



# Care Ecosystem Toolkit

# LETTER FROM THE DIRECTORS

The Care Ecosystem (CE) model was first designed in 2013 to help address the unmet needs of persons with dementia and their caregivers. The goals of the program include improving quality of life for persons with dementia and their caregivers, preventing unnecessary hospitalizations, and delaying admissions to long-term care institutions. The program provides caregiver support, linkages to community-based resources, advance care planning, medication support, and care coordination via a multidisciplinary team. While the randomized controlled trial took place in two academic medical centers, the CE is now being replicated in three different settings: an integrated health system, a senior center for low-income individuals, and as a service embedded in a memory care clinic. We have developed this toolkit in response to a growing interest in the CE. This toolkit provides an overview of the CE model, how to prepare for and implement the CE model, and details of the CE protocols. In the appendices, you will find valuable resources including job descriptions, templates, and other workflow diagrams, as well as useful references. We hope you find this toolkit helpful, and we welcome your feedback on how it could be improved. We look forward to working together to improve care for persons with dementia and their caregivers.

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## ORGANIZATION & INTENDED USES FOR THIS TOOLKIT

This CE toolkit is based on the experiences of the randomized controlled trial, funded by the Centers for Medicare and Medicaid Health Care Innovation Award, at UCSF and UNMC that began in March 2015 and is expected to conclude in February 2018. It is designed to guide organizations through the process of implementing the CE and is organized into four sections: an overview of the CE model; a readiness guide; a guide to implementation of the day-to-day operations of the CE model; and a detailed description of the care protocols that form the backbone of the CE. The links to supplementary materials may be affected by high-security firewalls. If you experience difficulty accessing the links, please consult your IT services.

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## **Letter from the Directors 2**

Acknowledgments 2

Organization & Intended Uses for This Toolkit 3

License 3

## **Section 1: Introduction & Overview of the Care Ecosystem 6**

Introduction 6

Overview of the Care Ecosystem 7

## **Section 2: Implementation Guide 11**

Organizational Readiness & Capabilities 11

Roles & Staffing 12

Training 14

Monitoring & Evaluation 15

Physical Space & Systems 15

## **Section 3: Operational Details of the Care Ecosystem 17**

Pilots 17

Outreach & Enrollment 18

Caseload 20

Intake 20

Development of Individualized Care Plans 22

Ongoing Contacts with Caregiver 22

Escalation Guidelines, Tools & Process 24

Team Meetings 25

Care Coordination Practices/Engaging Providers 25

Care Transitions 26

Graduation Planning 26

Process Improvement Feedback Loop 27

Funding Model for a Care Ecosystem Program 27

## **Section 4: Care Ecosystem Protocols 31**

Immediate Needs 31

Medication Reconciliation & Review 32

Behavior Management 34

Safety Screen & Recommendations 35

Caregiver Well-Being 36

Referrals & Education 37  
Decision Making (Advance Care Planning) 38

**Appendices 41**

Section 2: Implementation Guide 41  
Section 3: Operational Details of the Care Ecosystem 41  
Section 4: Care Ecosystem Protocols 42

**Glossary of Key Terms 44**

Decision Making Terms 44  
Other Key Terms 44

# SECTION 1: INTRODUCTION & OVERVIEW OF THE CARE ECOSYSTEM

## INTRODUCTION

One in three seniors will die with dementia.<sup>1</sup> Persons with dementia (PWD) suffer from functional and cognitive decline, reduced quality of life, financial problems, social isolation, iatrogenic medical complications, and are more vulnerable to delirium and abuse. However, the US medical system is not well positioned to diagnose and care for PWD. The US suffers from a shortage of dementia specialists.<sup>2</sup> In addition, there are increased costs to the healthcare system to care for PWD. In 2015, researchers were able to determine that the cost of caring for Medicare beneficiaries with functional impairments was, on average, \$23,497, while the cost of caring for beneficiaries without functional impairments was \$7,223.<sup>3</sup> This is further compounded by the fact that, in many cases, there is a lack of integration and communication between medical providers, as well as between medical providers and other community-based supports that might help PWD.<sup>4</sup>

The challenges of negotiating the health care system, identifying resources, and providing day-to-day care often falls on caregivers (CG) for PWD who are often unprepared for and overwhelmed by these responsibilities. The Alzheimer's Association reports that more than 15 million Americans provide care for PWD and estimates the value of this unpaid care at \$230 billion in 2016 alone. In turn, CGs for PWD are themselves prone to higher rates of depression, social isolation, and physical health problems than non-caregivers.<sup>5</sup> Thirty-five percent of CGs of PWD report that their own health has gotten worse due to care responsibilities, compared to 19 percent of CGs for older people without dementia.<sup>6</sup> As dementia progresses, caregiver burden and patient quality of life worsen,<sup>7,8</sup> thus increasing the risk of unnecessary hospitalizations and premature placement in long-term care.<sup>9,10</sup>

There is hopeful news, however, since caregiver support and navigation programs have demonstrated beneficial effects on psychosocial dimensions of PWD and caregiver health,<sup>11</sup> and recent policy changes to Medicare could

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<sup>1</sup> Alzheimer's Assn

<sup>2</sup> Warshaw, G., Bragg, E.J. *Preparing The Health Care Workforce To Care For Adults With Alzheimer's Disease And Related Dementias*. *Health Affairs*. April 2014 vol. 33 no. 4 633-641.

<sup>3</sup> Kelly MD, Amy S., et al. *The Burden of Health Care Costs for Patients with Dementia in the Last 5 Years of Life*, *Annals of Internal Medicine* 2015; 163:729-736. (2015).

<sup>4</sup> Bunn, F., Burn, A. M., Goodman, C., Robinson, L., Rait, G., Norton, S., Bennett, H., Poole, M., Schoeman, J. & Brayne, C. *Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem)*. Southampton (UK): NIHR Journals Library (2016).

<sup>5</sup> Baumgarten, M., Battista, R. N., Infante-Rivard, C., Hanley, J. A., Becker, R. & Gauthier, S. *The psychological and physical health of family members caring for an elderly person with dementia*. *J.Clin.Epidemiol.* 45 1 61-70. (1992).

<sup>6</sup> Alzheimer's Association

<sup>7</sup> Dauphinot, V., Delphin-Combe, F., Mouchoux, C., Dorey, A., Bathsavanis, A., Makaroff, Z., Rouch, I. & Krolak-Salmon, P. *Risk factors of caregiver burden among patients with Alzheimer's disease or related disorders: a cross-sectional study*. *J.Alzheimers Dis.* 44 3 907-916. (2015).

<sup>8</sup> Olsen, C., Pedersen, I., Bergland, A., Enders-Slegers, M. J., Joranson, N., Calogiuri, G. & Ihlebaek, C. *Differences in quality of life in home-dwelling persons and nursing home residents with dementia - a cross-sectional study*. *BMC Geriatr.* 16 137-016-0312-4. PMC4939817 (2016).

<sup>9</sup> Lin, P. J., Fillit, H. M., Cohen, J. T. & Neumann, P. J. *Potentially avoidable hospitalizations among Medicare beneficiaries with Alzheimer's disease and related disorders*. *Alzheimers Dement.* 9 1 30-38. (2013).

<sup>10</sup> Mittelman, M. S., Haley, W. E., Clay, O. J. & Roth, D. L. *Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease*. *Neurology.* 67 9 1592-1599, (2006).

<sup>11</sup> Maslow, K. *Translating innovation to impact: Evidence-based interventions to support people with Alzheimer's disease and their caregivers at home and in the community (a white paper)*. Alliance for Aging Research, Administration on Aging, MetLife Foundation. (2012).

help to fund this type of care. The University of California, San Francisco (UCSF) and the University of Nebraska Medical Center (UNMC) have piloted the Care Ecosystem (CE), a patient- and family-centered model of dementia care designed to improve quality of life for PWD and their CGs. This telephone- and web-based care program is continuous, proactive, personalized, and scalable. It offers support and education for CGs, provides medication and safety guidance, and promotes proactive decision-making, thereby complementing the PWD’s existing clinical team. A Care Team Navigator (CTN), the primary point of contact for each PWD and CG dyad, is trained and supervised by an expert clinical team that typically includes a nurse, pharmacist, and social worker.

## OVERVIEW OF THE CARE ECOSYSTEM

The CE model is based on a randomized controlled trial at UCSF and UNMC that began in March 2015 and will continue until February 2018 with funding from the Centers for Medicare and Medicaid Innovation and thereafter with funding from the National Institute on Aging until September 2022. The CE model focuses specifically on PWD and their CGs (“dyads”) whose quality of life could be improved and whose preventable hospital use could be reduced through caregiver support, linkages to community-based resources, advance care planning, and care coordination. Figure 1 depicts the core elements of the CE.

**Figure 1.** The Care Ecosystem Core Elements



1. The Dyad: A PWD and a Caregiver. Caregiver can be a family member or friend, paid staff, or other combination of people who support the PWD.
2. Care Team Navigator: actively supports the Dyad, empowers the CG to be the advocate for the PWD and leverages the protocols, resources, and clinical resources available. The Care Team Navigator receives training, has access to resources, and receives ongoing consultative support from licensed clinical experts.
3. The Care Ecosystem model is built around clinical expertise in dementia.
4. The Care Ecosystem has evidence-based protocols designed to support a PWD and the needs of the CG. The protocols address: medications, safety, behaviors, caregiver support, and advance care planning.
5. The Care Ecosystem model is person-centered and customized. Its resources are provided on an as-needed basis that is proactive and responsive, rather than in a prescribed order.
6. A distinctive part of the Care Ecosystem model is its focus on both the PWD and the Caregiver. The Care Team Navigator provides curated resources to alleviate caregiver burden in addition to addressing the needs of the PWD.

The CE model employs a multidisciplinary team to support each dyad. At the heart of the multidisciplinary team is a Care Team Navigator (CTN) who extends the reach of a team of licensed clinical dementia specialists. The CTN:

- Acts as the primary point of contact for the dyad
- Provides education and support around dementia and what to expect
- Screens for unmet care needs including clinical or medication issues, behavioral issues, safety risks, and psychosocial well-being
- Guides each dyad through the process of advance care planning
- Provides connections to local community services
- Reconciles medications and assists with medication management strategies
- Follows up to ask caregiver about possible medication side effects and changes in function or behavior
- Consults with and triages complex or medical issues to the CE's licensed clinical team members, such as a nurse, social worker, or pharmacist

While they play a vital role in the CE model, CTNs do not need to have college degrees or come to the job with a background in health care. Excellent communications skills are a key attribute of successful CTNs. If possible, for dyads who are non-native English speakers, or not English speakers, having a CTN with language skills in the dyad's native language is helpful. CTNs receive training in aging and ethics, dementia care, and advance care planning and have access to a library of resources. In addition, each CTN receives ongoing support from the clinical team, which has dementia expertise in pharmacy, nursing, and social work.

Personalization is a key feature of the program. A series of protocols create a framework to guide care delivery, but the sequence and dosage of the protocols are flexible, which allows support to be tailored to the needs of each dyad and delivered in a proactive and responsive manner.

The CE is designed to be delivered remotely. It can be run outside of, or in parallel to, the health care delivery system or it can be integrated into the delivery system. Initially, the CE was implemented as a telephonic program, with teams at UCSF and UNMC serving dyads in their regions (CA, NE, and IA). More recently, the CE has also been implemented in UCSF's Memory and Aging Clinic and the Curry Senior Center in San Francisco (with CTNs embedded onsite) and at Allina Health, in Minnesota (by training existing Care Guides to serve as CTNs). Table 1 summarizes current implementations of the CE.



**Table 1.** Implementations of the Care Ecosystem as of August 2017

Current Models August 2017	University of California, San Francisco (UCSF) Research Study	Memory and Aging Center (MAC), Department of Neurology, UCSF	University of Nebraska Medical Center (UNMC) Research Study	Allina Health	Curry Senior Center Clinic San Francisco, CA
<b>Description of the Implementation</b>	Care Ecosystem model being tested in randomized controlled trial for PWD funded with three-year CMS Innovation Grant.	Care Ecosystem model for PWD embedded in an academic specialty practice.	Care Ecosystem model being tested in randomized controlled trial for PWD funded with three-year CMS Innovation Grant.	Care Ecosystem spread to existing Care Guides and Advanced Care Team (pharmacist, social worker, nurse, care guide), in large integrated health system.	Care Ecosystem model for PWD spread to urban comprehensive primary care center for low-income seniors.
<b>Patient Recruitment &amp; Referrals</b>	<p>Patient recruitment efforts focused on primary care and specialty physician practices, hospitals, health plans, and community agencies across California.</p> <p>Referrals came from providers and communities across California.</p>	<p>Patient recruitment efforts via Memory and Aging Clinic physicians and staff, located in an academic specialty practice.</p> <p>Referrals are from the behavioral neurology practice.</p>	<p>Patient recruitment focused on primary care and specialty physician practices in academic medical center.</p> <p>Outreach coordinators targeted rural practices and promoted the program via state fairs, TV and radio ads, and outreach to community agencies.</p> <p>Referrals came from providers and communities in rural NE and IA and from urban Omaha.</p>	<p>Elements of the Care Ecosystem are being incorporated into Allina’s existing care programs, eliminating the need for recruitment.</p> <p>The initial programs targeted for LifeCourse Care Guide pilots are: brain tumor program, heart institute, and two general medicine clinics that have PWD. The Advanced Care Team serves ACO patients throughout Allina Health.</p>	<p>Patient recruitment through physicians and staff located in a safety-net clinic serving older adults in the Tenderloin neighborhood of San Francisco.</p> <p>Referrals are from primary care providers.</p>
<b>Patient Enrollment</b>	<p>The PWDs and their CGs that are enrolled in the Care Ecosystem program represent rural and urban locales with a range of socioeconomic characteristics, and include monolingual Spanish and Cantonese speaking persons.</p> <p>320 PWD and their CGs are enrolled in the study group and 132 in control group.</p>	Enrollment started July 1, 2017.	<p>The PWDs and their CGs that are enrolled in the Care Ecosystem program represent rural and urban locales with a range of socioeconomic characteristics.</p> <p>221 PWDs and their CGs are enrolled in the study group and 108 in control group.</p>	Dyads will be enrolled by Allina’s clinic-based Care Guides and the Advanced Care Team.	Enrollment started July 1, 2017. The Curry Senior Center Clinic serves a marginalized low income population. Most patients are socially isolated and do not have informal CGs.

The CE shares features with dementia care programs developed at UCLA, Johns Hopkins, and the Indiana Healthy Aging Brain Center. These programs similarly provide support, education, medication guidance, advance care planning, and care coordination for PWD and their CGs. Whereas the CE model is designed to be delivered telephonically, the Johns Hopkins program delivers care in the home, and the UCLA program is delivered in the clinic.

The CE model could potentially be deployed in other organizations, such as:

- Provider-based delivery systems (Hospitals, Medical Groups, ACOs)
- Payers – Health plans, Medicare Advantage or Medicaid Managed Care plans
- State/County Health and Social Service Systems
- Home Care Services companies, Home Health organizations
- Adult Day Care Providers

**Expected outcomes of the Care Ecosystem model:**

Long-term care placement is a primary driver of overall dementia care costs.<sup>12</sup> The CE model supports CGs to care for PWD in the home for as long as possible. In addition, by providing medication reconciliation services, safety screens, and referrals to community-based resources the CE model may reduce Emergency Room visits, ambulance costs, hospitalizations, and adverse medication events. Finally, by supporting CGs, the CE model aims to reduce caregiver stress and associated poor health outcomes. Initial formal evaluation of the CE model is expected in 2018 or 2019, with ongoing evaluation for longer-term outcomes.

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<sup>12</sup> Hurd et al., *Monetary Costs of Dementia in the United States*. *N Engl J Med* 2013; 368:1326-1334 (2013).

## SECTION 2: IMPLEMENTATION GUIDE

This toolkit includes many documents and workflows utilized by teams at UCSF and UNMC and have been reviewed for institutional and state compliance only for those sites. Organizations implementing the CE model must conduct an independent legal and risk review of all documents and processes before using them to ensure compliance with all applicable institutional and local regulations and laws. In addition, materials, referrals, and resources should be updated to reflect local resources, law, and best practices. Consultation with local community service and legal organizations is advised.

### ORGANIZATIONAL READINESS & CAPABILITIES

The list of questions below may be a useful guide for preparing to launch the CE program.

#### Clinical Need

- How many patients with or at risk for dementia does your organization serve?
- Can your organization articulate the value of a program that supports a PWD and their CG?
- Can you identify your target population (both who you would start with and who you would ultimately like to serve)?
- What data does your organization have that can help you identify the target population (utilization, diagnoses, pharmacy data, etc.)?

#### Organizational Alignment

- Does your organization have a senior leader who is willing to serve as a sponsor of the program and champion the needs of the program to ensure the required financial support?
- Is your organization's leadership team engaged and committed to minimizing barriers to success?
- Are practice site and facility leaders involved, engaged, and supportive?
- Has your organization identified and engaged critical partners, such as payers, hospitals, and specialists? The CE Program can provide value to many partners outside of the walls of the clinic or hospital. For example, a health plan or insurer who bears the risk for the care of the population may be a partner and needs to be willing to share utilization data for outcomes assessment.

#### Organizational Structure

- Does your organization have a "business case" that includes improving care for PWDs and CGs with complex conditions or dementia? For example, does your organization assume any financial risk for patients, are there management fees, or are shared savings dollars available?
- Does your organization have a way to implement a data measurement plan to measure program effectiveness?
- Does your organization have a process that can be used to get feedback from PWDs and their CGs on an ongoing basis?

#### Clinical Preparedness

- Are physicians engaged and do they understand the program? (proxy: if you ask physicians what the intervention is, can they describe it and do they support it?)

- Has your organization identified the clinical department which will “own” the CE program (e.g., neurology, geriatrics, primary care, social work, nurse care management)?
- Does your organization have access to clinically licensed specialists with dementia expertise (i.e. pharmacist, social workers, nurses, case managers)?
- Does your organization have staff members who can complete the Care Ecosystem tasks or will you need to hire staff to fulfill the roles of navigator and dementia expert?
- Does your organization have an existing process to document ongoing care management needs of patients and methods to track applied interventions?

## ROLES & STAFFING

Figure 2 depicts the multidisciplinary CE team. The CTN can be housed in a number of departments or in a central location and will benefit from a strong manager (ideally with clinical expertise) who can connect the CTN to appropriate clinical resources.

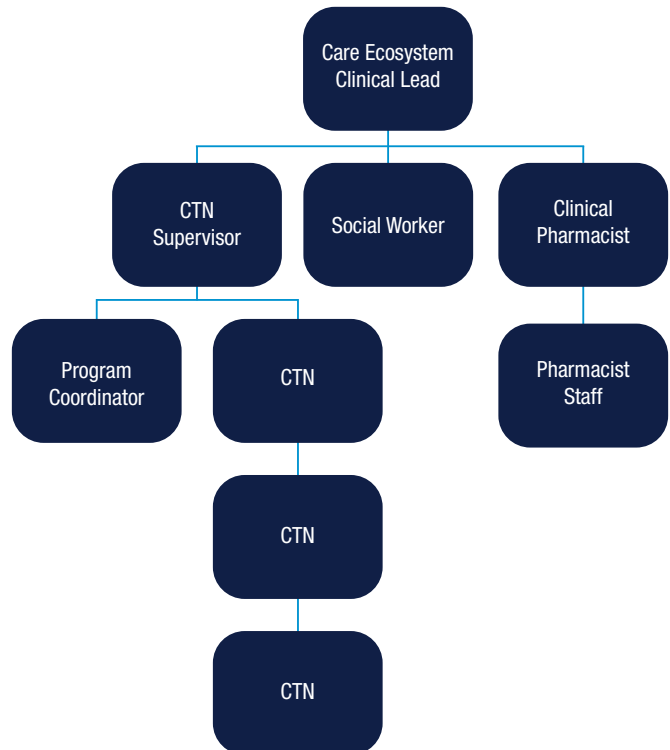
The Clinical team (e.g., Pharmacist, Social Worker, Nurse) can also be housed in any department as long as they are available to support the CTN. A key to the success of the CTN is that there is a manager who has the clinical expertise to manage the CTN, including providing clinical advice and connecting the CTN to appropriate clinical resources as needed.

Figure 3 below, depicts the CE team in a traditional hierarchical organizational chart. However, current implementations of the CE model have “flatter” approaches; CTNs work directly with the pharmacists and social workers as needed to provide support to each dyad.

**Figure 2.** The Care Ecosystem Model



**Figure 3.** Key Positions in the CE Model



## **Program Coordination**

The CE coordination activities can be managed by a single person or shared by multiple staff. Key activities include: recruiting and enrolling dyads, managing CTN caseloads, and developing and maintaining resources (e.g., a library of local support resources for CGs). The scope of the role is entirely non-clinical and can be completed by any employee who has access to medical records and who has the communication skills required to gather basic medical background information. In environments where staffing is limited or the need for program coordination is limited, the tasks of the Program Coordinator can be assumed by the CTN Supervisor or the Social Worker. The details of the Program Coordinator activities are provided in *Section 3: Outreach & Enrollment*.

## **Care Team Navigator**

The CTN is the core member of the CE team and is the primary point of contact for all dyads. Your organization may find that a healthcare advocate or other existing staff member can be trained to play the CTN role. For example, Allina Health provided extra training to existing Care Guides who already played similar roles. UCSF and UNMC identified the following key attributes for the CTN. These strengths are assessed during the interview process and evaluated through ongoing supervision.

### ***Communication and Learning Skills***

Successful CTNs will develop a basic understanding of medical issues commonly faced by PWD and their CGs, such as delirium, falls, infections, and medication side effects. The CTN will develop these skills through initial training, ongoing training, and ad hoc support from the manager and the clinical team. The CTN will use this foundational knowledge, the information included in the CE protocols, and their direct communication with CGs to identify and triage clinical issues. In addition, the CTN will need to interact with dyads without being judgmental or directive. Successful CTNs will be able to generate rapport with CGs while maintaining boundaries aligned with the scope of their role and with the extent of services and support offered through the CE model.

### ***Problem Solving Skills***

Key attributes of the CE model include its flexibility and personalization. The CTN will be expected to use their judgment to implement protocols according to the needs of each dyad rather than in a linear, prescribed manner. Additionally, when a CG needs a resource that is not already available, the CTN will need to take the initiative to identify resources and (if needed) ask for help from the clinical team so that others can provide assistance. Similarly, the CTN is expected to think critically and creatively to solve problems related to behavioral issues and safety concerns that may require prompt escalation to the clinical team.

### ***Organizational Skills***

The CTN will need to be able to use strong organizational skills to manage both routine, scheduled tasks as well as unexpected needs. Your organization will need to identify systems for tracking issues and scheduling contacts with the dyads, and the CTN will need to master these systems.

## **Clinical Support Team**

The Clinical Support team is available to support the CTN for ongoing training and for resolving cases identified as needing immediate attention from a licensed professional. Ideally, clinical team members will enjoy working collaboratively and leveraging the CTN to extend their reach. Potential team members include:

- Clinical pharmacist with training in geriatrics/dementia
- Clinical social worker with training in geriatrics/dementia
- Clinical nurse with training in geriatrics/dementia

In addition, the CTN will need a manager, who could be a member of the clinical team. A key to the success of the CTN is that they have a manager who has the expertise to provide clinical advice and connect the CTN to appropriate clinical resources as needed.

The CE model requires that the clinical team have (or have access to) dementia expertise. This may be provided in-house or on a consulting basis. During the planning phase, your organization will need to assess the skill sets of existing staff to identify any training or hiring needs. For example, the role of the pharmacist may decrease in settings where other clinical providers (e.g., neurologists or geriatricians) have a strong understanding of the pharmacological standards of care in dementia, expertise with new medications, and experience with complex medication regimens. UCSF has provided sample job descriptions below.

#### **Supporting Materials:**

- [CTN Job Description](#)
- [Pharmacist Job Description](#)
- [Nurse Coordinator Job Description](#)
- [Social Worker Job Description](#)

## **TRAINING**

Training about the CE model may benefit all members of the clinical team. For example, if the CE model is being added to an existing care management program, clinical staff may benefit from training about dementia, the value of supporting CGs, and medications for dementia.

UCSF developed a series of PowerPoint presentations that provide foundational knowledge for implementing the CE and is willing to share some recordings of CTNs being trained with these presentations. A new CTN will require approximately three weeks of training and orientation to become fully independent. A sample schedule for a three-week orientation can be found in the link below. Also included are an example checklist of orientation topics, skills, goals, and tasks. A typical CTN orientation will include: a program overview; training about aging and dementia; discussion and training about the role of families and CGs in dementia care; review of effective communication and problem-solving skills; a detailed review of the CE workflow, including how to identify and escalate issues; and a review of education materials and resources, including materials for patients and CGs. The CTN will be introduced to your organization's tracking and charting system and will also become familiar with chart reviews, including medical terminology and your organization's process for debriefing or case review. In addition to didactic training, the CTN will ideally shadow an experienced team member in each step of the CE workflow (e.g., conducting an intake interview; conducting a routine check-in call with a CG). Ideally, the CTN will be able to spend time in a dementia care setting to observe and interact with a PWD and also attend a community caregiver support group (e.g., Alzheimer's Association meeting).

#### **Supporting Materials:**

- [Training PowerPoints](#)
- [Training Recordings](#)
- [CTN Training Checklist](#)

## MONITORING & EVALUATION

An initial needs and assessment survey (detailed in Section 3 of this toolkit) is completed for each dyad upon enrollment in the CE program and is repeated every six months while the dyad is engaged with the program. Longitudinal survey results can be used to assess satisfaction with the CE program, as well as efficacy. Your organization may wish to combine or align these data with other measurement and benchmarking already in place. In addition to the baseline survey, your organization will need to create a monitoring and evaluation program that tracks both operational metrics and evaluation metrics. Based on the experiences at UCSF and UNMC, the following metrics are suggested:

1. **Operational Metrics** – to know if the CE program is running efficiently. These measures can also include key performance indicators that your organization uses across business units to ensure organizational fitness. Sample metrics include:
  - a. Encounters by Dyad
  - b. Progress against milestones (e.g., medication review completed; care plan completed)
  - c. CTN caseload
  - d. Response time to inbound dyad care requests
  - e. Survey completion rates
  - f. Time to resolve issues escalated to clinical team
2. **Evaluation Metrics** – to assess the impact of the CE program. Your organization could consider using metrics that can be benchmarked across the organization, such as Medicare Stars Quality Measures, or Patient Experience Measures (such as CAHPS Clinician & Group Surveys). Links to the standard measures are below. Sample metrics include:
  - a. Utilization measures
    - i. Hospitalizations
    - ii. Emergency care visits
    - iii. Same day medical office appointments
  - b. High-Risk Medication Adherence
  - c. Falls and injuries
  - d. Missed days of work for the caregiver

### Supporting Materials:

- [Medicare 2017 Part C & D Star Rating](#)
- [CAHPS Clinician & Group Survey](#)

## PHYSICAL SPACE & SYSTEMS

### Space Requirements

The CE is designed to be delivered remotely, with the majority of communication managed telephonically. Your organization may have administrative buildings or locations where call centers are co-located in which the CTN can work. Ideally, the person managing the CTN and the social worker will also be located near the CTN. Each CTN must

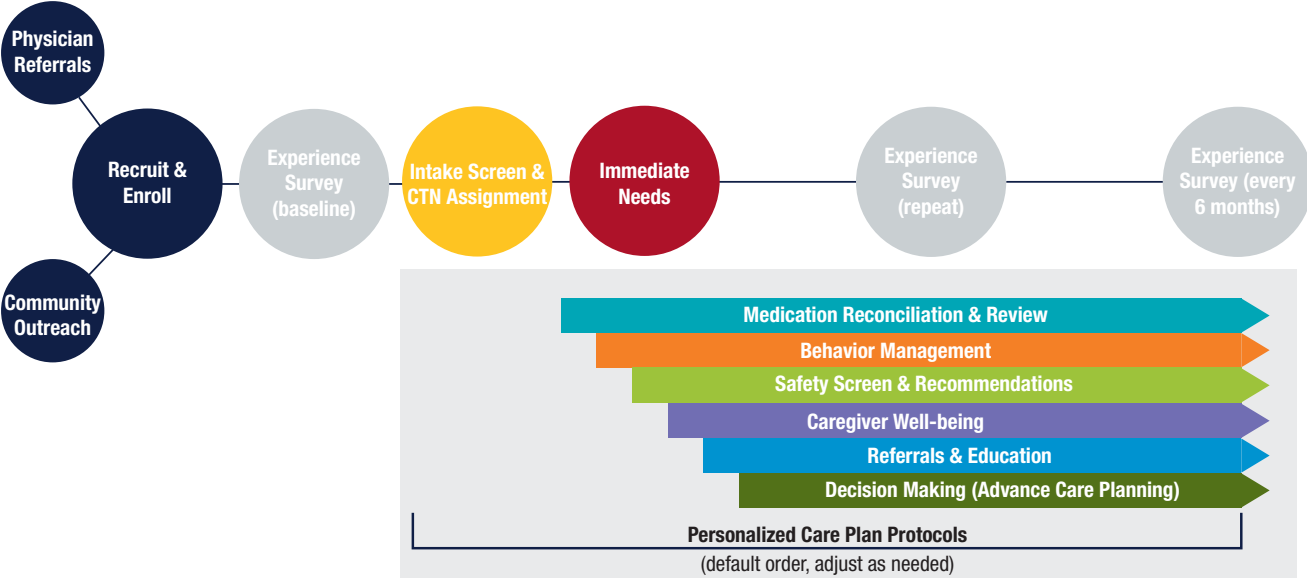
have a dedicated phone line. In addition, your organization may find it beneficial to have a centralized phone number for the CE program that can be used for promotional documents and general inquiries.

### **Systems Requirements**

The CE requires capabilities for team members to access shared resource documents, store and track documentation about specific dyads and their care plans, and provide a way for CTNs to manage their calendars. These capabilities can be embedded in an electronic medical record or be provided via stand-alone systems, as long as all members of the care team are able to track their cases; search records by dyad; and develop, update, and share individual care plans. If your organization is interested in billing Medicare or reporting quality performance measures, you will need to consider those requirements as well. A more detailed discussion of these requirements can be found in the Funding section of this toolkit.



# SECTION 3: OPERATIONAL DETAILS OF THE CARE ECOSYSTEM



**Figure 4.** The Care Ecosystem operational details

## PILOTS

Your organization may decide to introduce the CE as a pilot program. This may be a pilot led by a team in the neurology or geriatrics department, a single clinic location (e.g., a primary care practice with a significant dementia population), or even a few providers who agree to pilot the program.

For example, Allina Health in Minnesota decided to integrate dementia training and aspects of the CE program into their existing Care Guide programs. Allina began by piloting the training in three hospital-based clinics (brain tumor, heart failure, and general medicine) with existing Care Guides, an Advanced Care Team (pharmacist, social worker, nurse, care guide), and three primary care nurses. Once the program is fully launched, Allina plans to expand some elements of the program to their entire Advanced Care Team program. Those teams serve high-risk ACO patients after hospitalizations. They do home visits for an average of 90 days post-hospitalization to develop a care plan that incorporates patient-identified goals to ensure that the patient is getting the right level of support. By adding caregiver support and dementia training for the Advanced Care Teams, Allina plans to provide supportive services beyond the 90-day mark, as appropriate.

Figure 4 depicts key operational details of the CE. The sections below provide details about the processes and are color-coded so that you can see which process is being referred to. Section 4 of this toolkit provides detailed information about each of the CE protocols listed in Figure 4. The sections below also provide details about workflow, problem resolution, and other operational details of the CE model.

## OUTREACH & ENROLLMENT

Your organization may already know what population you are targeting and have an existing referral network, in which case you may want to skim or skip the next few sections. The following sections are included for those organizations wishing to have more detail about the learnings from the UCSF and UNMC programs.

### **Determine Target Population:**

At UCSF's Memory and Aging Clinic and University of Nebraska Medical Center (where the CE model was implemented as a research study) eligibility criteria were designed to identify persons already diagnosed with dementia who did not live in a nursing home and who had Medicare or Medicaid benefits, as well as a few other inclusion and exclusion criteria specific to the research study. Your organization may choose to have a different set of criteria depending on the needs of your organization. When you are choosing your criteria, pay attention to screening factors that will help your organization identify those who will most benefit from the CE program. For example, criteria could include dyads where the CG is experiencing a high degree of burden or where the PWD is a high user of emergency-related care.

Your outreach and enrollment plan will vary depending on how your organization chooses to roll out the CE program and the population you are targeting. The steps outlined below are illustrative and may not apply to every organization, especially if the CE is being added to an existing care program.

### **Identify Candidates:**

Every organization will have different methods for referrals into the program depending on the volume of patients with dementia served. It will be helpful to have one or two providers champion the program to help with initial referrals. One way to start would be to produce a summary report that identifies all patients in a practice or clinic that have a diagnosis of dementia. This list could be reviewed at a team meeting or individually with providers to determine which patients might benefit from the CE. Over time, the report could be run for more providers to determine the all potential participants and then scheduled to show only newly diagnosed patients. In addition, once a CE program is established, referrals may come directly from clinical staff and community groups who are aware of the benefits of the CE.

Once a PWD is identified, a records review will be required to determine if they have a CG and if they would benefit from the CE. The progression from this point will vary based on the type of organization implementing the CE. For instance, a fully capitated managed care delivery system with care management programs will have a mechanism to alert the primary care clinic as to the plan to reach out to the dyad and may have existing protocols that do not require the primary care provider to give approval for the patient to be contacted. Alternatively, a distributed model (such as a third-party management organization that is contracted to deliver care management programs for an IPA) will have to determine whether the management organization is contracted for these activities and whether the IPA physicians are interested in having their patients participate in the program.

Your organization may decide to offer the CE to all PWD or only to a subset. If offering only to a subset, the criteria used should identify PWD and CG(s) who could benefit most from additional support. This could be based on a provider's impression of need—for example, if the CG is stressed, the PWD's condition is particularly complicated to manage, community supports are underutilized, or the PWD's utilization of emergency-related care is high. Self-selection could also be helpful—for example, the program could be described to all PWD and CGs, and they could be asked whether they think they would derive benefit from the program.

### **Set Up and Track Outreach:**

Your organization will need to: identify a person who can do initial outreach to prospective dyads and manage enrollment for the dyads, and establish a tracking system. The tracking system needs to track potential dyads, their contact history, and their decision regarding enrollment.

The person in your organization who has been identified as responsible for outreach will contact eligible dyads by phone, by mail, or in the clinic (if you are implementing a clinic-based model). The document provided below, [“What to expect from the Care Ecosystem,”](#) was a useful resource for both UCSF and UNMC.

During outreach, the following information should be collected:

- Patient name
- Patient date of birth
- Dementia diagnosis and date initially diagnosed
- Primary Care Provider name
- Primary Care Provider contact number
- Approval to contact patient or caregiver
- Number of contact attempts
- Whether the Dyad wants to participate
- If care is declined, whether future outreach is desired
- Whether the information packet was sent

#### **Obtain Authorization:**

Once the dyad agrees to join the program, the person coordinating outreach will need to obtain documentation that the CG is authorized to discuss and disclose the PWD’s medical care. A sample authorization for medical disclosure form is provided from the State of California. Your organization should use a form authorized by your internal risk and legal department.

#### **Set Up the Case:**

UCSF and UNMC tracked the following information for enrolled dyads:

- Caregiver name
- Caregiver contact number
- CTN assigned to the dyad
- Patient name
- Patient date of birth
- Dementia diagnosis and date initially diagnosed
- Dementia subtype (e.g., Alzheimer’s disease, frontotemporal dementia, not otherwise specified)
- Primary Care Provider name
- Primary Care Provider contact number
- Authorization to disclose health information received

#### **Administer Baseline Survey:**

Your organization will decide what information to gather on a baseline survey. UCSF and UNMC used a baseline survey to assess caregiver burden and gather utilization information about the PWD. The survey guide below was developed based on the learnings from the various implementations and was crafted to meet the many data needs of a care program, such as resource utilization, caregiver burden, quality of life questions for both the PWD and the

CG, and general satisfaction with the program. It is suggested that the survey be repeated with a frequency that supports a longitudinal survey methodology.

### Supporting Materials:

- [Care Ecosystem Needs and Assessment Survey Guide](#)
- [Sample Authorization for Release of Medical Records](#)

## CASELOAD

Once the dyad has been enrolled in the program, they are assigned to the CTN who will be their primary contact. There are a number of factors that impact CTN caseload size and your organization will need to determine the appropriate caseload for your CTNs. Based on UCSF's and UNMC's experience in the research study, an active caseload of 60–80 dyads constituted a full load for monolingual English speaking dyads and CTNs. However, for bilingual dyads and CTNs (for which the CTN had the added responsibility of translating), a caseload of 50–60 dyads was appropriate. Depending on the mix of PWD in any CTN's caseload and the length of time that the dyad has been enrolled in the CE, CTNs may be able to carry even higher caseloads. The Care Management Institute Guidelines by the American Association of Managed Care Nurses can be found [here](#) and offer guidance as to appropriate caseloads based on the type of care management program implemented.

## INTAKE

Your organization may have an established intake process for new cases. The following information is provided based on best practices identified in the current implementation of the CE model, and your organization may choose to adapt it.

Once a dyad has been assigned to a CTN, the CTN makes an introductory call to the dyad, explains that they will be receiving a welcome packet (see Supporting Materials below) and schedules an intake call. If the CTN is unable to make contact, a welcome packet is mailed along with the request that the CG reach out directly to schedule an introductory call. As the intake call can take between one and two hours, it is important to set clear expectations for the length of the first call and let the CG know that the follow-up calls can be much shorter in duration. It is helpful for CTNs to have a personalized letterhead template in a Word document and business cards to include in correspondence with the dyads.

The Intake process is both an opportunity to build rapport with the dyad and to conduct an initial needs assessment. Before the Intake call is initiated, the CTN reviews all enrollment documentation (including any medical records if available), as well as the results of the baseline survey. It may be helpful for the CTN to create a document containing a brief snapshot of the dyad prior to the Intake call.

During the call, the CTN presents the dyad with an overview of the CE program, explains the CTN's role, and uses a templated series of questions to identify immediate needs. The Intake call is also used for the CTN to assess the immediate needs of the dyad. While Medication Reconciliation protocol is presented in the CE model as the first protocol to be completed, the CTN should initiate the protocol that meets the dyad's most immediate needs first. For example, if the CG expresses a need for personal mental health support, the first protocol to be completed is Caregiver Well-Being. Although there is a default order for the care protocols, one of the cornerstones of the CE is that the CTN delivers them in the order that the dyad needs them and does not need to adhere to the prescribed order.

During the Intake call, the CTN ideally:

- Obtains contact information
  - Confirms contact preferences
  - Confirms PCP information
- Gathers details on current situation
  - Current living situation
  - PWD's caregiving needs
  - Current respite arrangements or plans towards getting respite
  - Challenges
- Gathers information on PWD's medications
  - Depending on the situation of the dyad, the CTN may use the CE Medication Reconciliation protocol
  - Current list of prescribed medications the PWD is actually taking
  - Current list of over the counter medications and supplements the patient is actually taking
  - Systems PWD and CG use to ensure medications are taken appropriately
  - Tobacco, alcohol, and marijuana usage
  - Side effects and allergies
- Administers the Neuropsychological Inventory (NPI-Q)
  - Review of 12 behaviors common in patients with dementia
- Summarizes and discusses next steps:
  - Summarizes needs identified during the call, works with dyad to prioritize the needs, and comes up with a follow-up plan
  - Reviews the length of the engagement and the possibility of a graduation process that initiates approximately 12 months post-intake and indicates that the dyad has received all available resources in the CE
  - Explains the packet that will be sent post call
  - Explains the packet that will be sent to PCP and Specialists
  - Negotiates frequency of calls based on dyad's needs and preferences and schedules next call

During or immediately following the Intake call, the CTN will document his/her findings in your organization's electronic system. Your organization may find it helpful to see the template (see link below) developed by the UCSF research team. The UCSF team pasted this template into their encounter tracking system and the CTNs completed it during the Intake call.

After the completion of the intake call, the CTN will complete a series of post-call tasks. The CTN consults with the clinical team as needed, submits medications for the pharmacist to review, and creates a packet of information to be sent to the dyad that is specific to the needs identified during the call. The packet will include: a cover letter that includes the time and date of the next scheduled call, the individualized care plan, and referrals and resources specific to the needs assessed during the call. The UCSF and UNMC teams found that CGs were

sometimes overwhelmed with the volume of educational content available online, and appreciated receiving a curated packet of resources.

### Supporting Materials:

- Sample Welcome Packet
  - [What to Expect from the Care Ecosystem](#)
  - [Introduction to Behavioral Changes](#)
  - [Taking Care of You: Self-Care for Family Caregivers](#)
  - [DICE: A Tool for Understanding and Responding to Behavior](#)
- Intake Instruction
- IntakeNotes Template
- Top Tips for Building and Preserving Rapport With Dyads
- Neuropsychological Inventory (NPI) toolkit

## DEVELOPMENT OF INDIVIDUALIZED CARE PLANS

Following the Intake call, the CTN creates an individualized Care Plan that is mailed or emailed to the CG. The Care Plan outlines the dyad's current needs, issues, and goals and contains information and resources to help address them. UCSF and UNMC developed a template that is provided in a link below. Your organization will need to train the CTN to edit the template to complete only the sections relevant to the Intake call and remove any sections that were not covered during the call. The template will also be used over time and sections relevant to the dyad will be included in future versions. The care plan will be updated every 3–6 months as the dyad proceeds through the CE protocols.

If your organization wants to meet billing and reimbursement requirements of fee-for-service billing codes (described in the Funding Model section of this toolkit), you will need to factor this into your planning for tracking key metrics and in your care planning process. For example, your organization will need to assess how your process would fulfill the requirements for Medicare's G505 code, most of which are covered by CE Protocols.

A copy of the care plan (a sample of which is shown in Figure 5) will be sent to the CG (either electronically or through the mail) at regular intervals, as negotiated between the CTN and the dyad (typically every 3–6 months).

### Supporting Materials:

- [Comprehensive Dementia Care Plan Template](#)

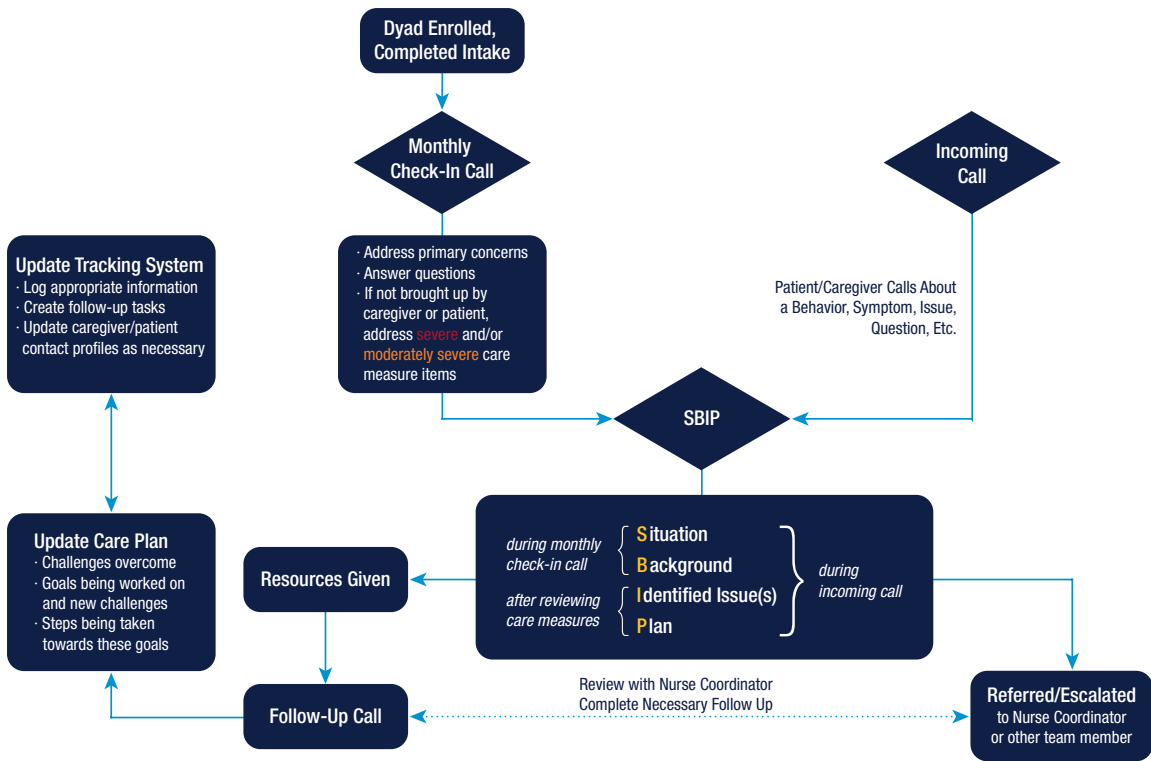
## ONGOING CONTACTS WITH CAREGIVER

During the Intake call, the CTN and CG will decide on the frequency of contact by phone and email. Over the course of these calls, the CTN and the dyad will progress through the CE protocols in an order tailored to meet the needs of the dyad. Details of the protocols are found in *Section 4: Care Ecosystem Protocols*. At UCSF and UNMC, CTNs found that scheduling monthly calls of 15–30 minutes was sufficient for most dyads. Figure 6 depicts the CE workflow in a typical system.

**Figure 5.** The Care Ecosystem Care Plan

Care Plan	Care Plan
<p>Date: _____                      Patient Name: _____ Caregiver Name: _____</p> <p><b>Care Team Contact Information:</b>                      CTN: INSERT PCP and/or specialist, case manager info here</p> <p><b>Goals:</b></p> <p><b>Medical Summary and Plan:</b>                      CTN: INSERT assessment/plan section including specific referrals or medical recommendations from provider and ability to participate in medical decisions</p> <p><b>Red Flags to Report to your Doctor:</b>                      Here are signs and symptoms that you should tell your doctor about right away:</p> <ul style="list-style-type: none"> <li>• Weight loss, change in appetite, or problems with swallowing</li> <li>• Changes in bowel or bladder habits like new incontinence or diarrhea</li> <li>• Any sudden change in behavior, sleep, or energy level</li> <li>• Aggressive, violent, or distressing behaviors</li> <li>• Alcohol or other substance use</li> <li>• Tearfulness, crying, or anxiety</li> <li>• Signs of possible infection like coughing, pain, upset stomach, rash, or fever</li> <li>• Signs of other medical problems like pain, swelling, or shortness of breath</li> <li>• Falls or accidental injury</li> </ul> <p><b>Medications</b>                      Here is a list of the medications your doctor ordered to help you stay healthy as of [date]. If you have any questions about your medications, please contact your doctor or pharmacist.                      CTN: INSERT medication schedule</p> <p><b>Medication Safety Tips:</b></p> <ul style="list-style-type: none"> <li>• Keep a routine to help you take your medications on time</li> <li>• Use a pillbox, alarm, and/or a notebook to help you remember</li> <li>• Ask someone to help you manage your medications if you have difficulty</li> </ul>	<ul style="list-style-type: none"> <li>• Tell your doctor about any medication side effects, for example: upset stomach, constipation, diarrhea, dizziness, drowsiness, itchy skin rash, headache, confusion, or balance problems.</li> <li>• For medication discounts and cost comparisons, go to <a href="http://www.GoodRx.com">www.GoodRx.com</a>.</li> <li>• Questions about prescription coverage through Medicare Part D:                             <ul style="list-style-type: none"> <li>• Contact your local Health Insurance Counseling and Advocacy Program (HICAP) office at 1-800-434-0222. You can also go to the California Health Advocates website for more information: <a href="http://www.CAHealthAdvocates.org/HICAP">www.CAHealthAdvocates.org/HICAP</a>.</li> </ul> </li> <li>• For more detailed information about your medications, go to <a href="http://www.Drugs.com">www.Drugs.com</a>.</li> </ul> <p><b>Take Care of Yourself</b>                      Here are some ways to promote health and independence.</p> <ul style="list-style-type: none"> <li>• <b>Self-Check Tool for Patients and Caregivers</b>  <a href="https://drive.google.com/file/d/0B2eIApcDPpJPWnZIR16UkHnsMW8/view?usp=sharing">https://drive.google.com/file/d/0B2eIApcDPpJPWnZIR16UkHnsMW8/view?usp=sharing</a></li> <li>• <b>Make a Routine</b>                      Use a calendar and make a list to manage your schedule and help you keep track of what to do. Try to do daily tasks at around the same time most days of the week.</li> <li>• <b>Reduce Clutter and Get Organized</b>                      Put things you use often within reach where you can see them easily. Labels or brightly colored containers can also be helpful.</li> <li>• <b>Eat Well and Stay Hydrated</b>                      Keep snacks and a water bottle with you throughout the day. Eat a lot of fruits and vegetables. Have lunch with friends at the senior center. Sign-up to have meals delivered to your home. Check the expiration date on your food before eating it. Throw away spoiled food to avoid getting sick.  <a href="https://drive.google.com/file/d/0B56wwcdIF4qmeTINU2kxeG13RG8/view?usp=sharing">https://drive.google.com/file/d/0B56wwcdIF4qmeTINU2kxeG13RG8/view?usp=sharing</a></li> <li>• <b>Stay Well Groomed</b>                      Change your clothes daily or at least when they become soiled. Brush and floss your teeth twice a day. Try an electric toothbrush, and fluoride toothpaste and mouth rinse for better oral care. Bathe or shower at least twice a week. Trim your finger and toe nails every few weeks, consider going to a nail salon for a manicure and pedicure.</li> <li>• <b>Stay Physically Active</b></li> </ul>
1	2

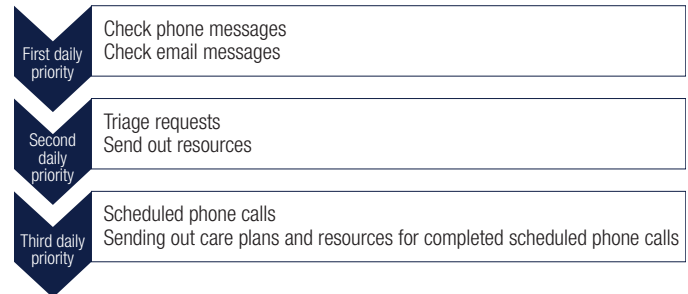
**Figure 6.** The Care Ecosystem Workflow



CGs may initiate contact with the CTN outside of scheduled calls. The CTN will treat these calls in a way consistent with your organization's triage protocols and typical response times for other inbound patient-led communications. If the needs expressed are beyond the skill set of the CTN, the CTN will ask for assistance using a process such as the one described in the Escalation Guidelines below.

### Workflow Management

The CE requires tracking and management of tasks and workflows, and your organization will already have access to a number of software and organizational tools that you can leverage to track the daily activities of the CTN and the rest of the care team. At UCSF and UNMC, CTNs found that the most efficient way to keep track of their scheduled calls was through the use of their individual calendars attached to their organizational email addresses, rather than through a centralized scheduling system.



**Figure 7.** The Care Ecosystem Daily Tasks

Your organization will also need an operational dashboard for the CTNs, which can be located inside a medical record, outside a medical record in a database or spreadsheet, or in a comprehensive care management system that is intended to track care interventions. The dashboard is a summary of contacts with the dyad (either inbound or outbound calls), as well as a place to document which protocols have been completed and what protocol is scheduled next. Details of the encounter should each be recorded in a separate entry that clearly identifies the date of service, documents the progression of the care plan, and indicates which resources have been shared with the CG. These elements are important both from the perspective of monitoring patient care and the purposes of billing for care.

The daily tasks of the CE should be managed after any incoming calls or emails are triaged and flagged for follow up. The escalation process that is used to triage clinical or behavioral issues during all calls should be utilized to assess the requests that are generated when a CG proactively calls the program for resource support.

## ESCALATION GUIDELINES, TOOLS & PROCESS

While the CTN will be capable of managing the non-clinical resource needs of most dyads, there will be some instances in which the clinical team should be leveraged as the dyad needs will be beyond the scope of work for the CTN. The current implementations of the CE program have identified some warning signs and red flags that CTNs should be aware of:

- The CG describes a complex situation that is difficult to sort out and prioritize a plan
- The CG verbalizes feelings of resentment, guilt, or being burdened by their responsibilities
- Situations where the PWD is presenting distressing, aggressive, or threatening behaviors
- The CG expresses symptoms of severe depression or suicidal ideation
- The PWD or CG are not sleeping well and this is causing distress for the CG
- The PWD's safety seems to be at risk and the CG does not seem to recognize the seriousness of the situation (e.g., the PWD is still driving even though their license was revoked, the PWD is falling a lot, or wandering and getting lost and the CG is not taking any action to try to protect the PWD)



- The PWD seems to be in a situation where their needs might be neglected or they may be emotionally or physically abused
- The PWD is making frequent and potentially inappropriate Emergency Department or hospital visits
- The CG is repeatedly unable to facilitate change based on the suggestions and resources provided by the CTN
- The CTN has concerns about clear communication or believes there is a barrier to building rapport
- The PWD or CG has a rapid change in health status

Your organization will need to decide what the CTN should do if he/she identifies one of these red flags. Your organization should have plans in place to address suicide ideation and suspected abuse or neglect.

The outline in Figure 6 details the process at UCSF and UNMC, and the escalation tool they developed is also provided here as an example. Your organization will need to review this tool before and adapt it to fit your needs and any legal or regulatory requirements you may have.

UCSF and UNMC found that it was important for a CTN's manager to ensure that the CTN adhered to the scope of his/her role and did not become overwhelmed. Over time, CTNs will be able to identify statements or situations that require clinical support. In addition, ongoing case reviews will help CTNs acquire the knowledge about what to do in situations like those identified above.

#### **Supporting Materials:**

- [Behavior Escalation Tool](#)

## **TEAM MEETINGS**

Having a dedicated time for the multidisciplinary CE team to meet to complete case reviews, to problem solve, and to support the CTNs was critical at UCSF and UNMC. These meetings played a key role in supplementing the ongoing, daily clinical support that the CTNs received through the Escalation Process described above. Based on the experience of UCSF and UNMC, some key uses of weekly team meetings were:

- Clinical debriefings and case reviews
- Identifying operational improvements
- Ongoing education
- CTN support around stress and coping (i.e., group session for CTNs only facilitated by social worker or psychologist)

#### **Supporting Materials:**

- [Care Ecosystem SBIP Presentation Template](#)

## **CARE COORDINATION PRACTICES/ENGAGING PROVIDERS**

The CTN works to educate CGs and equip them with tools to advocate for the PWD. However, it is critical that the CTN represent the CE tools in ways that will be seen by the PWD's providers and other care team staff as a benefit to them, not just the dyads. If your organization is a health system, you may be able to identify a strong physician

champion for the CE and use this leader to communicate with other providers. This champion could be supported by an overall communication plan, including presentations at provider meetings and success stories from CGs and patients helped by the CE. In the implementation at Allina, they discovered that some of the CE training materials about aging and dementia were valued by seasoned clinical staff. Sharing the data and materials might help your organization to increase buy-in among providers.

UCSF and UNMC developed some sample communication templates, which are shared below as examples.

### Supporting Materials

- [Intake Provider Update](#)

## CARE TRANSITIONS

Over time, PWDs will need more care and supervision to help them stay healthy and safe. The CTN may need to support the CG as they deal with increasing needs, including choosing care options, introducing new caregivers, and introducing a new home. UCSF and UNMC gathered materials (shared here) which your organization may find helpful to guide those discussions.

### Supporting Materials:

- [Dealing with Increasing Caregiving Needs](#)
- [Overview of Care Options](#)
- [Tips for Introducing a New Caregiver](#)
- [Tips for Introducing a New Home](#)

## GRADUATION PLANNING

The programs at UCSF and UNMC found that the need for support was more intense at the beginning of the program and tapered down over time for most dyads. By the 12-month mark, most of the protocols had been completed and calls between the CTN and the CG were required less frequently for the CGs. In the initial UCSF and UNMC research studies, the CE model included tapering down support and even graduating some dyads from the program. Your organization will need to determine the length of your intervention, including whether to transition dyads to a less-intensive maintenance mode as they complete the CE protocols.

The caregiver burden, initially measured by the intake interviews and baseline survey, should be diminished before any tapering process begins. Each organization will set its own threshold for low burden by using the data gathered during the follow-up surveys, assessing the effectiveness of interventions and any ongoing needs as communicated by the CG to the CTN. Once the CTN has provided all available resources and the CG has received all available interventions, the relationship between the CTN and the CG may shift to a primarily emotionally supportive role rather than a proactive interventional role. At this point, the activities of the CTN could be refocused on dyads who have more potential to benefit from the core protocols and resources. Nevertheless, the challenges of dementia care change throughout disease progression and a dyad who is functioning well now may require additional support at a later time. The ability to return as needed for support at a later time should be clearly explained to the dyad during the graduation process.

Learnings from the experience of UCSF and UNMC suggest that setting expectations at the beginning of the program is an imperative. Your organization will need to determine whether to have a process of tapering down support or graduation plan for dyads in the CE program. It is important to communicate this to the dyad at the beginning of the program and remind them over time. It is also important to reinforce the idea that if the CG identifies new unmet needs, the dyad is welcome to reinitiate contact with the CE team.

#### Supporting materials:

- [Graduation Instructions](#)
- [Community Resource List](#)

## PROCESS IMPROVEMENT FEEDBACK LOOP

As with any program, your organization will have opportunities to personalize the CE model and protocols to best fit your needs. We recommend having a deliberate process improvement orientation so that you are on the lookout for inefficiencies, as well as for ways to innovate and modify the protocols. For example, based on their experience and feedback from CGs, UCSF and UNMC modified the program several times during the first year of the program. During weekly team meetings, your team should consider common issues that they face and create new materials and processes that are specific to the resources available at your organization. As mentioned earlier, feedback from CGs may also identify areas for improvement or innovation. All feedback – whether delivered during the satisfaction surveys, ongoing calls with the CTN, and other outlets through which CGs share their experiences – should be considered as valid sources for identifying opportunities for improvement.

## FUNDING MODEL FOR A CARE ECOSYSTEM PROGRAM

Your organization may need to make the business case for the costs and benefits of implementing the CE program. While each organization will differ (e.g., current services and clinical capabilities, geographically, or in terms of how you are implementing the model), there are some key inputs to a financial model that you may want to consider:

#### Costs:

Potential costs may include:

- **Staffing:** Any additional staffing costs, e.g., CTN salary and benefits, as well as any salary support for clinical staff supervising and supporting the CTN.
- **Space:** workspace for the CTN
- **Equipment:** telephone, furniture and computer support associated with additional staff
- **Systems:** Any costs to adapt your electronic systems so that CE services are tracked and documented, creation of the PWD's care plan, and the production of any other documents for the PWD and CG to ensure compliance with Medicare or other billing requirements

#### Revenue:

Potential revenue may include:

- Medicare's chronic care management program's monthly fee for chronic care management; the monthly fee may help to cover the cost of the CTN
- Consultation services provided by the CE clinical team, e.g., E&M codes and other billing codes (see Table 2)

- Other clinical services provided by the CE clinical team or a licensed Navigator “incident to” physician services (for Medicare)
- A Commercial or Medicaid payer that pays your organization a care management or coordination fee that may help to cover the CTN salary
- Performance-based revenue enhancements, such as those under MACRA – Merit-Based Incentive Payment System or Alternative Payment Models, that are based on Quality scores and Clinical Practice Improvement Activities; the CE may contribute to those for Neurology, Integrated Behavioral and Mental Health, and Dementia
- Self-pay by caregivers and families for home-based provider services
- The CE can also improve Medicare STARS quality scores (see [Medicare 2017 Part C & D Star Rating](#) and [CAHPS Clinician & Group Survey](#))

### Savings:

Potential savings that you may be able to quantify, using your own organization’s assumptions:

- Avoided hospitalizations
- Avoided readmissions
- Avoided ED visits
- Fewer duplicative services (e.g., care is more proactive, so PWD may require fewer in-person visits)
- Delayed or avoided skilled nursing admissions
- Delayed or avoided long-term care admissions

Organizations with risk-based financial arrangements may find the savings of the CE even more compelling since any savings may accrue directly to your organization. For example, accountable care organizations (ACOs) and organizations accepting a capitated payment for the care of a patient may find the financial benefits of the CE easy to illustrate. While the UCSF and UNMC Care Eco program has not yet published results, findings in an Inquiry article, “Medicare Expenditures Associated With Hospital and Emergency Department Use Among Beneficiaries With Dementia,” by Laura Coots Daras, MS, MA, et al. [journals.sagepub.com/doi/pdf/10.1177/0046958017696757](https://journals.sagepub.com/doi/pdf/10.1177/0046958017696757) may provide inputs to your planning.

Other useful sources for creating a balanced value proposition and a detailed return on investment are:

- The SCAN Foundation has a white paper and return on investment calculator for person-centered care (including sample assumptions) that you may find helpful to review at [www.thescanfoundation.org/business-case-person-centered-care](http://www.thescanfoundation.org/business-case-person-centered-care)
- UCLA’s Alzheimer’s and Dementia Care Program has shared results that show how reduced caregiver stress and depression affect the cost of care and that can be found at [dementia.uclahealth.org](http://dementia.uclahealth.org)
- The Johns Hopkins MIND at Home program reports how costs from admission to long-term care for a PWD can be delayed or avoided and is found at [www.mindathome.org/publication](http://www.mindathome.org/publication)

**Table 2.** Fee-for-Service Revenue Considerations\*

**Fee-for-Service Billing Codes to Support Care Ecosystem Services**

<b>Chronic Care Management</b>	
<b>CPT 99490</b>	<p>Chronic care management services, at least 20 minutes of clinical staff time directed by a physician or other qualified healthcare professional, per calendar month, with the following required elements:</p> <ul style="list-style-type: none"> <li>• Multiple (two or more) chronic conditions expected to last at least 12 months or until the death of the patient</li> <li>• Chronic conditions place the patient at significant risk of death, acute exacerbation/decompensation, or functional decline</li> <li>• Comprehensive care plan established, implemented, revised, or monitored</li> </ul> <p>Assumes 15 minutes of work by the billing practitioner per month.</p>
<b>CPT 99487</b>	<p>Complex chronic care management services, with the following required elements:</p> <ul style="list-style-type: none"> <li>• Multiple (two or more) chronic conditions expected to last at least 12 months, or until the death of the patient</li> <li>• Chronic conditions place the patient at significant risk of death, acute exacerbation/decompensation, or functional decline</li> <li>• Establishment or substantial revision of a comprehensive care plan</li> <li>• Moderate or high complexity medical decision making</li> <li>• 60 minutes of clinical staff time directed by a physician or other qualified healthcare professional, per calendar month</li> </ul>
<b>CPT 99489</b>	<p>Each additional 30 minutes of clinical staff time directed by a physician or other qualified healthcare professional, per calendar month. (List separately in addition to code for primary procedure.)</p>
<b>Medicare Cognitive Impairment Assessment</b>	
<b>HCPCS G0505 (CPT 99483 as of January, 2018)</b>	<p>Provides enhanced reimbursement to physicians and other eligible billing practitioners for a clinical visit that results in a comprehensive care plan (\$238).</p> <p>Requires a cognition and functional assessment using standardized instruments with development of recorded care plan for the patient with cognitive impairment, history obtained from patient and/or caregiver, in office or other outpatient setting or home or domiciliary or rest home. Reimbursement not available if assessment is provided by telephone.</p>
<b>Advance Care Planning</b>	
<b>CPT 99497</b>	<p>Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified healthcare professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate.</p> <p>May be provided and billed on same day as Annual Wellness Visit.</p> <p>(\$86 in doctor's office; \$80 in hospital)</p>
<b>+CPT 99498</b>	<p>Each additional 30 minutes. (List separately in addition to code for primary procedure.) (Use 99498 in conjunction with 99497.) (Do not report 99497 and 99498 on the same date of service as 99291, 99292, 99468, 99469, 99471, 99472, 99475, 99476, 99477, 99478, 99479, 99480.)</p> <p>May be provided and billed on same day as Annual Wellness Visit.</p> <p>(\$75)</p>

The following is a description of the Care Plan requirement for the Chronic Care Management Services.

#### Comprehensive Care Plan

- A person-centered, electronic care plan based on a physical, mental, cognitive, psychosocial, functional, and environmental (re)assessment, and an inventory of resources (a comprehensive plan of care for all health issues, with particular focus on the chronic conditions being managed)
- Provide the PWD and/or CG with a copy of the care plan
- Ensure the electronic care plan is available and shared in a timely manner within and outside the billing practice to individuals involved in the PWD's care
- Care planning tools and resources are publicly available from a number of organizations
- Although patient cost-sharing applies to the CCM service, most patients have supplemental insurance to help cover CCM cost sharing. CCM may also help avoid the need for more costly services in the future by proactively managing patient health, rather than only treating severe or acute disease and illness.

Comprehensive Care Plan – A comprehensive care plan for all health issues typically includes, but is not limited to, the following elements

- Problem list
- Expected outcome and prognosis
- Measurable treatment goals
- Symptom management
- Planned interventions and identification of the individuals responsible for each intervention
- Medication management
- Community/social services ordered
- A description of how services of agencies and specialists outside the practice will be directed/coordinated
- Schedule for periodic review and revision of the care plan

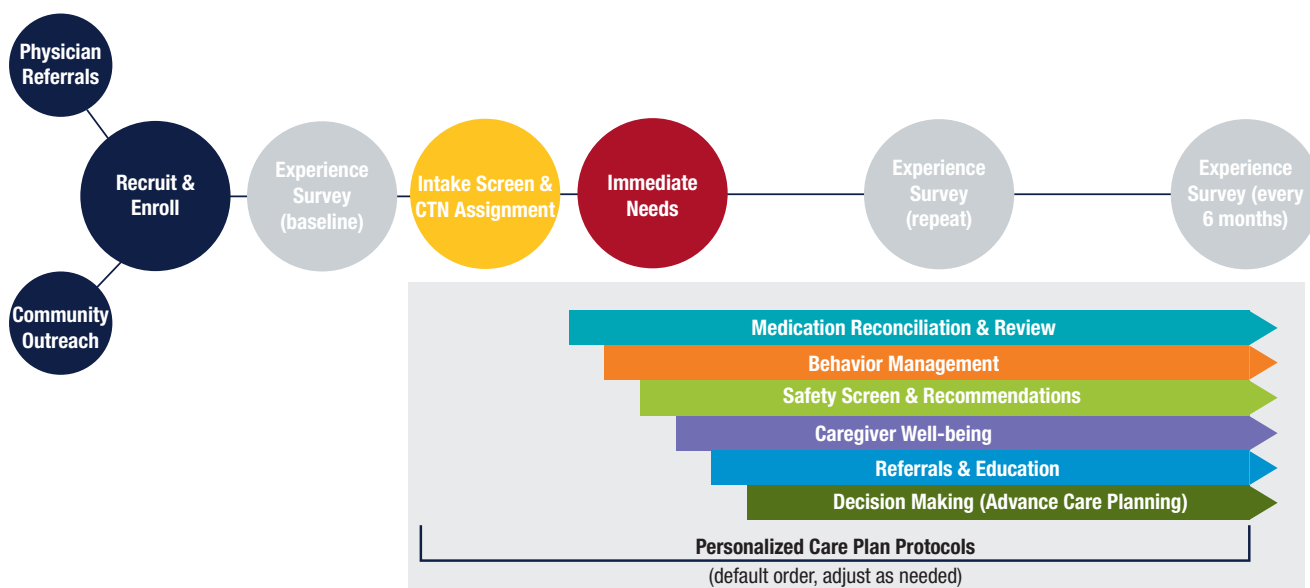
#### Supporting Materials:

- [Medicare Expenditures Associated with Hospital and Emergency Department Use Among Beneficiaries with Dementia](#)
- [Medicare's Cognitive Impairment Assessment and Care Planning Code](#)
- [DHHS Chronic Care Management Services](#)
- [Frequently Asked Questions about Billing the Physician Fee Schedule for Advance Care Planning Services](#)

# SECTION 4: CARE ECOSYSTEM PROTOCOLS

The CE model is centered around a set of care protocols. The research study identified a default order for delivering the protocols but also found that delivering them flexibly to meet the needs of each dyad was most successful. Baseline information about the PWD’s behavior is collected during the intake process and used to determine the best protocol order to follow. It is recommended that Medication Reconciliation and Review occur within the first month of engagement and be updated during every contact with the dyad. As depicted in Figure 4, the default order of the protocols is: Immediate Needs Assessments; Medication Reconciliation and Review; Behavior Management; Safety Screen and Recommendations; Caregiver Well-Being; Referrals and Education; and Advance Care Planning.

Your organization should consider developing standard packets of materials for each protocol (sections below have examples and templates) for both the CG and PWD and storing them in a shared drive or electronic location where they can easily be accessed by the CTN. You may also consider having materials translated and available in whatever languages are most prevalent in the population enrolled in the CE program.



**Figure 4.** The Care Ecosystem operational details

## IMMEDIATE NEEDS

### Goal:

Create a baseline understanding of the dyad’s current needs, issues, and goals in order to craft a care plan to help address the dyad’s care needs in priority order.

### Why This Is Important:

The CE model is based on the notion that while many PWD have similar needs, the order in which those needs are addressed should be based on the order of importance identified through conversation with the CG.

## MEDICATION RECONCILIATION & REVIEW

### Goal:

Reduce medication-related problems, prevent adverse drug events, optimize health outcomes, and improve quality of life for PWD.

### Why This Is Important:

Adverse drug events (ADEs) are common. An ADE is defined as any injury resulting from medication use, including physical harm, mental harm, or loss of function. Each year, ADEs in the outpatient setting account for over 3.5 million physician office visits, an estimated 1 million emergency department visits, and approximately 125,000 hospital admissions. About 33% of community-dwelling older adults experience an ADE annually. Most ADEs are due to suboptimal prescribing, poor communication and inadequate monitoring or follow up. ADEs can include:

- Medication errors
- Adverse drug events, reactions, and side effects
- Over or underdosing
- Drug interactions

ADEs are often mistaken for the onset of a new illness, which then leads to prescribing unnecessary drugs. The good news is that many ADEs are preventable. Reducing ADEs leads to safer and better health care services, reduced healthcare costs, more informed and engaged consumers, and improved health outcomes.

### Key Activities:

- Perform an initial reconciliation of all medications (prescription, over-the-counter, vitamins, supplements)
- Continue to screen periodically for medication issues
- Support the PWD-CG dyad by:
  - Responding to medication questions or concerns
  - Creating an up-to-date medication list and schedule that can be printed and displayed at home, as well as shared with all PWD's healthcare providers
  - Developing strategies to manage and appropriately use medications at home to optimize health outcomes

This toolkit describes the major steps of the CE Medication Reconciliation and Review process. Your organization can do this using paper, your electronic systems, or other means. The instructions below describe the high-level steps involved in gathering a complete medication history to reconcile and review a patient's medications, prevent ADEs, and optimize their drug therapy.

At UCSF and UNMC, the CE uses medication software called [mHealthCoach](#) to create a personalized medication schedule and screen for inappropriate or high-risk medications. Use of the mHealthCoach software is optional and may not be necessary for organizations and institutions managing patients within their own medical record system. If you are interested in using mHealthCoach, please contact our team at [careecosystem@ucsf.edu](mailto:careecosystem@ucsf.edu).

There are four key steps involved in medication reconciliation and review:

1. Reconcile the PWD's medications:
  - a. Review use of all prescription, non-prescription, supplements, vitamins, and herbal products.



- b. Describe what they are actually taking and note if this differs from what has been prescribed or the medical records you have access to.
2. Screen for any possible medication issues, including side effects, issues with adherence, and PWD and CG perception of the efficacy of the medications.
3. Obtain a comprehensive medication review by a trained pharmacist, physician, or nurse to evaluate appropriateness, efficacy, and safety of current medication use.
4. Develop a medication care plan including education, counseling, and recommendations for the PWD and CG. Include materials that can be printed out and used at home, as well as communications for the PWD and CG to share with the PWD's prescribing clinicians or clinical team should there be any recommendations to stop, start, or adjust medications.

The CTN should re-review the medication care plan at each follow-up session with the dyad, document any changes, and get answers to any new questions.

### **Roles & Resources:**

The *CTN* is the primary contact with the PWD and CG. They receive support from a trained pharmacist, physician, or nurse for medication screening, clinical review, and development of the medication care plan. Once the CTN has completed a medication history, reconciled current medications, and documented current medication use in an updated medication list, the pharmacist (or other trained clinician) will optimize drug therapy by conducting a comprehensive medication review, screening for inappropriate or suboptimal therapy, drug interactions, and other potential medication-related problems.

The *pharmacist* (or other trained clinician) will provide written and/or verbal education and counseling points that can be relayed by the CTN to the dyad. Examples include: drug and non-drug education and interventions, strategies to manage side effects, ways to improve adherence, and opportunities to reduce drug costs. In addition, the pharmacist will provide written recommendations, which can be relayed by the CTN or CG to the prescribing physicians regarding drug or non-drug interventions to reduce ADEs or optimize drug therapy. Examples include stopping or substituting unnecessary, inappropriate, or high-risk medications for safer alternatives; adjusting doses or frequencies up or down; starting new medications; implementing non-drug strategies; and any recommended monitoring parameters.

The *clinical team* supports the CTN. Depending on your organization, there are different options for support – from within or outside of your organization. For example, a consulting pharmacist with expertise in geriatrics and/or dementia care is ideal. However, the neurologist or geriatrician caring for the PWD may also have the appropriate expertise to support a CTN who is embedded in a clinic setting. You will need to evaluate the resources in your setting to identify what is most appropriate. The UCSF team would be willing to consult with you if you have questions or concerns as you set up your organization.

### **Supporting Materials:**

- [Caregiver Medication Resources](#)
- [MARQUIS Handout: How to Do a Medication History](#)
- [MARQUIS Pocket Card: Best Possible Medication History](#)

## BEHAVIOR MANAGEMENT

### Goal:

Provide personalized assistance with management of dementia-related behavioral symptoms that is in keeping with the dyad's care plan and focused on their values and resources.

### Why This Is Important:

Behavioral symptoms such as apathy, irritability, sleep disturbance, anxiety, and delusions are common in dementia and are a significant source of stress and burden for CGs. Behavioral symptoms are multifactorial; they are influenced by the type of dementia the person has and the area of their brain that is affected. For example, visual hallucinations occur commonly with Lewy body dementia but are less common in frontotemporal dementia. Behavioral symptoms may also be influenced by CG's personality or communication style, environmental factors, and the patient's personality and personal history. Some behaviors can be annoying, while others can be hazardous. The CE model helps identify the differences and ensures that the right interventions are delivered for all problematic behaviors.

### Key Activities:

- During the intake call, the CTN completes the Neuropsychiatric Inventory (NPI-Q), which asks about 12 behaviors common in dementia. The NPI is completed with the CG. To speed up administration, the CTN does not have to require the CG to rate the severity and distress associated with each behavior, although by the end of the call it is helpful to know what behavior(s) are the most distressing for the caregiver.
- For any behavior endorsed, the CTN asks open-ended questions and records responses to learn more about the behaviors and how distressing they are to the patient and the CG. CTNs ask targeted questions from the escalation tool, such as what strategies have been tried, what has worked, and what has made things worse.
- The CTN may offer some ideas or suggestions derived from the training and educational materials in addition to validating the CG's experience. The CTN sends informational handouts about the behaviors the CG endorsed in the NPI.
- Challenging and distressing behaviors will be escalated to the nurse and pharmacist for input. The social worker may also be included for help with CG counseling, respite, or placement needs. Depending on the severity of distress, the CTN may wait to bring up the issues during the weekly debriefing session.
- The CTN follows up with CG to see how new strategies and/or medication changes are working and if there are any unintended consequences or side effects.
- When challenging behaviors are not resolved, the CTN will proactively provide education about communication, delirium, and common personality and behaviors changes in dementia.
- The Behavior Management protocol content is interwoven in each scheduled call with the CG as the CTN asks the CG about any changes in behavior or function.
- The CTN repeats the NPI screen annually to ensure that the CTN and CG are addressing the behavioral needs of the patient in a comprehensive manner.

### Supporting Materials:

- [Delirium Handout](#)
- [DICE: A Tool for Understanding and Responding to Behavior](#)
- [Introduction to Behavioral Changes](#)
- [Apathy](#)
- [Communication](#)
- [NPI](#)

## SAFETY SCREEN & RECOMMENDATIONS

### Goal:

Provide personalized information, recommendations, and links to resources to help promote PWD safety both in-home and in the community or long-term care setting.

### Why This Is Important:

Persons with dementia face known safety risks that can significantly affect their health, including serious injury from falls, choking or aspiration due to swallowing difficulty, decompensation from wandering and getting lost, and accidents from driving or using household tools or appliances unsafely. These risks will vary in importance depending on each person's symptom profile and living situation. It is important to screen for existing issues and provide proactive education about other risks that may arise in the future so that CGs can plan accordingly.

### Key Activities:

- The CTN will work with the dyad, nurse, and social worker to
  - Talk with CG about identifying someone who could be their backup in case they get sick or anything happens to them
  - Clarify understanding of the dyad's situation including the PWD's function, mobility, and daily routine
  - Identify safety needs by screening for home safety issues including:
    - Falls and injuries
    - Accessibility of weapons
    - Use of tools and appliances
    - Wandering and getting lost
    - Signs of swallowing problems while eating or drinking
    - Driving and other transportation issues
    - Unmet need for protective supervision
    - CG concerns about future home safety/patient mobility
  - Complete the safety plan document with all of the pertinent information that should be posted prominently in the dyad's home
  - Follow up with the CG to assess if the safety plan needs to be modified and if the supporting resources were useful

### Supporting Materials:

- [Safety Plan](#)
- [CDC Check for Safety](#)
- [Safety Plan Case Notes Template](#)
- [Safety Plan Protocol Instructions](#)

## CAREGIVER WELL-BEING

### Goals:

Promote caregiver well-being and sense of preparedness in managing caregiving responsibilities. The CTN provides active listening, personalized assistance in identifying educational and support needs, and a problem-solving approach to support the CG.

### Why This Is Important:

Family CGs provide the bulk of care to people with dementia; thus supporting the CG becomes a key factor in dementia care. CGs face negative outcomes to their own health and well-being as a result of the demands of caregiving. Caring for a family member with dementia is associated with high rates of depression, anxiety, morbidity, and mortality. Additionally, CGs report having a decreased social network. A critical part of the CE model is to provide ongoing individualized support to CGs through links to educational and supportive community resources, by developing strategies to improve burdensome and stressful aspects of patient care, and by encouraging self-care, as well as the pursuit of their own personal goals.

Research has shown that providing education and support to CGs can alleviate some of these negative outcomes. According to the program impact assessment for the UCLA Alzheimer's and Dementia Care Program:

Before entering the program, many CGs reported they felt poorly informed and that they were fighting this battle alone.

- 13% were depressed
- 33% had high stress
- 62% felt that they didn't know where to turn for answers
- 76% believed that they had no healthcare professional to help with dementia issues

After receiving support via the program, 94% of the participants felt that their role was supported and 92% would recommend the program to others. By the end of a year, the following results were reported:

- Confidence in handling problems and complications of Alzheimer's disease and dementia improved by 72%
- Strain was reduced by 12%
- Depressive symptoms were reduced by 24%
- Distress was reduced by 23%

Additionally, despite disease progression, the program improved patients' health:

- Problem behaviors (agitation, irritability, apathy, nighttime behaviors, etc.) were reduced by 12%
- Depressive symptoms were reduced by 24%

### Key Activities:

- Validate the CG's experience, support their efforts, and build rapport
- Introduce CG to the idea that their health and well-being are priorities



Figure 8. Caregiver Interventions

- Identify and explore primary concerns and issues using questions from the Question Bank in the Caregiver Well-Being Workflow as guides for discussion
- Confirm plan for action items and/or goals if identified by the CTN/CG
- Plan/schedule next call to follow up on goals or action items, as appropriate
- Escalate to the nurse or social worker for issues that are beyond the scope of the CTN, for example, the social worker should be directly involved if the CG endorses severe depression and/or suicidal ideation
- Important community resources for CGs (e.g., respite, educational workshops, counseling, and therapy)

**Supporting Materials:**

- [Caregiver Well-Being Case Instructions \(workflow\)](#)
- [Caregiver Well-being Notes Template](#)
- [Taking Care of You: Self-Care for Family Caregivers](#)
- [The Stress of Caregiving: Dementia, Caregiving, and Controlling Frustration](#)

## REFERRALS & EDUCATION

**Goal:**

Provide personalized and anticipatory guidance to help the dyad manage their needs through the use of community resources. Counsel the dyad about the process involved in accessing services and provide information to help initiate services as smoothly as possible (i.e., Introducing a New Caregiver). The CTN may also provide education that may be useful in the future as the PWD's dementia progresses.

**Why This Is Important:**

There are volumes of information available in books and on the web. CGs want information and services that are reliable and relevant to their needs and they often do not have time to do the research necessary to find such resources. Additionally, many CGs state that well-intentioned healthcare staff, family, and friends offer all kinds of directive advice that they do not find helpful. By using a collaborative problem-solving approach, the CTN can better understand the CG's needs and be more effective in helping to identify information and resources to meet those needs. The CTN may also be in a position of working with the dyad to understand what resources are available to them and to adjust their goals and expectations accordingly.

**Key Activities:**

The CTN creates a plan of referrals and education for each dyad, identifies their specific needs and what resources can address those needs, and educates the CG on the ongoing resources available for the patient as the disease progresses.

- The CTN will work with the dyad, nurse and social worker to
  - Clarify understanding of the dyad's situation
  - Identify unmet need(s)
  - Establish goals related to unmet needs
  - Identify strengths, barriers, and referral options for meeting goals using the resource library to leverage community resources
  - Discuss referral options with the CG and support them in evaluating the different options for their needs/goals

- Follow up with the CG to assess if the goals were met or if additional resources or approaches/strategies are required
- Ongoing CTN tasks
  - Maintaining and updating resource directory and search tools
  - Developing a resource library of community-based services
  - Finding and vetting service providers

As mentioned throughout this toolkit, the resource library is the key tool for referrals and caregiver education. While there are many educational websites that offer support and ideas, these resources may be limited based on the location of the dyad. The local resources accumulated through experience with the dyads is the primary resource for referrals. In some communities, it is important to directly call local senior centers which may not have an online presence but are very knowledgeable about programs such as Meals on Wheels or respite opportunities, while in other communities a CTN can simply complete a Google query to identify resources. The CTN may be able to determine additional resources by contacting the patient’s insurer. Every dyad will have a different need and the outcome will create a different support plan; however, the social worker should work with CTNs to create a resource library that is shared amongst all the care team members so that they can best serve the next dyad who resides in the same community.

**Supporting Materials:**

- [The Dementia Curriculum](#)
- [Caregiver Education Websites](#)
- [Home Safety Websites](#)
- [CTN Resource Referral Protocol](#)
- [Overview of Care Options](#)
- [Community Based Resource Library Topics](#)

**DECISION MAKING (ADVANCE CARE PLANNING)**

**Goals:**

Facilitate ongoing and comprehensive advance planning for future medical, legal, and financial needs.

**Why This Is Important:**

Given the progressive nature of dementia, it is important to view Advance Care Planning (ACP) with the PWD as an ongoing process. While much of the literature discusses ACP for end-of-life care, the PWD must start the planning process early since they are likely to lose their ability to participate in decision making over time. Decisions about health care, housing, finances, and long-term support are critical for the PWD and their CGs.

Advance care planning includes discussions about:

- Clarification of values and goals
- Choosing someone the PWD trusts to help make decisions on their behalf when they lose capacity to do so independently

- The documentation of preferences in written legal forms and medical orders
- It is also important to consider planning for legal/financial/housing issues
  - Where will the PWD live?
  - Who will be responsible for meeting patient care needs?
  - Who will pay for care for the PWD?
- End-of-life care

Heyland and collaborators describe the general need for advance care planning in a 2013 *JAMA Internal Medicine* article. In their article, of 278 patients at high risk of dying in six months:

- Before hospitalization, 76% had thought about their future care. Of these:
  - 89% had discussions with someone
  - 48% had a living will
  - 73% had a designated agent
- Once in the hospital, 25% reported being asked about prior discussions or docs on admission
  - Of those with a preference, 28% did not have an order in the record stating the goal of care.
  - Of those with an order, 30% matched patient preferences.

#### **Key Activities:**

- Identify medical, legal, and financial planning status and needs
- Address dyad needs through targeted educational handouts and community referrals (e.g., lawyer) with supervision/input from the social worker
- Emphasize choosing a healthcare and financial agent and having a broad discussion of goals

Advance planning is not a one-time activity. In the CE model, early discussions focus on identifying values and decision making surrogates. Later, discussions can be more specific. Goals of early discussions should emphasize the appointment of healthcare and financial agents and then focus on preparing the agent. Throughout all of this, the CTN and the social worker must pay attention to differences in cultural, ethnic, and spiritual values that the dyad may hold.

The aims of advance medical planning aims depend on patient capacity. For example, a patient may have the capacity to appoint an appropriate agent but lack the capacity to make day-to-day decisions about their medical care or finances. Capacity is usually determined informally by a lawyer or physician. Adults are generally presumed to have capacity; many cases of medical incapacity are clear-cut. In some cases, MDs/lawyers seek an expert opinion from a psychiatrist for particular types of decisions or functional activities like managing finances or a psychologist who can apply formal tests of cognitive function and/or formal tests of capacity.

Health systems implementing the CE should consider access to a lawyer as part of the care team. There is an established national model for this called the [medical-legal partnership model](#). This model has demonstrated ROI to health systems, reductions in utilization, and improved chronic care management. It allows members of the healthcare team — including social workers and CTNs — to work at top of their scope and to meet needs they otherwise may not be able to address alone.

Table 3 provides a summary of key concepts in legal and financial planning.

**Table 3.** Key concepts in legal and financial planning.

	<b>Fiduciary is Called</b>	<b>Fiduciary Authority</b>	<b>Who Chooses</b>	<b>When Used</b>
<b>Durable Power of Attorney for Finances (DPOAF)</b>	Agent	As stated in DPOAF, or by state law	Patient with capacity	Patient lifetime, now and/or after incapacity
<b>Conservatorship of the Estate (CA)</b>	Conservator	As determined by judge, defaults in state law	Judge	Patient lifetime when criteria met for conservatorship (generally, loss of capacity to manage affairs)
<b>Social Security Rep Payee</b>	Rep payee	SS benefits only	Social Security	Patient lifetime during incapacity
<b>VA Fiduciary</b>	VA fiduciary	VA benefits only	VA	Patient lifetime during incapacity
<b>Living Trust</b>	Trustee	Trust assets only	Patient with capacity	Patient lifetime and incapacity and death
<b>Will</b>	Executor	As stated in will	Patient with capacity	Patient death

**Supporting Materials:**

- [Decision Making Workflow](#)
- [Advance Care Planning Worksheet](#)
- [Capacity Guidelines](#)
- [Glossary in Appendix](#)
- Handouts for patients and caregivers before starting advance care planning:
  - [Who can make financial decisions for the person I care for? Caregiver handout](#)
  - [Who can make financial decisions for me? Patient handout](#)
  - [Planning for healthcare decisions patient and caregiver handout](#)
  - [Advance care planning review for caregivers](#)
  - [Advance care planning review for patients](#)



# APPENDICES

## SECTION 2: IMPLEMENTATION GUIDE

### Roles & Staffing Supporting Materials:

- [CTN Job Description](#)
- [Pharmacist Job Description](#)
- [Nurse Coordinator Job Description](#)
- [Social Worker Job Description](#)

### Training Supporting Materials:

- [Training PowerPoints](#)
- [Training Recordings](#)
- [CTN Training Checklist](#)

### Monitoring & Evaluation Supporting Materials:

- [Medicare 2017 Part C & D Star Rating](#)
- [CAHPS Clinician & Group Survey](#)

## SECTION 3: OPERATIONAL DETAILS OF THE CARE ECOSYSTEM

### Outreach & Enrollment Supporting Materials:

- [Care Ecosystem Needs and Assessment Survey](#)
- [Sample Authorization for Release of Medical Records](#)

### Caseload Supporting Materials:

Sample Welcome Packet

- [What to Expect from the Care Ecosystem](#)
- [Introduction to Behavioral Changes](#)
- [Taking Care of You: Self-Care for Family Caregivers](#)
- [DICE: A Tool for Understanding and Responding to Behavior](#)

### Intake Supporting Materials:

- [Intake Instruction](#)
- [IntakeNotes Template](#)
- [Top Tips for Building and Preserving Rapport With Dyads](#)
- [Neuropsychological Inventory \(NPI\) toolkit](#)

#### **Development of Individualized Care Plans Supporting Materials:**

- [Comprehensive Dementia Care Plan Template](#)

#### **Escalation Guidelines, Tools & Process Supporting Materials:**

- [Behavior Escalation Tool](#)

#### **Team Meetings Supporting Materials:**

- [Care Ecosystem SBIP Presentation Template](#)

#### **Care Coordination Practices/Engaging Providers Supporting Materials:**

- [Intake Provider Update](#)

#### **Care Transitions Supporting Materials:**

- [Dealing with Increasing Caregiving Needs](#)
- [Overview of Care Options](#)
- [Tips for Introducing a New Caregiver](#)
- [Tips for Introducing a New Home](#)

#### **Graduation Planning Supporting Materials:**

- [Graduation Instructions](#)
- [Community Resource List](#)

#### **Funding Model Supporting Materials:**

- [Medicare Expenditures Associated with Hospital and Emergency Department Use Among Beneficiaries with Dementia](#)
- [Medicare's Cognitive Impairment Assessment and Care Planning Code](#)
- [DHHS Chronic Care Management Services](#)
- [Frequently Asked Questions about Billing the Physician Fee Schedule for Advance Care Planning Services](#)

## **SECTION 4: CARE ECOSYSTEM PROTOCOLS**

#### **Medication Reconciliation & Review Supporting Materials:**

- [Caregiver Medication Resources](#)
- [MARQUIS Handout: How to Do a Medication History](#)
- [MARQUIS Pocket Card: Best Possible Medication History](#)

#### **Behavior Management Supporting Materials:**

- [Delirium Handout](#)
- [DICE: A Tool for Understanding and Responding to Behavior](#)

- [Introduction to Behavioral Changes](#)
- [Apathy](#)
- [Communication](#)
- [NPI](#)

#### **Safety Screen & Recommendations Supporting Materials:**

- [Safety Plan](#)
- [Balancing Safety and Independence](#)
- [CDC Check for Safety](#)
- [Safety Plan Case Notes Template](#)
- [Safety Plan Instructions](#)

#### **Caregiver Well-Being Supporting Materials:**

- [Caregiver Well-Being Case Instructions \(workflow\)](#)
- [Caregiver Well-Being Notes Template](#)
- [Taking Care of You: Self-Care for Family Caregivers](#)
- [The Stress of Caregiving: Dementia, Caregiving, and Controlling Frustration](#)

#### **Referrals & Education Supporting Materials:**

- [The Dementia Curriculum](#)
- [CTN Resource Referral Protocol](#)
- [Overview of Care Options](#)
- [Community Based Resource Library Topics](#)

#### **Decision Making (Advance Care Planning) Supporting materials for CTNs:**

- [Decision Making Workflow](#)
- [Advance Care Planning Worksheet](#)
- [Capacity Guidelines](#)
- [Glossary in Appendix](#)
- Handouts for patients and caregivers before starting advance care planning:
  - [Who can make financial decisions for the person I care for? Caregiver handout](#)
  - [Who can make financial decisions for me? Patient handout](#)
  - [Planning for healthcare decisions patient and caregiver handout](#)
  - [Advance care planning review for caregivers](#)
  - [Advance care planning review for patients](#)

# GLOSSARY OF KEY TERMS

## DECISION MAKING TERMS

- [Key Decision Making Terms Glossary Document](#)

## OTHER KEY TERMS

**Characterize** “The following descriptions characterize changes in the patient’s cognitive and functional abilities” – describe, identify

**Cognitive Abilities** – thinking and memory, mental/intellectual abilities, how they are able to problem solve

**Functional Abilities** – ability to do everyday tasks

**Inconsistent** – not the same; unpredictable, uncertain

**Recollection** – remember

**Oriented** – awareness of time, place, event

**Impairment** – problems thinking and/or doing things

**Insight** – awareness of problems with thinking and ability to do things

**Pretense** “no pretense of independent function outside of home; appears well enough to be taken to activities outside of family home but generally needs to be accompanied” – emphasize second half of this sentence “appears well enough...,” no signs of independent function

**“Socially appropriate behavior”** – Behavior that could be considered offensive to some, more than usual/normal

**“Word searching”** – word finding, trouble finding the right words to say in conversations

**“Speech production”** – difficulty speaking, difficulty getting any words out or expressing thoughts