniornavigator.org/">http://www.seniornavigator.org/</a>
Riverside: Lifelong Health: Senior Care Navigation	<a href="https://www.riversideonline.com/services/seniors/senior-care-navigation.cfm">https://www.riversideonline.com/services/seniors/senior-care-navigation.cfm</a>
National Institute on Aging	<a href="https://www.nia.nih.gov/health">https://www.nia.nih.gov/health</a>
Administration for Community Living: Administration on Aging	<a href="https://www.acl.gov/aging-and-disability-in-america">https://www.acl.gov/aging-and-disability-in-america</a>
National Council on Aging: Center for Healthy Aging	<a href="https://www.ncoa.org/center-for-healthy-aging/">https://www.ncoa.org/center-for-healthy-aging/</a>

RESOURCES FOR CAREGIVERS	
<b>Alzheimer's Association: Training and Education Center</b>	
<i>Living with Alzheimer's: For Caregivers - Early Stage</i>	<a href="http://training.alz.org/products/1019/living-with-alzheimers-for-caregivers-early-stage">http://training.alz.org/products/1019/living-with-alzheimers-for-caregivers-early-stage</a>
<i>Living with Alzheimer's: For Caregivers - Middle Stage</i>	<a href="http://training.alz.org/products/1023/living-with-alzheimers-for-caregivers-middle-stage">http://training.alz.org/products/1023/living-with-alzheimers-for-caregivers-middle-stage</a>
<i>Living with Alzheimer's: For Caregivers - Late Stage</i>	<a href="http://training.alz.org/products/1024/living-with-alzheimers-for-caregivers-late-stage">http://training.alz.org/products/1024/living-with-alzheimers-for-caregivers-late-stage</a>
<i>Effective Communication Strategies</i>	<a href="http://training.alz.org/products/4036/effective-communication-strategies">http://training.alz.org/products/4036/effective-communication-strategies</a>
<i>Understanding and Responding to Dementia-Related Behavior</i>	<a href="http://training.alz.org/products/4037/understanding-and-responding-to-dementia-related-behavior">http://training.alz.org/products/4037/understanding-and-responding-to-dementia-related-behavior</a>
<b>Virginia Alzheimer's Commission AlzPossible Initiative</b>	
<b>Family: Role and Influence of the Family</b>	
<i>Caring for a Spouse with Mild Cognitive Impairment: Daily Challenges...</i>	<a href="http://alzpossible.org/caring-for-a-spouse-with-mild-cognitive-impairment-daily-challenges-marital-relations-and-physiological-indicators-of-health/">http://alzpossible.org/caring-for-a-spouse-with-mild-cognitive-impairment-daily-challenges-marital-relations-and-physiological-indicators-of-health/</a>
<i>Telephone Support Program for Caregivers: A Pilot Project</i>	<a href="http://alzpossible.org/telephone-support-program-for-caregivers-a-pilot-project/">http://alzpossible.org/telephone-support-program-for-caregivers-a-pilot-project/</a>
<i>End-of-Life Care Experiences for Individuals with Alzheimer's Disease...</i>	<a href="http://alzpossible.org/end-of-life-care-experiences/">http://alzpossible.org/end-of-life-care-experiences/</a>
<i>Family Quality of Life in Dementia: Key Concepts in Dementia Care</i>	<a href="http://alzpossible.org/family-quality-of-life-in-dementia-key-concepts-in-dementia-care/">http://alzpossible.org/family-quality-of-life-in-dementia-key-concepts-in-dementia-care/</a>
<i>Compassion Fatigue</i>	<a href="http://alzpossible.org/compassion-fatigue-2/">http://alzpossible.org/compassion-fatigue-2/</a>
<b>Additional resources</b>	
Alzheimer's Association: Alzheimer's & Dementia Caregiver Center	<a href="https://www.alz.org/help-support/resources/care-training-resources">https://www.alz.org/help-support/resources/care-training-resources</a>
Senior Navigator	<a href="http://www.seniornavigator.org/">http://www.seniornavigator.org/</a>
Riverside: Lifelong Health	<a href="http://www.riversideonline.com/services/seniors/">http://www.riversideonline.com/services/seniors/</a>
National Institute on Aging: <i>Managing Personality and Behavior Changes</i>	<a href="https://www.nia.nih.gov/health/managing-personality-and-behavior-changes-alzheimers">https://www.nia.nih.gov/health/managing-personality-and-behavior-changes-alzheimers</a>
Administration for Community Living: Administration on Aging	<a href="https://www.acl.gov/aging-and-disability-in-america">https://www.acl.gov/aging-and-disability-in-america</a>

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<p><b>ADDITIONAL RESOURCES FOR PROFESSIONALS</b></p>	
<p>Virginia Alzheimer's Commission AlzPossible Initiative</p>	
<p><b>Professionals: Concrete Challenges and Solutions for Professionals...</b></p>	
<p>Geriatric Care Manager</p>	<p><a href="http://alzpossible.org/geriatric-care-manager/">http://alzpossible.org/geriatric-care-manager/</a></p>
<p>Behavioral Disturbances of Dementia: Interventions to Reduce the...</p>	<p><a href="http://www.worldeventsforum.net/mhathi/webinars/behavioral-disturbances-of-dementia-interventions-to-reduce-the-use-of-psychootropic-medications/">http://www.worldeventsforum.net/mhathi/webinars/behavioral-disturbances-of-dementia-interventions-to-reduce-the-use-of-psychootropic-medications/</a></p>
<p>Medications: Friend or Foe? The Role of Medications in both Causing...</p>	<p><a href="http://www.worldeventsforum.net/mhathi/medications/">http://www.worldeventsforum.net/mhathi/medications/</a></p>
<p>The Temporary Detention Order (TDO) Process: What Staff Need to...</p>	<p><a href="http://www.worldeventsforum.net/mhathi/the-temporary-detention-order-tdo-process-what-staff-need-to-know/">http://www.worldeventsforum.net/mhathi/the-temporary-detention-order-tdo-process-what-staff-need-to-know/</a></p>
<p>The Temporary Detention Order (TDO) Process: Part II</p>	<p><a href="http://www.worldeventsforum.net/mhathi/the-temporary-detention-order-tdo-process-part-ii/">http://www.worldeventsforum.net/mhathi/the-temporary-detention-order-tdo-process-part-ii/</a></p>
<p>Personality Disorders and Aging</p>	<p><a href="http://www.worldeventsforum.net/mhathi/personality-disorders-and-aging/">http://www.worldeventsforum.net/mhathi/personality-disorders-and-aging/</a></p>
<p>Best Practices for Medication Management of Dementia-related Behaviors</p>	<p><a href="http://www.worldeventsforum.net/mhathi/best-practices-for-medication-management-of-dementia-related-behaviors/">http://www.worldeventsforum.net/mhathi/best-practices-for-medication-management-of-dementia-related-behaviors/</a></p>
<p>The Use of Technology to Engage Persons with Dementia</p>	<p><a href="http://www.worldeventsforum.net/mhathi/the-use-of-technology-to-engage-persons-with-dementia/">http://www.worldeventsforum.net/mhathi/the-use-of-technology-to-engage-persons-with-dementia/</a></p>
<p>Advance Care Planning for Dementia and Serious Mental Illness</p>	<p><a href="http://www.worldeventsforum.net/mhathi/advance-care-planning-for-dementia-and-serious-mental-illness/">http://www.worldeventsforum.net/mhathi/advance-care-planning-for-dementia-and-serious-mental-illness/</a></p>
<p><b>Individual: Person-centered Principles</b></p>	
<p>Connections</p>	<p><a href="http://alzpossible.org/connections/">http://alzpossible.org/connections/</a></p>
<p><b>Communication: Communication Tools, Challenges, Opportunities</b></p>	<p><a href="http://alzpossible.org/webinars-2/">http://alzpossible.org/webinars-2/</a></p>
<p>Environment &amp; Communication Assessment Toolkit for Dementia...</p>	<p><a href="http://alzpossible.org/environment-communication-assessment-toolkit-for-dementia-care/">http://alzpossible.org/environment-communication-assessment-toolkit-for-dementia-care/</a></p>
<p>Effective Communication with Physicians (2007)</p>	<p><a href="http://alzpossible.org/communication-with-your-doctor-1/">http://alzpossible.org/communication-with-your-doctor-1/</a></p>
<p>The Triad in Dementia Care: Methods for Strengthening the...</p>	<p><a href="http://alzpossible.org/the-triad-in-dementia-care-methods-for-strengthening-the-partnership/">http://alzpossible.org/the-triad-in-dementia-care-methods-for-strengthening-the-partnership/</a></p>

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<b>ADDITIONAL RESOURCES FOR PROFESSIONALS (con't)</b>	
<b>Alzheimer's Association: Training and Education Center</b>	
<i>Dementia Conversations: Driving, Doctor Visits, Legal &amp; Financial...</i>	<a href="http://training.alz.org/products/4031/dementia-conversations-driving-doctor-visits-legal-financial-planning">http://training.alz.org/products/4031/dementia-conversations-driving-doctor-visits-legal-financial-planning</a>
<i>Legal and Financial Planning for Alzheimer's Disease</i>	<a href="http://training.alz.org/products/1017/legal-and-financial-planning-for-alzheimers-disease">http://training.alz.org/products/1017/legal-and-financial-planning-for-alzheimers-disease</a>
<b>Virginia Alzheimer's Commission AlzPossible Initiative</b>	
<b><i>Legal: What You Always Wanted to Know but Were Afraid to Ask</i></b>	
<i>Guardianships and Conservatorships</i>	<a href="http://alzpossible.org/guardianships-and-conservatorships/">http://alzpossible.org/guardianships-and-conservatorships/</a>
<i>Advance Medical Directives</i>	<a href="http://alzpossible.org/advance-medical-directives/">http://alzpossible.org/advance-medical-directives/</a>
<i>Power of Attorney</i>	<a href="http://alzpossible.org/power-of-attorney/">http://alzpossible.org/power-of-attorney/</a>
<i>Medicare</i>	<a href="http://alzpossible.org/medicare/">http://alzpossible.org/medicare/</a>
<i>Medicaid -- An Introduction</i>	<a href="http://alzpossible.org/medicaid-a-basic-guide/">http://alzpossible.org/medicaid-a-basic-guide/</a>
<i>Elder Abuse and Domestic Violence in Later Life: What Staff Need to...</i>	<a href="http://alzpossible.org/elder-abuse-and-domestic-violence-in-later-life-innovative-new-resources-for-the-community/">http://alzpossible.org/elder-abuse-and-domestic-violence-in-later-life-innovative-new-resources-for-the-community/</a>
<i>Elder Abuse, Neglect, and Exploitation</i>	<a href="http://alzpossible.org/elder-abuse-neglect-and-exploitation/">http://alzpossible.org/elder-abuse-neglect-and-exploitation/</a>
<i>Compassion Fatigue</i>	<a href="http://alzpossible.org/compassion-fatigue-2/">http://alzpossible.org/compassion-fatigue-2/</a>
<b>Virginia Department of Social Services: Mandated Reporters...</b>	<a href="http://www.dss.virginia.gov/abuse/mr.cgi">http://www.dss.virginia.gov/abuse/mr.cgi</a>
<i>Mandated Reporters: Recognizing and Reporting Abuse, Neglect...</i>	<a href="http://www.dss.virginia.gov/family/as/mandated_reporters/ads5055/index.html">http://www.dss.virginia.gov/family/as/mandated_reporters/ads5055/index.html</a>
<b>Rosalynn Carter Institute for Caring: Resources</b>	
<i>Alzheimer's Association Dementia Training for AAA Case Managers</i>	<a href="http://www.rosalynncarter.org/gdas_trainings/">http://www.rosalynncarter.org/gdas_trainings/</a>
<i>Dementia Capability Webinars</i>	<a href="http://www.rosalynncarter.org/AAA%20Dementia%20Training/">http://www.rosalynncarter.org/AAA%20Dementia%20Training/</a>
	<a href="http://www.rosalynncarter.org/gdas_trainings/">http://www.rosalynncarter.org/gdas_trainings/</a>



## Materials E. Measures Used for Individual Living with Dementia and Caregiver

This contains the cover pages for the packet of measures used to evaluate program outcomes for the pilot program and a list of the measures used and where to locate them. Measures were administered at enrollment (or at the initial home visit) and at annual follow-ups.

## *Welcome Message: Participant Packet*

Welcome to the **Care Coordination Program**. This program is a pilot to improve the coordination and delivery of memory care in Virginia by the Jefferson Area Board of Aging (JABA) and the University of Virginia's Memory and Aging Care Clinic (MACC) in Charlottesville. It is funded by the Administration for Community Living through the Virginia Department of Aging and Rehabilitative Services (DARS).

Before beginning the program, we ask that you complete the following questionnaires. Please complete all pages, and answer as honestly as you can. If you have any questions, please ask your Care Coordinator.

Please carefully read the instructions at the top of each page and answer each question based on your own experience.

All your answers to the following questions will be kept confidential. Your responses will only be reported in aggregate together with those of all other participants; your individual responses will **not** be linked with any identifiable personal information.

*Welcome Message: Care Partner Packet*

Welcome to the **Care Coordination Program**. This program is a pilot to improve the coordination and delivery of memory care in Virginia by the Jefferson Area Board of Aging (JABA) and the University of Virginia's Memory and Aging Care Clinic (MACC) in Charlottesville. It is funded by the Administration for Community Living through the Virginia Department of Aging and Rehabilitative Services (DARS).

Before beginning the program, we ask that you complete the following questionnaires. Please complete all pages, and answer as honestly as you can. If you have any questions, please ask your Care Coordinator.

Some questions ask about the care partner's own experience, others ask about the care partner's observations of the person they are caring for, and some ask about the person receiving care. Please carefully read the instructions at the top of each page and answer each question.

All your answers to the following questions will be kept confidential. Your responses will only be reported in aggregate together with those of all other participants; your individual responses will **not** be linked with any identifiable personal information.



List of measures used:

Measures were administered to both individuals living with dementia and to caregivers unless otherwise noted.

For the Stanford Health Care Utilization, caregivers were asked to respond twice, once reporting on the individual living with dementia and once as a self-report.

Domain	Measure	Items	See for more information
Depression	Center for Epidemiologic Studies Depression Scale - Revised (CESD-R) (Eaton et al.)	20	<a href="https://www.albany.edu/~me888931/CESD-R.pdf">https://www.albany.edu/~me888931/CESD-R.pdf</a>
Behavioral symptoms	Neuropsychiatric Inventory, Short Form (NPI-Q) (Cummings)	12	<a href="http://npitest.net/">http://npitest.net/</a>
ADL/IADL	Instrumental Activities of Daily Living Scale (IADL) (Lawton & Brody)	8	<a href="https://www.abramsoncenter.org/media/1197/instrumental-activities-of-daily-living.pdf">https://www.abramsoncenter.org/media/1197/instrumental-activities-of-daily-living.pdf</a>
ADL/IADL	Index of Independence in Activities of Daily Living (ADL) (Katz)	6	<a href="http://medicalcriteria.com/web/gerik/">http://medicalcriteria.com/web/gerik/</a>
Quality of Life	Quality of Life in Alzheimer's Disease (QOL-AD) (Logsdon et al.)	13	<a href="https://eprovide.mapi-trust.org/instruments/quality-of-life-in-alzheimer-s-disease/rc_qol-ad">https://eprovide.mapi-trust.org/instruments/quality-of-life-in-alzheimer-s-disease/rc_qol-ad</a>
Behavioral symptoms	Revised Memory and Behavior Problems Checklist (RMBPC) (Teri et al.)	24	<a href="http://www.alz.org/national/documents/C_ASSESS-RevisedMemoryandBehCheck.pdf">http://www.alz.org/national/documents/C_ASSESS-RevisedMemoryandBehCheck.pdf</a>
Health Care Utilization	Stanford Health Care Utilization Questionnaire (Ritter et al.)	4	<a href="https://www.selfmanagementresource.com/docs/pdfs/English_-_health_care_utilization.pdf">https://www.selfmanagementresource.com/docs/pdfs/English_-_health_care_utilization.pdf</a>
The following measures were administered to caregivers only:			
Caregiver Burden	Shortened Zarit Revised Burden Interview (Bédard et al.)	4	<a href="http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.499.8567&amp;rep=rep1&amp;type=pdf">http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.499.8567&amp;rep=rep1&amp;type=pdf</a>
Unmet Needs	Caregiver Well-Being Scale (short)	14	<a href="https://nadrc.acl.gov/node/141">https://nadrc.acl.gov/node/141</a>

## Materials F. Satisfaction Survey for Individuals Living with Dementia and Caregivers

The Satisfaction Surveys are completed by enrolled individuals and caregivers at annual follow-ups.

## Care Coordination Program –Participant Satisfaction Survey

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Please circle the answer that best describes how you feel.

1. Overall, having a Dementia Care Manager was beneficial	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
2. Overall, my Dementia Care Manager met my needs in a timely manner	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
3. I was happy with the coordination of care I received from my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
4. My Dementia Care Manager helped me make my own decisions	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
5. My Dementia Care Manager was an important part of my treatment team	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
6. Having a Dementia Care Manager improved my clinical care/treatment	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
7. My health is better because I had a Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
8. Having a Dementia Care Manager helped me adjust to my diagnosis	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
9. My Dementia Care Manager was emotionally supportive	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

## Care Coordination Program - Satisfaction Survey

10. My Dementia Care Manager had a positive impact on my mood	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
11. I have less stress because of my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
12. I learned valuable coping skills from my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
13. I learned valuable information about memory loss and dementia from my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
14. My Dementia Care Manager provided me access to community resources	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
15. I increased my participation in activities due to my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
16. I have more support from family/friends due to my Dementia Care Coordinator	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
17. I am better prepared for the future because of my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
18. My Dementia Care Manager taught me valuable information about legal issues (Health insurance, Power of Attorney, Medical Directive, etc.)	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
19. I changed my living environment because I had a Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
20. I would recommend my Dementia Care Manager to others	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

## Care Coordination Program – Caregiver Satisfaction Survey

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Please circle the answer that best describes how you feel.

1. Overall, having a Dementia Care Manager was beneficial	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
2. Overall, my Dementia Care Manager met my needs in a timely manner	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
3. I was happy with the coordination of care received from my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
4. My Dementia Care Manager helped me make my own decisions	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
5. My Dementia Care Manager was an important part of my treatment team	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
6. Having a Dementia Care Manager improved clinical care/treatment	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
7. My health is better because I had a Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
8. Having a Dementia Care Manager helped me adjust to the diagnosis	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
9. My Dementia Care Manager was emotionally supportive	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

## Care Coordination Program - Satisfaction Survey

10. My Dementia Care Manager had a positive impact on my mood	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
11. I have less stress because of my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
12. I learned valuable coping skills from my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
13. I learned valuable information about memory loss and dementia from my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
14. My Dementia Care Manager provided me access to community resources	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
15. I increased my participation in activities due to my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
16. I have more support from family/friends due to my Dementia Care Coordinator	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
17. I am better prepared for the future because of my Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
18. My Dementia Care Manager taught me valuable information about legal issues (Health insurance, Power of Attorney, Medical Directive, etc.)	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
19. I changed my living environment because I had a Dementia Care Manager	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
20. I would recommend my Dementia Care Manager to others	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree



## Materials G. Sample Care Coordination Guide

The Care Coordination Guide is provided to participants on enrollment, preferably contained in a binder where all materials related to the participant's memory care can be kept.



# Care Coordination Guide

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For Individuals Living with MCI or Dementia and  
their Care Partners

# Care Coordination Guide

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# Care Coordination Guide

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## 1. Welcome Letter

Dear **Mr./Mrs./Ms.**,

Welcome to the Memory and Aging Care Clinic, otherwise known as MACC. It is my pleasure to introduce myself to you as your care coordinator.

The care coordinator serves to provide individuals with a new diagnosis of mild cognitive impairment (MCI) or dementia, and their care partners, knowledge of the disorder and appropriate supports.

For some, getting a diagnosis can feel like the end of one's journey in life. But this can be the beginning of a new journey, filled with meaning and beauty. As you decide what you want your life to look like in the days ahead, I would be happy to support your wishes and preferences. I am also here to help you think about the things that will be important in time, such as your safety and overall well-being.

It is important to know that I am here to support your decisions, and I look forward to working with you and your care partner(s) from this point forward. I am providing you this binder with materials. You can take it home and we can go through it together.

Please remember I am here to help you, contact me. You can reach me through MyChart or call me at **434-XXX-XXXX**.

Sincerely,

**Care Coordinator**



### 2. Introduction to Mild Cognitive Impairment (MCI) and Dementia

#### **What is Memory Decline and Dementia?**

Mild memory decline is a normal part of aging. Normal age-related memory decline does not indicate a disease process. However, greater-than-expected decline significantly affects daily life and can indicate a dementia such as Alzheimer's disease.

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. Dementia can include problems with memory loss, thinking speed, mental agility, language, understanding and judgment. Dementia does not imply a cause or a specific disease. As such, it is not by itself a diagnosis. You can think of the term 'dementia' as an umbrella term that is caused by many different processes, some of which are treatable and some of which are not.

In the United States, more than 7 million people live with some form of dementia. Alzheimer's disease is the most common cause of dementia. Roughly 70% of people with dementia have Alzheimer's disease. About one out of every twenty people over the age of 65, and one in two over age 85, are living with some form of dementia.

Different disease processes have different symptoms, for example, significant memory decline is the hallmark of Alzheimer's disease. Other forms of dementia include: fronto-temporal dementia, also called Pick's disease, which typically has a younger onset than other diseases causing dementia; vascular dementia, the result of reduced blood flow to the brain; and dementia with Lewy bodies. These diseases have different characteristics and varying levels of severity. They also have different patterns of progression and treatment.

Diagnosis of these disorders typically involves a neurological examination, neuropsychological testing and imaging of the brain through MRI and/or PET scan. People with dementia can experience a range of symptoms in addition to cognitive difficulties, including depression, irritability, and anxiety. Dementia is often progressive so patients and families need ongoing help and support to

## **Care Coordination Guide**

maintain a high quality of life. Accurate diagnosis and ongoing treatment are essential to maximize treatment and good health.

### **Mild Cognitive Impairment**

Mild Cognitive Impairment, often abbreviated as MCI, is when an individual has mild but measurable changes in brain function. These can be noticed by the individual and people around them, but do not interfere with the ability to carry out daily activities. A person with MCI will experience memory difficulties that are greater than those associated with normal aging, but does not experience other symptoms characteristic of dementia such as impaired judgment. Individuals diagnosed with MCI are at higher risk of developing a dementia such as Alzheimer's disease, but MCI does not always lead to dementia. For some people, MCI is a stable condition.



### 3. Introduction to the Memory and Aging Care Clinic (MACC) & Team

The Memory and Aging Care Clinic (MACC) at University of Virginia Health System, now located on the fourth floor of the Primary Care Clinic, is a multidisciplinary team approach for individuals diagnosed with MCI or dementia in order to

- provide expert diagnosis and treatment and
- adequately attend to the changing needs of individuals and their families or care partners.

The team consists of neurologists, neuropsychologists, a social worker, a nurse practitioner, a nurse coordinator, and care coordinators. Referrals to additional care team members can be made as well.

Your personal treatment team can be listed below with the assistance of your Clinical Care Coordinator, if you choose.

Neurologist:

Neuropsychologist:

Nurse Practitioner:

Nurse Coordinator:

Care Coordinator:

Social Worker:

If you have questions for any member of the MACC team, please contact me, your care coordinator, and I will be happy to assist you with providing an answer or getting into contact with a team member.

Please contact me through MyChart. As a second option, I can be reached by phone at 434-XXX-XXXX.

### 4. Explanation of the Care Coordination Program (CCP)

The Care Coordination Program offered through the Memory and Aging Care Clinic (MACC) at the University of Virginia in partnership with the Jefferson Area Board for Aging (JABA) is open to any individual living in Virginia with a diagnosis of mild cognitive impairment (MCI) or dementia in the previous six months.

The aim of the program is to provide you with coordination of services and to promote education and well-being to you and your care partner(s).

I, \_\_\_\_\_ **Care Coordinator** \_\_\_\_\_, will be your care coordinator. I will be keeping in close touch with you over the next few years, assisting you in navigating the health system and in accessing other resources that you may need.

#### **What you can expect from the program**

##### *Individualized attention*

We recognize that everybody's needs are different. I can help you

- get information and assistance that are tailored to your own needs.
- answer questions you may have concerning your diagnosis and help you learn more about it
- assist you in identifying your short and long-term care goals, and in achieving those goals

##### *Help with future planning*

I will be able to help you plan for the future. This could include

- assisting you with financial and legal planning
- making plans for home care
- introducing you to resources available in the community for people with similar needs

##### *Frequent contact*

As your care coordinator, I will

- meet with you when you have an appointment at MACC

## Care Coordination Guide

- call you on the phone once a month or as needed for the first six months after you enroll, and at least once every three months after that
- plan to visit you **at home** within three months of enrolling in the program *While a home visit is not essential, it will help me better understand your current situation, and enable me to better help you achieve your goals.*
- meet with you and your care partner after you have been in the program for 12 months to complete a series of questionnaires.

If you would like to talk to me at another time, please contact me through MyChart, or call me on **434-XXX-XXX** from Monday to Friday, 8:30am to 4:30pm. If I am not available, please leave a message with your name and phone number, and I will aim to call you back within one business day.

### *Examples of services your Care Coordinator can help you with*

- Getting information about the disorder or disease process
- Understanding behavioral changes related to the disorder or disease process
- Managing behavioral symptoms
- Making medical appointments and accessing MyChart
- Getting information on services that will help you remain at home
- Getting practical information on home safety, driving safety, and other areas of concern
- Remaining actively engaged with your community
- Finding information about programs available in the community for people like you
- Providing specific information for care partners
- Accessing clinical trials
- Learning about resources for individuals with MCI or dementia and their care partners in your community and on-line
- Learning about and accessing support you may be eligible for

### *Important note:*

The Care Coordination Program is **not** a crisis-intervention service.

If at any point you have an emergency, **immediately call 911.**

For other after-hours assistance, you may call the Alzheimer's Association Helpline 1-800-272-3900 (24 hours, 7 days a week).



### 5. What to Expect at MACC

When you arrive at the Memory and Aging Care Clinic (MACC) for follow-up visits:

- Nursing staff will check in with you and provide routine care (check your blood pressure, for example) prior to bringing you to a clinic room where you will be seen by members of the multidisciplinary team.
- The nurse practitioner and/or neuropsychologist will check-in with you about changes in memory, physical and emotional wellbeing, and care needs, for instance, that might have come up since your last visit at the clinic. Medication and other treatment recommendations will be made, including adjustments to your current plan or continuing your plan as is.
- The social worker and a member from the Alzheimer's Association can meet with you if you have questions that they can answer about transitions and relevant supports and resources.
- And as previously shared in the Explanation of the Care Coordination Program section, I look forward to meeting with you at clinic to provide care and support to you and your care partner(s).



### 6. Future Needs Check-List

Throughout our time together I will make sure to provide you and your care partner with information on the topics below.

- Understanding your diagnosis of MCI or dementia
- Telling others about the diagnosis
- Maintaining healthy relationships with family and friends
- Emotional wellbeing
- Dementia related behaviors
- Changes with language/speech and communication strategies
- Daily strategies
- Legal and financial planning
- Elder abuse and exploitation
- Falls, home safety, disaster management
- Wandering
- Driving
- Medications
- Sleep
- Exercise
- Nutrition
- Care partner self-care, supports, resources
- Task management – online applications (apps) or resources
- Social programs, such as Memory Café and Arts Fusion (Fusion First and Fusion Plus programs) from Alzheimer's Association
- Social engagement – online community of newly diagnosed individuals, community centers
- Clinical trials, trial match (Alzheimer's Association)
- Other:
- Other:
- Other:
- Other:

Please let me know if there is anything that is not on this list that you want to discuss and I can assist you with writing those at the bottom under “Other”.

**At this time please let me know if there are one or more topics you would like to cover first as a priority.**

### 7. Helpful Resources

#### **State and Local Organizations**

##### **Virginia Division for the Aging**

*Can provide general referrals in your area including for VICAP (Virginia Insurance Counseling and Assistance Program)*

Tel: 1-800-552-3402 Voice/TTY

Monday-Friday 8:30 a.m. to 5:00 p.m. (excluding major holidays).

##### **U.S. Administration on Aging**

*A public service connecting you to services for older adults and their families*

Tel: 1-800-677-1116

[www.eldercare.gov](http://www.eldercare.gov)

##### **Virginia Navigator (Department of Aging and Rehabilitative Services)**

*The most comprehensive and up-to-date listing of services and supports in every Virginia community*

Senior Navigator

[www.seniornavigator.com](http://www.seniornavigator.com)

##### **Virginia Easy Access & 2-1-1 Virginia**

*Information about topics, programs and long-term supports for older adults, adults with disabilities and those who support them*

Tel: 211

[www.easyaccess.virginia.gov](http://www.easyaccess.virginia.gov)

## **Care Coordination Guide**

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### **Area Agency on Aging**

*Virginia's 25 Area Agencies on Aging offer a broad range of programs, educate and provide assistance and serve as portals to care, all with the aim of helping to support individuals in their homes and communities. The programs and services they offer differ depending on the needs of their local areas.*

### **Your local Area Agency on Aging:**

#### **Jefferson Area Board for Aging (JABA)**

674 Hillside Road, Suite 9  
Charlottesville, VA 22901

Tel: 434 817 5222

Fax: 434 817 5230

[info@jabacares.org](mailto:info@jabacares.org)

[www.jabacares.org](http://www.jabacares.org)

#### **Serving:**

**Albemarle, Fluvanna, Greene,  
Louisa and Nelson Counties  
City of Charlottesville**

## **Care Coordination Guide**

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### **National Organizations**

#### ***Alzheimer's Disease and Related Dementias (e.g., Vascular Dementia)***

##### **Alzheimer's Association**

*Information about Alzheimer's disease and related dementias for families and caregivers*

**Tel: 800-272-3900 (24-hour helpline)**

TDD: 312-335-5886

Fax: 866.699.1246

info@alz.org

www.alz.org

##### **Central and Western Virginia Chapter**

1160 Pepsi Place, Suite 306  
Charlottesville, VA 22901

Tel: 434-973-6122

alzcwva@alz.org

www.alz.org/cwva/

##### **Greater Richmond Chapter**

4600 Cox Road, Suite 130  
Glen Allen, VA 23060

Tel: 804-967-2580

Fax: 804-967-2588

nlentz@alz.org

www.alz.org/grva/

##### **Southeastern Virginia Chapter**

6350 Center Drive, Suite 102  
Norfolk, VA 23502

Tel: 757-459-2405

Fax: 757-461-7902

InfoSEVA@alz.org

www.alz.org/seva

##### **National Capital Area Chapter**

3701 Pender Drive, Suite 400  
Fairfax, VA 22030

Tel: 703-359-4440

Fax: 703-359-4441

alznca@alz.org

www.alz.org/nca/

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### ***Alzheimer's Disease and Related Dementias (continued)***

#### **Alzheimer's Disease Education and Referral Center (ADEAR)**

*Information about Alzheimer's disease and clinical trials for individuals and caregivers*

Tel: 1-800-438-4380

Fax: 301-495-3334

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

#### **Alzheimer's Drug Discovery Foundation**

*Information about Alzheimer's disease and research, focusing on drug development*

Tel: 212-901-8000

Fax: 212-901-8010

info@alzdiscovery.org

www.alzdiscovery.org

#### **Alzheimer's Foundation of America**

*Information and counseling about Alzheimer's disease and related dementias for individuals and care partners*

Tel: 866-232-8484

Fax: 646-638-1546

info@alzfdn.org

www.alzfdn.org

#### **John Douglas French Alzheimer's Foundation**

*Information about research into Alzheimer's disease*

Tel: 310-445-4650

Fax: 310-479-0516

www.jdfaf.org

#### **BrightFocus Foundation**

*Information about Alzheimer's disease for individuals and care partners*

Tel: 800-437-2423

Fax: 301-258-9454

info@brightfocus.org

www.brightfocus.org/alzheimers/

## **Care Coordination Guide**

### ***For Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia***

#### **Lewy Body Dementia Association**

*Information and resources about Dementia with Lewy Bodies and related dementias for individuals and care partners including on-line support groups*

Tel: 404-935-6444

LBD Caregiver Link: 800-539-9767

Fax: 480-422-5434

lbda@lbda.org

www.lbda.org

### ***For Frontotemporal Dementia***

#### **Association for Frontotemporal Degeneration (AFTD)**

*Information and resources for individuals with frontotemporal dementia and their care partners*

Tel: 866-507-7222 (toll-free helpline)

info@theaftd.org

www.theaftd.org

### ***For Rarer Forms of Dementia***

#### **Hydrocephalus Association**

*Information and resources on Normal Pressure Hydrocephalus*

Tel: 888-598-3789

info@hydroassoc.org

www.hydroassoc.org

#### **National Organization for Rare Disorders (NORD)**

*Information and resources about rarer forms of dementia, for example Creutzfeldt Jakob disease*

Tel: 203-744-0100

Voice Mail 800-999-NORD (6673)

Fax: 203-798-2291

orphan@rarediseases.org

www.rarediseases.org

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### For Caregivers

#### **Family Caregiver Alliance/ National Center on Caregiving**

*Educational resources and support for care partners (not limited to dementia)*

Tel: 415-434-3388, 800-445-8106

Fax: 415-434-3508

info@caregiver.org

www.caregiver.org

#### **Virginia Family Caregiver Solution Center**

*Respite resources for care partners*

vf.virginiannavigator.org

#### **ARCH National Respite Network and Resource Center**

*Resources and information about respite programs available to care partners*

www.archrespite.org

#### **Caregiver Action Network (formerly National Family Caregiver Association)**

*Resources and information for care partners (not limited to dementia)*

Tel: 202-454-3970

info@caregiveraction.org

caregiveraction.org

#### **Virginia Caregiver Coalition**

*Education and advocacy for care partners*

Judy Hutchinson

sw3@paaainc.org or 757-246-1914

Mauretta Copeland

mcopeland@vcu.edu or 804-827-0423

#### **Well Spouse Association**

*Peer support and education for spousal care partners*

Tel: 800-838-0879

Fax: 732-577-8644

info@wellspouse.org

www.wellspouse.org



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**Resources You Have Found**

**Name:** \_\_\_\_\_

**Name:** \_\_\_\_\_

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**Website:** \_\_\_\_\_

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**Website:** \_\_\_\_\_

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### 8. Consent Forms

- Commonwealth of Virginia Uniform Authorization to Use and Exchange Information *This form needs to be renewed annually*



## Materials H. Other Forms Used

1. Virginia Uniform Authorization to Use and Exchange Information (consent form)

Available on:

[https://www.dss.virginia.gov/files/division/dfs/as/as\\_intro\\_page/forms/032-01-0005-02-eng.pdf](https://www.dss.virginia.gov/files/division/dfs/as/as_intro_page/forms/032-01-0005-02-eng.pdf)

2. Virginia Uniform Assessment Instrument (UAI)

Available on:

[https://www.dss.virginia.gov/files/division/dfs/as/as\\_intro\\_page/forms/032-02-0168-01-eng.pdf](https://www.dss.virginia.gov/files/division/dfs/as/as_intro_page/forms/032-02-0168-01-eng.pdf)

