



Improving Dementia Care

GETTING STARTED

Acknowledgments

The Center to Advance Palliative Care (CAPC) would like to thank the following individuals, both for their leadership in developing dementia care and caregiver support programs, and for their contributions to reviewing the content contained in this toolkit:

Lead Authors

- Robin Fail, MPP
- Brynn Bowman, MPA
- Diane E. Meier, MD, FACP, FAAHPM

Project Steering Committee

- David Bass, PhD
- Debra Cherry, PhD
- Maribeth Gallagher, DNP, PMHNP-BC, FAAN
- Greg A. Sachs, MD, FACP
- Jennifer Schlesinger, MPH, CHES
- Alan Stevens, PhD

Reviewers

- Lynn Hill Spragens, MBA

This toolkit was created with generous support from the Gary and Mary West Health Institute.

Suggested Citation: Fail RE, Bowman BA, Meier DE. *Improving Dementia Care: Getting Started*. Center to Advance Palliative Care. February 2019.

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Introduction

The Challenge

As a disease with no known cure, dementia stymies our health system. Individuals living with cognitive impairment and their caregivers suffer from a combination of under-diagnosis, lack of clinician training in dementia care best practices, and lack of systematic support for dementia caregivers. People living with dementia have complex care needs, multi-year periods of disability, and rely heavily on the support of their families and other caregivers. In addition to widespread suffering, dementia is the costliest disease to our health system, incurring higher expenses than heart disease or cancer in the last five years of life.¹ Improving the quality of dementia care and caregiver support can alleviate suffering for patients and caregivers, and reduce avoidable utilization and health care costs.

Dementia care is challenging because people's needs cross multiple social and medical silos, and the time and training required to improve care have not historically been aligned with our medical system's financing and delivery incentives. While the data on dementia burden for people and health systems are daunting, there are strategies that health care organizations can adopt to mitigate costs and improve care quality for people living with dementia and their caregivers. **The time to act is now, and this guide can help you get started.**

In the context of this toolkit, the word "caregiver" refers to any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.

Source: Family Caregiver Alliance



Getting Started

This guide can be used to improve care for people living with dementia and their caregivers to:

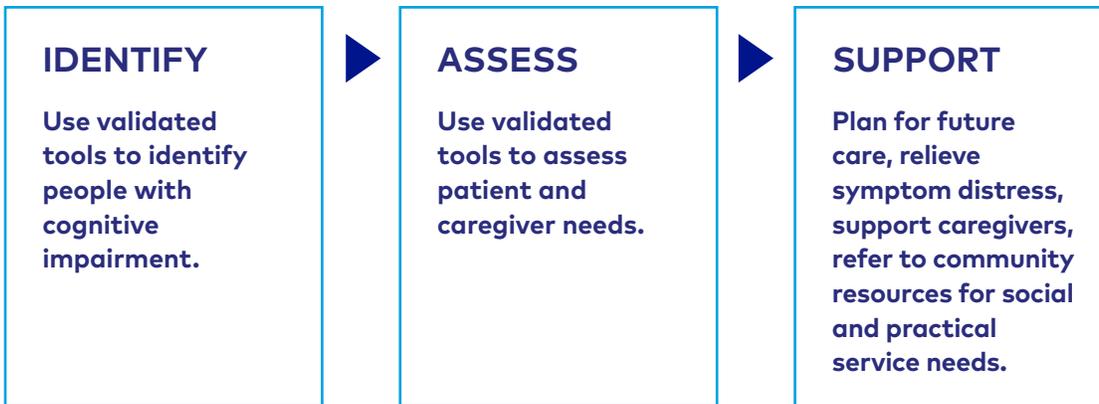
- Identify the context and the case or rationale for practice change
- Perform a gap analysis to understand what your organization currently does and does not offer people living with dementia and their caregivers, and identify the priorities of key stakeholders
- Design interventions to identify and support people living with dementia and their caregivers
- Train staff in the clinical and communication skills necessary to improve support for people living with dementia and their caregivers

Getting started requires engaging leadership, and aligning initiatives with their institutional priorities. Convening a workgroup to help you design and implement initiatives can ensure feasibility and alignment with stakeholder priorities. For any initiative that affects operations, workflow, or technology at your organization, it is always advisable to test change with a pilot before moving forward.



Framework for Dementia Best Practices

For any organization, best care for people living with dementia and their caregivers involves three critical capabilities:



DEMENTIA CARE BEST PRACTICES

There is no one-size-fits-all solution for improving dementia care, but many programs nationwide successfully incorporate best practices and caregiver support into their care models. Though dementia support programs vary in setting and service features, essential core characteristics include:

- Counseling and support for caregivers
- Caregiver education about what to expect
- Caregiver training and skill building, including how to understand and respond to behavioral symptoms of dementia
- Partnerships with community-based organizations (CBOs)
- Care coordination

THE BOTTOM LINE

Patients experiencing cognitive impairment—and their caregivers—need timely diagnosis, care management, goal-concordant care plans, and referral to support services.



This guide identifies key principles of dementia care and caregiver support, outlines core capabilities of dementia support programs, and describes the steps needed to improve care for people living with dementia and their caregivers.

Keep the following strategies in mind:

- Dementia care **aligns with major organizational goals** around value-based care, both improving quality and reducing unnecessary utilization.
- **Start small.** Set realistic short-term and achievable goals, such as identifying community-based dementia resources in your area, or scheduling an initial set of meetings with institutional leadership and clinical leads by a certain date.
- **Support for caregivers is support for the patient.** People with dementia rely heavily on their caregivers. Providing caregivers with education and training and meeting their physical, practical, and emotional needs are essential supports to maintaining the health and well-being of people living with dementia. Design your services with this fact in mind.
- **Role clarity** is critical for efficiency and effectiveness among teams caring for patients with dementia. There are many services that can (and should) be delivered by non-physicians.
- **Electronic health records** enable coordination and communication. Routine addition of fields such as caregiver name, caregiver contact information, and cognitive/functional assessment results improves quality of care for people living with dementia.
- **Educate clinical teams** in the assessment tools, the communication skills, the management strategies, and referral to available community supports. See Appendix A for online courses from the Center to Advance Palliative Care (CAPC) that cover these topics.
- **Utilize community resources and partners.** Work closely with community-based organizations to meet the needs of people living with dementia and their caregivers where they live.

Gap Analysis

Improving care for people living with dementia and their caregivers requires staff training, workflow re-design, and partnership—all of which are aligned with organizational objectives for quality, affordability, reliability, and addressing social determinants of health. Design of a reliable system of dementia identification and management should always begin with interviews with key organizational and community stakeholders.

A gap analysis is the first step. Done well, it can guide you past potential design pitfalls and ensure continued engagement from key stakeholders over time. The gap analysis includes:

- Assessing organizational motivation for, and capacity to, develop dementia care services
- Identifying priorities of key stakeholders both within the organization and among CBOs
- Identifying unmet needs of people living with dementia and their caregivers
- Synthesizing qualitative and quantitative information from the gap analysis to guide design of the new initiative

“Providers and the health care system want to take good care of dementia patients and their caregivers. But gaps exist and are often unseen by the system. Use the gap analysis process to engage stakeholders, assess prevalence of dementia patients, and brainstorm about ways to meet needs.”

Lynn Hill Spragens, 2019



CONSIDER THE FOLLOWING QUESTIONS AS PART OF YOUR ANALYSIS:

1. Who within the organization is most motivated to improve care for people living with dementia? Who are the champions for quality improvement?
2. Does the organization already offer dementia-specific services? If so, are they accessible, standardized, and effective?
3. Does the organization systematically capture information about caregivers? Is caregiver identification entered into a standard and retrievable place in the electronic health record (EHR)?
4. What processes or services are in place to assess and support caregivers?
5. Does your organization have a process for identifying people with cognitive impairment? If so, how many people living with dementia are served by the organization each year?
6. Of these people, what are the patterns of their health crises/utilization? What is the impact of their health crises/utilizations? How well can the organization identify these patterns?
7. Which clinicians see these patients? When? In what care settings?

Once you have explored the questions above, organize your analysis in terms of opportunities, building blocks, gaps, and challenges as outlined below.

OPPORTUNITIES

What data, payment or delivery models, or health policies are driving your organization to improve care for this complex patient population?

Examples:

- We are moving toward value-based payment and must improve outcomes for high-need, high-cost patients.
- Our state Medicaid requirements mean that we must improve dementia care (e.g., under California's Cal MediConnect Program, health plans must train care managers in dementia management; Maine's Medicaid program requires dementia-specific training for nursing home staff).
- Our health system is financially penalized for avoidable Medicare readmissions.
- The Medicare Annual Wellness Visit and CPT Code 99483 now allow providers to bill for cognitive assessment and care planning for people with dementia.



BUILDING BLOCKS

What tools are clinical teams already using to identify people living with cognitive impairment and assess their needs? What services are you and your community partners already offering?

Examples:

- We conduct routine cognitive assessment as part of the Medicare Annual Wellness Visit.
- Every patient in our system has a field in their EHR for caregiver name and phone number.
- Our local Alzheimer's organization and several local churches offer monthly support groups for caregivers of people with dementia.
- Social workers already refer patients with dementia to local service agencies.

GAPS

What goes wrong for patients with dementia now? What do their caregivers struggle with the most? What community-based services are currently underutilized?

Examples:

- Primary care providers report high no-show rates and difficulty with timely rescheduling, impeding their efforts to provide care.
- People living with dementia repeatedly end up in the ED.
- EHR does not currently support collection of information about caregivers or have a standard field for recording results of cognitive and functional status screening.
- EHR does not clearly alert referring providers about the presence of a dementia diagnosis or trigger any recommendations for follow-up or additional assessment.



CHALLENGES

What are the most likely hurdles that will hamper success of a given intervention?

Examples:

- Leadership or clinical staff's perceived lack of time and capacity to address the needs of people living with dementia.
- Staff training is required to meet patient and caregiver needs.
- The organization lacks processes to support systematic cognitive and functional assessment and caregiver assessment.
- The organization lacks access to resources and financing for needed services.
- Silos between medical and social services make it difficult to coordinate interventions across sites of care, with limited structure for reliable information sharing.
- Electronic health record does not currently support data fields for cognitive and functional assessment or caregiver information and assessment.

No matter your setting, best care for people living with dementia and their caregivers involves three critical capabilities:

- 1. Identify:** Identify patients living with dementia and their caregivers, and document the diagnosis and caregiver information in the EHR.
- 2. Assess:** Use validated tools to assess patient and caregiver needs and risk factors.
- 3. Support:** Implement and coordinate the care plan for patients and caregivers, educate caregivers about what to expect and how to manage at home, and refer them to community-based social support services.

Compare the findings of your gap analysis to the three processes listed above (Identify, Assess, and Support) to determine which of these processes could benefit from improvement. Dementia is a multi-year disease, and patients' and caregivers' needs are complex and ever-changing. Organizational commitment to support clinicians in the processes required for identification, assessment, and support is critical. This guide provides suggestions about how to implement each of these steps, and highlights how model programs meet the complex needs of people living with dementia and their caregivers.

Identification

“Without effective strategies to prevent or reverse the brain disorders that cause most cognitive decline in older people, the primary goal of screening for these conditions is to identify individuals—and their family and other caregivers—who may benefit from tailored medical and psychosocial interventions to improve outcomes and mitigate harms.”

Soo Borson, 2017²

Patient Identification

It is estimated that only half of the people living with Alzheimer’s dementia have been diagnosed,³ and fewer still have the diagnosis documented in their medical record.

Timely diagnosis enables people living with dementia and their care partners to plan for the future, and to access support resources necessary to prevent crises, manage daily life with the disease, and maximize function and quality of life.

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Caregiver Identification

Caregivers of cognitively impaired people assist with daily activities, and report to clinicians about patients' behaviors and symptoms, often over many years. **The success of any care plan is dependent upon the caregiver's well-being.** Caregiver support is a critical intervention in dementia care, and it starts with patient identification.

THE BOTTOM LINE

Standard processes to identify patients with memory loss and dementia—and their caregivers—enable clinicians and organizations to trigger support resources that prevent health crises and reduce avoidable utilization.

COMMON BARRIERS TO PATIENT AND CAREGIVER IDENTIFICATION INCLUDE:

- Lack of clinician training in the signs/symptoms of dementia and in screening/diagnosis
- EHR not designed to capture a dementia diagnosis
- EHR not designed to capture functional status
- EHR not designed to capture caregiver information
- Dementia screening not a standardized part of clinician workflow
- Perceived lack of effective treatment options and systemic supports for patient and caregiver if diagnosed (“better not to know if we can’t do anything to help”)





Improving Patient and Caregiver Identification

WORKFLOW DESIGN

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> • Early identification and routine screening of at-risk populations is critical to identifying individuals living with cognitive impairment to preserve their independence and quality of life for as long as possible and prepare for the future. • Specified procedures, adequate appointment time, and building effective assessment tools into workflow all minimize disruption and increase frequency and reliability of cognitive and functional screening. 	<ul style="list-style-type: none"> • Consult with clinical teams to determine whether cognitive assessment, via either case finding or standardized screening procedures, already occurs. • Consider whether standardized screening makes sense for your organization's teams, and if so, when and by whom it should be performed and with which populations. • Conduct a pilot to test proposed changes and collect feedback. Develop a working list of logistical challenges for further improvements. • Draft definitions of roles and responsibilities for cognitive assessment (note that while this may be performed by various members of the care team, the formal diagnosis must be made by a physician or advanced practice provider). 	<ul style="list-style-type: none"> • Assessing for cognitive impairment is the first step in diagnosing dementia. • The Annual Wellness Visit (AWV) requires assessment for cognitive impairment, and can be an efficient touchpoint for patient identification. Refer to the Alzheimer's Association's Algorithm about how to use the AWV. • Cognitive assessments should <i>always</i> be completed if a concern about memory loss is reported by either the patient or an informant. • Schedule must allow time for cognitive assessment using a validated tool (many of which can be administered in under five minutes).





EHR

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> When cognitive impairment is identified, clinicians must have a place to document the diagnosis. When functional impairment is identified, clinicians must have a place to document it. As dementia progresses, the caregiver becomes a critical partner to the clinical team—and their well-being can determine the well-being of the patient. Identifying caregivers is the first step in supporting them, and their information must be documented and easily retrieved. 	<ul style="list-style-type: none"> Review the gap analysis findings on your EHR's ability to capture dementia diagnoses and functional and caregiver information. Consult with members of the IT team and clinical leads about adding templates or using existing fields to address gaps in documentation. Consider whether adding a trigger to populate the caregiver field once a dementia diagnosis is recorded is a viable option. If there is a place to document cognitive and functional assessment scores and/or caregiver information in the EHR, is it accessible and utilized by other providers? 	<ul style="list-style-type: none"> Review the "ACT on Alzheimer's Electronic Medical Record Decision Support Tools" for details on incorporating screening and diagnostic tools in EHRs. A diagnosis must be recorded in a standardized part of the EHR where it is easy for other clinicians to see it. If it's easy to miss the diagnosis, it's less likely that appropriate care decisions and care coordination will occur. When caregiver information is easy to find, clinicians are able to include the caregiver in appointments and conversations, and can easily reach them. Noting the absence of caregivers for patients without them is equally important, as these individuals may require additional support from clinical teams and community-based services.

CLINICAL TOOLS

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> Standardized workflow procedures regarding the use of validated tools for cognitive assessment ensures detection and diagnosis. 	<ul style="list-style-type: none"> Ask clinical teams which cognitive impairment assessment tools they already use and seek agreement on a consistent approach. Discuss with clinical leads which staff are responsible for conducting cognitive assessment and what training is necessary to start. 	<ul style="list-style-type: none"> Refer to Appendix B for a list of cognitive impairment assessment tools and their characteristics. Using standardized tools across your clinical teams simplifies training and evaluation and enables system-wide identification of all patients with memory loss. Cognitive assessment tools vary in time required—consider which are most feasible for clinical teams.



TRAINING

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> Clinicians need to feel confident about the use of cognitive assessment tools and confident that better assessment is paired with effective supports for patients and caregivers. Dementia is a difficult diagnosis to discuss. Clinicians can be trained on how to identify and disclose a dementia diagnosis, and how to discuss what to expect with patients and caregivers. 	<ul style="list-style-type: none"> Work with clinical leads/ education managers to identify options for skill building, including CAPC's online curriculum Best Practices in Dementia Care and Caregiver Support. Develop a training plan with learning objectives and a timeline. <p>Based on workflow design (above), determine which teams need training in the following topics:</p> <ul style="list-style-type: none"> Using cognitive impairment assessment tools Using clinical guidelines for diagnosing dementia Conducting conversations with patients and caregivers about the diagnosis Identifying caregivers and documenting their information 	<ul style="list-style-type: none"> Clinicians may feel ill-equipped to offer meaningful assistance to people living with dementia and their caregivers, or fear that the diagnosis will incite more anxiety than relief. However, many people with cognitive impairment report a sense of relief in knowing the cause of worrisome symptoms, and being able to take steps to prepare for the future.⁴ Protected training time, rewards, team discussions, and improvements in metrics may incentivize staff to engage in training. Some states mandate that clinicians report dementia diagnoses to the DMV. Clinical teams will need training in these laws when applicable.

Training Tools

CAPC online courses in Best Practices in Dementia Care and Caregiver Support curriculum

- Discussing Your Patient's Dementia Diagnosis
- Communicating about What to Expect as Dementia Progresses
- Planning for the Future with People Living with Dementia and Their Caregivers

List of Cognitive Assessment Tools in Appendix B



Examples of Patient Identification in Action

Allina Health

In 2011 Allina Health began using the Mini-Cog® to conduct cognitive screening as part of the Annual Medicare Wellness Visit for all beneficiaries.⁵ Patients with a positive screen were asked to return to their primary care physician with a friend or family member for more evaluation. Clinicians assessed caregiver needs and abilities, and then developed and implemented a care plan that was shared with the patient and caregiver and recorded in the electronic health record.

Hospice of the Valley's (HOV) Palliative Care for Dementia (PCD) Program

Hospice of the Valley's (HOV) **Palliative Care for Dementia (PCD) Program** takes a case-finding approach to identification of people with dementia. When individuals referred to the agency do not yet meet Medicare's hospice eligibility criteria, admission nurses offer the PCD program to those who present with any stage of cognitive deficits or diagnosis of dementia. HOV also has nurses who serve as Admissions Coordinators (ACs) in all of the area's hospitals. When hospital staff alert ACs that an individual and/or their family is struggling with dementia-related issues, the ACs are invited to offer those interested support through the PCD program. Hospice of the Valley also engages with first responders, church leaders, assisted living staff, neurologists, and primary care offices to raise awareness about dementia and the PCD program. These community partners serve as a bridge to connect individuals to the program.

For detailed case studies of dementia care and caregiver support programs, visit the Case Studies section of CAPC's dementia toolkit.

Assessment

“The person living with dementia and care partners exist in a world of shifting salience where some things show up in the foreground as more important at a given time, and other things take the background. This means that person-centered assessment and care planning is an ongoing process, and not a one-time, finite task.”

Molony, et al., 2018⁶

Patient Assessment

At least 85% of people living with dementia have one or more chronic comorbid condition(s). The ensuing medical complications result in more than twice as many hospitalizations for people living with dementia than for those without cognitive impairment.⁷ In addition, common clinical problems, including pain and mood disorders, are often undetected or unmanaged in people living with dementia because the behaviors are mistakenly assumed to be the result of dementia progression—and because patients with dementia may be unable to verbally communicate their feelings and needs.



Caregiver Assessment

High caregiver strain increases the likelihood of nursing home placement for the care recipient⁸ and results in increased health care utilization for both the patient and caregiver. Compared with caregivers for people with conditions other than dementia, twice as many caregivers of people living with dementia report substantial financial, emotional, and physical difficulties. Caregiver stress results in poor health, depression, and increased mortality. Fewer than half of caregivers for people with dementia receive counseling or other support,⁹ and only about a quarter report a clinician ever asking them about their own self-care needs.¹⁰

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THE BOTTOM LINE

After identifying patients with cognitive impairment and their caregivers, the next step is to assess patient and caregiver needs using validated instruments.

PREREQUISITES OF PATIENT AND CAREGIVER ASSESSMENT INCLUDE:

- Clinical staff training on the impact that caregiver burden has on patient and caregiver outcomes
- Clinical staff training on behavior as communication in people with dementia (e.g., agitated or resistant behaviors as indicators of physical symptom distress, such as infection or constipation)
- Helping clinical staff understand that there are, in fact, effective care options and system supports for patient and caregiver when needs are identified
- Ensuring that patient and caregiver assessment is a standardized part of clinician workflow
- Ensuring appointment duration adequate to conduct patient and caregiver assessment
- EHR designed to ensure and capture patient and caregiver assessment findings
- Role clarity on which team members are responsible for standardized patient and caregiver assessment and documentation



Improving Patient and Caregiver Assessment

WORKFLOW DESIGN

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> • Since people with advanced dementia may be unable to communicate about their physical and emotional experiences, assessment often relies upon caregiver report and may require extra time. Clinical teams must be able to allocate time for assessment and regularly scheduled follow-ups. • Role clarity on who is responsible for conducting patient and caregiver assessment and follow-up is necessary to ensure accountability and to monitor efficacy of the care plan. 	<ul style="list-style-type: none"> • Find out what patient and caregiver assessments are currently conducted, if any. • Examine current workflow to inform role clarity and assign responsibility for assessment of both the patient and the caregiver. • Consult clinical leads to determine appointment length necessary for patient and caregiver assessment, and the appropriate frequency of follow-ups. • Discuss workflow, documentation templates, and correct use of billing codes with clinical leads and billers. 	<ul style="list-style-type: none"> • Longer appointments are needed for patients with dementia. • An interdisciplinary approach can mitigate the impact on physicians' schedules and ensure that each member of a team works to the top of their license (e.g., a physician or advanced practice provider must deliver a dementia diagnosis, but an RN or social worker may be in an ideal position to assess caregiver needs and engage in disease education or emotional support). • For professional Part B billing, consider use of the CPT Code 99483 (formerly G0505) cognitive assessment and care planning services code.

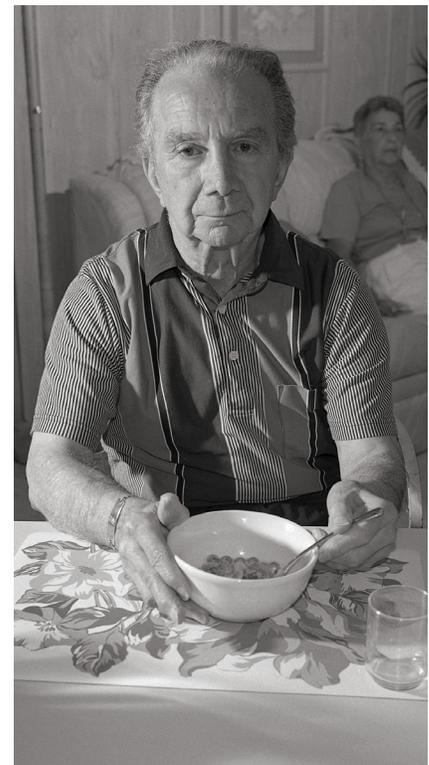
EHR

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> • Findings of patient and caregiver assessments must be documented and accessible in the EHR, to ensure care plan aligned with needs. • Documenting caregiver well-being and needs in the EHR is essential for identifying and securing appropriate supports, informing all providers and CBOs of the responsible caregiver, and for evaluating their capacity over time. 	<p>Identify EHR modifications necessary for standardized documentation of assessments:</p> <ul style="list-style-type: none"> • Is there an easy-to-find and standardized EHR template for the patient and caregiver assessment? • Is it feasible to build EHR triggers for specific clinical patient and caregiver assessments upon documentation of a dementia diagnosis? (e.g., routine depression screens for patients identified with memory loss; routine stress and depression screens for caregivers of people with memory loss) 	<ul style="list-style-type: none"> • Discuss feasibility with your organization's IT team and clinical leads involved in dementia care. • If your EHR has the capacity to record assessment findings, build screening tools directly into the platform so that cognitive assessment is as routine as weight or vital signs, and results are immediately integrated into the patient's record and easily accessible. • If gaps cannot be addressed through your EHR (e.g., interoperability with CBOs), determine workflow workarounds that will allow for communication of critical information without placing undue burden on providers.



CLINICAL TOOLS

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> • Use of consistent and validated assessment tools specifically designed for people living with dementia and their caregivers is necessary for accurate assessment over time and across settings. • Unmanaged pain in people with dementia is associated with a nearly 50% higher rate of ED visits in the last month of life, compared to those without unmet needs.¹¹ • The prevalence of depression is much higher for those living with dementia than those without, yet they receive less treatment.¹² • 30-40% of caregivers of people with dementia suffer from depression, compared with 5-17% of their non-caregiving peers. Risk of depression increases as cognitive impairment worsens.¹³ 	<ul style="list-style-type: none"> • Ask clinical leads which, if any, assessment tools are already being used. • Select and implement validated assessment tools—for both patients with dementia and their caregivers—from Appendix C of this toolkit. Aim for consistency across the organization. • Determine where and how results of assessments will be recorded. 	<ul style="list-style-type: none"> • Check with clinical teams caring for people with dementia to see if they're already routinely using validated assessment tools they feel comfortable with for dementia patients and caregivers. • Assessments of both patients and caregivers are a source of valuable data over time. Standardized reminders and documentation will make it easier to harvest and use that data.





TRAINING

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> Meeting the needs of people living with dementia requires repeated assessment over time—conditions and challenges vary widely as the disease progresses. Caregiver capacity also varies over time. For many patients living with dementia, behavior is communication. Training in interpreting behaviors as physical and emotional distress enables clinicians to reliably use assessment tools and care practices specific to the needs of cognitively impaired patients and better address their unmet needs. 	<ul style="list-style-type: none"> Talk to clinical leads and education managers about using CAPC's online curriculum Best Practices in Dementia Care and Caregiver Support to train staff in skills required for patient and caregiver assessment and management. <p>Training Topics:</p> <ul style="list-style-type: none"> Appropriate clinical assessment tools for people living with dementia (e.g., PAIN-AD or CSDD, see Appendix C) Behavior as communication of unmet need Appropriate prescribing and avoidance of antipsychotics for people living with dementia Communication skills training for discussions with patients and caregivers about the diagnosis, what to expect, and how to plan for the future The importance of, and tools for, assessing caregiver well-being and needs 	<ul style="list-style-type: none"> Use grand rounds or lunch-and-learns as a platform for training staff in the importance and routine use of standardized assessment tools. Caregiver assessment affects your bottom line: one recent study found that caregiver fatigue and sadness were associated with increased expenditures of more than \$1,300 per care recipient in a 6-month period.¹⁴

Training Tools

- CAPC online courses in Best Practices in Dementia Care and Caregiver Support curriculum:**
 - Supporting the Caregivers of People Living with Dementia
 - Understanding and Responding to Behavioral and Psychological Symptoms of Dementia
 - Mood and Sleep Disturbances in People Living with Dementia
 - Critical Decisions in Advanced Dementia
- Refer to the handout in Appendix C, Assessing Needs of People Living with Dementia, for a list of clinical assessment tools for people living with dementia.**
- Refer to the Caring for the Caregiver resources in Appendix C for validated caregiver assessment tools.**
- Recommend the [Physician Pocketcard App](#) from the Alzheimer's Association for quick access to cognitive assessment tools, functional assessment tools, and disease management information.**



Examples of Caregiver Assessment in Action

UCLA Alzheimer's and Dementia Care (UCLA ADC) Program

The **UCLA Alzheimer's and Dementia Care (UCLA ADC) Program** is a co-management model between nurse practitioners trained as Dementia Care Specialist(s) (DCS) and primary care providers that aims to improve care coordination and patient and caregiver health.¹⁵ A DCS is responsible for dementia care beginning with a 90-minute assessment of the needs and resources of the person with dementia and their caregiver. With the patient and caregiver, the DCS creates individualized care plans, which are sent to primary care providers for approval or modification. Care plans may include medication adjustment, caregiver counseling and education, linkage to CBOs, and, if needed, referral to psychiatry or neurology.

Aging Brain Care Program

The **Aging Brain Care (ABC)** program at Eskenazi Health in Indiana supports people living with dementia through collaboration between the ABC team and the patient's primary care physician. The ABC team includes a geriatrician or behavioral neurologist, two care coordinators (one a social worker and one an RN), and a technician trained in administering neuropsychological tests. Components of the program include patient and caregiver education, support groups, telephone support, monitoring caregiver health and strain, and managing the symptoms of the person living with dementia.¹⁶ The care team develops individualized care plans for each patient and family, which the care coordinators implement and monitor. Initially piloted as the Aging Brain Care Medical Home, the program demonstrated a 50% reduction in caregiver stress for more than half of the caregivers and reduced the severity of patients' depression over time.¹⁷

Support

“...it is imperative that adequate person- and family- centered systems, programs, and resources are in place to address the unique needs of individuals living with dementia and the family members who care for them.”

Carol Whitlatch and Silvia Orsulic-Jeras, 2018¹⁸

Despite an absence of effective treatments for the underlying disease, there are myriad ways that clinicians can alleviate suffering and improve quality of life for patients with dementia and their caregivers.

Partnerships with CBOs are fundamental to meeting the needs of people living with dementia and their caregivers. Identifying community partners offering support services for people living with dementia and their caregivers, and making staff aware of how to connect patients and caregivers to these resources, can address many unmet needs and improve quality of life for patients and caregivers alike.

Services offered by CBOs may include:

- Counseling
- Support groups
- Disease education and caregiver skills training
- In-home respite care
- Home health care
- Personal care services
- Adult day services
- Meal delivery
- Transportation
- Financial planning
- Legal assistance
- Supportive housing
- Friendly visitor programs

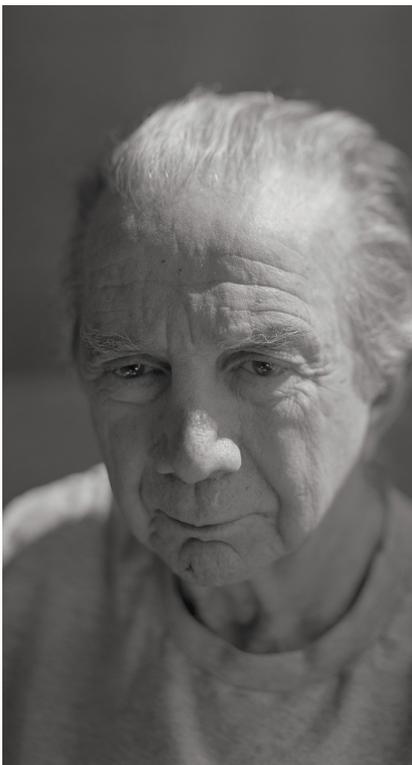


THE BOTTOM LINE

After comprehensive assessment of the needs of both the person living with dementia and their caregiver(s), clinicians must match services and referrals to these needs. Referrals to community-based support services should be a standard part of the care plan.

ESSENTIAL ELEMENTS FOR ENSURING THE NECESSARY PATIENT AND CAREGIVER SUPPORT INCLUDE:

- Connections between medical and social services, with systematic and reliable communication processes between them
- Role clarity on the team member responsible for providing and following up on referrals based on results of assessment
- Clinician awareness of local social services available
- Clinician training on engaging caregivers in assessment conversations about their own physical, emotional, and practical needs
- EHR interoperability with community-based service providers





Improving Patient and Caregiver Support

WORKFLOW DESIGN

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> • Clinical teams must be equipped with information about local resources in order to meet the non-medical needs of their patients and caregivers. • Caregivers' well-being strongly influences the health and function of the person living with dementia. Clinicians must take caregiver health into account when developing care plans and interventions for people living with dementia. • Only an estimated 19% of caregivers know how to access community services.¹⁹ • Low caregiver self-efficacy correlates to caregiver strain, which in turn increases health care utilization and institutionalization.²⁰ 	<ul style="list-style-type: none"> • Convene an interdisciplinary discussion about support services and education currently offered after a dementia diagnosis. Include clinical team leads, care managers, social workers, and counselors. • Ask this group about common unmet needs of individuals living with dementia. Using this list as a map, identify potential service partners in your area. Use resources listed in the Clinical Tools section below to help locate services in your area. • Refer to Appendix A for a list of roles and responsibilities of different team members to address the needs of patients with dementia and their caregivers. • Assess current capacity to offer a 24/7 call line for patients with dementia and their caregivers (e.g., does the organization already staff a 24/7 helpline that, with staff training, could be expanded to serve patients with dementia and their caregivers?). • Ensure that clinical leads and billers utilize the CPT codes for caregiver education, transition care management, advance care planning, and chronic care management for people living with dementia and their caregivers if applicable. 	<ul style="list-style-type: none"> • Providing referral to CBOs in the form of a doctor's order or prescription increases the likelihood that caregivers will connect with these services. • 24/7 coverage is an essential service in dementia care programs, since health crises arise at all hours and access to a clinician can prevent unnecessary hospitalizations. The Alzheimer's Association also has a 24/7 helpline available to all. Provide the number to all caregivers as a simple, cost-free means of support. • Train family and other caregivers in how to interpret and respond to behavior as communication of distress. • Collaborative care models (team-based, multicomponent interventions) increase use of community-based services,²¹ decrease caregiver strain and depression in people living with dementia,²² and decrease behavioral and psychological symptoms²⁴ of dementia.



EHR

Why this is important

- Documenting caregiver contact information and needs in the EHR is essential for both supplying their information to other involved clinicians or CBOs, and for evaluating caregiving capacity over time.
- EHR templates designed specifically to trigger and standardize assessment and documentation ensure match of services to needs over time.
- EHRs can record and track data on occurrence and impact of interventions. EHR data should include longitudinal assessments, care processes such as referrals, status of service, and utilization.

Options for getting started

Investigate the following questions:

- Are there EHR triggers for specific patient and caregiver assessments upon documentation of a dementia diagnosis?
- Are there triggers for referral to other providers or CBOs based on assessment findings?
- Are standardized templates available to seek and record inputs from CBOs about services offered or clinician/patient/caregiver observations?
- Can we print or email referrals for caregiver education and support, 24/7 call lines, or other services directly from the EHR?

Considerations

- In the absence of interoperable EHRs with referring providers/ community partners, establish protocols and procedures for communication between all clinicians and CBOs who interact with your patients and their caregivers. Use HIPAA-compliant phone calls, video chat, or emails for consistent communication across teams or settings in the absence of compatible EHRs.
- Patient permission is required before clinical teams can contact CBOs on their behalf or share patient information. When possible, permission should be visible in the EHR so that any clinician making the referral knows it is safe to do so.



CLINICAL TOOLS

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> Use of evidence-based practices to support people living with dementia and their caregivers can prevent avoidable health crises and hospitalizations, reduce suffering for patients and caregivers, and enable people living with dementia to reside at home for longer periods of time. 	<ul style="list-style-type: none"> Use the online resource directories provided by the Alzheimer's Association, Family Caregiver Alliance, and local Alzheimer's organizations to locate services for patients and caregivers specific to your area. Use the handout in Appendix D to find additional support services. Supply clinical teams with the Dementia Care Resources for Caregivers handout in Appendix D (for distribution to their patients and their caregivers). Supply clinical teams with Alzheimer's Association Referral Pads (free of charge) for warm handoff referrals to local Alzheimer's organizations. Supply clinical teams with the Assessing Needs of People Living with Dementia handout in Appendix C for a list of essential assessment tools. 	<ul style="list-style-type: none"> Local Alzheimer's organizations, senior centers, Area Agencies on Aging, and faith communities are all common sources of support for older people in the community. Clinician awareness of available organizational and community services, including disease education, personal care, or emotional/social support is key to connecting patients and families to these resources. Ensure that all clinical leads are aware of existing supports.





TRAINING

Why this is important	Options for getting started	Considerations
<ul style="list-style-type: none"> Caregivers state that clinicians are their most trusted source of information,²⁵ and per an ethical analysis from the AMA,²⁶ clinicians are obligated to assess and address the health and well-being of caregivers. Clinicians are responsible for meeting the medical needs of patients and caregivers, and need to feel confident that once they have identified other needs, there are services in their area that can offer support. Clinical teams need support and training in resources available to address non-medical needs of both patients and caregivers. All staff who encounter people living with dementia and their caregivers benefit from training in best dementia care practices and access to consultation from specialist geriatricians and neurologists. 	<ul style="list-style-type: none"> Talk to clinical leads or education managers about using CAPC's online curriculum Best Practices in Dementia Care and Caregiver Support to train staff in skills required for patient and caregiver support. <p>Training Topics:</p> <ul style="list-style-type: none"> Referral to local Alzheimer's organizations and the national Alzheimer's Association Role and responsibility of each team member in supporting patients and caregivers (e.g., management of symptoms, disease education and training for patients and caregivers, emotional and practical support for caregivers) Interpreting behavioral symptoms of dementia as communication of unmet needs, and strategies for meeting these needs Sources of emotional support for caregivers (both within health care organization and in the community) Initiating ongoing conversations about advance care planning, living arrangements and supports, legal and financial planning, driving, and more Nonpharmacological and pharmacological approaches to managing common clinical symptoms of dementia 	<ul style="list-style-type: none"> Consider using a lunch-and-learn or grand rounds to give clinical teams the opportunity to discuss which community resources their patients and caregivers need most, and which they find most useful. Many organizations offer disease-specific educational videos and handouts for caregivers, including the Alzheimer's Association, the Family Caregiver Alliance, local Alzheimer's organizations, and the National Institute on Aging. Support resources vary greatly among communities and health care organizations. Clinical staff require regularly updated guidance on services in their specific community.

Training Tools



CAPC online courses in Best Practices in Dementia Care and Caregiver Support curriculum:

- Supporting the Caregivers of People Living with Dementia
- Understanding and Responding to Behavioral and Psychological Symptoms of Dementia
- Planning for the Future with People Living with Dementia and their Caregivers



- Mood and Sleep Disturbances in People Living with Dementia
- Critical Decisions in Advanced Dementia

- Distribute the Referral to Community Resources handout and the Dementia Support Resources in Our Community worksheet in Appendix D to clinical teams.**
- Ensure that all staff are aware of the Alzheimer's Association's 24/7 Helpline, a free service offering confidential care consultations with clinicians who can help with decision making, crisis assistance, and disease education. The Helpline includes a translation service enabling consults in more than 200 languages.**

Examples of Caregiver Support in Action

UCLA Alzheimer's and Dementia Care (UCLA ADC)

Many dementia care programs have created formal agreements with CBOs in an effort to standardize care coordination between these partners and medical providers. For example, the **UCLA Alzheimer's and Dementia Care (UCLA ADC)** program involves formal partnerships between UCLA Health and eight CBOs. UCLA and each of the CBOs have a formalized referral agreement, and in some cases services provided by the CBO are reimbursed by UCLA. UCLA nurse practitioners trained as Dementia Care Specialists monitor the ongoing needs of patients and caregivers and help coordinate medical needs and services provided by the CBOs. The program also offers enrolled patients access to 24/7 phone support and has created 18 **caregiver training videos** on behavioral symptoms and common challenges.

Partners in Dementia Care (PDC)

Partners in Dementia Care (PDC) is the partnership version of the evidence-based BRI Care Consultation program. Through personalized coaching for the person living with dementia and their family or friend caregiver, the program coordinates care through a formalized partnership between a health care organization (e.g., VA Medical Center) and a community service organization (e.g., Alzheimer's Association Chapter, Area Agency on Aging).²⁷ A team comprised of a Care Consultant from the health care organization and a Care Consultant from the community organization delivers the program, with oversight by administrative champions and clinical supervisors following evidence-based protocols. Benjamin Rose Institute on Aging, which licenses organizations to deliver PDC and the single organization version BRI Care Consultation, provides training and ongoing support. Currently, there are approximately 50 licensed U.S. sites. Studies show the program successfully reduces illness- and care-related strain for both the person living with dementia and their caregiver, and reduces emergency department visits and hospital readmissions.²⁸



New York University Alzheimer's Disease and Related Dementias Family Support Program

The [New York University Alzheimer's Disease and Related Dementias Family Support Program](#) (originally called the [New York University Caregiver Intervention \(NYUCI\)](#)) aims to reduce the impact of caregiver burden and to delay nursing home placement for people living with dementia via individual caregiver and family counseling, weekly community support groups for caregivers, and ad hoc telephone counseling for caregivers of patients with Alzheimer's disease.

The model successfully reduces burden and distress for caregivers and improves their ability to cope with the behavioral symptoms of dementia. **The improvement in caregiver well-being was found to reduce nursing home placement for care recipients by 28.3%, an outcome with substantial economic implications for both state Medicaid programs and patient and caregiver personal finances.**²⁹ One model simulating the financial impact of this intervention on Medicaid enrollees in Minnesota estimated a cost savings to the state of \$40.4 million over 15 years if all eligible caregivers were enrolled in the program, driven by the delay in nursing home placement.³⁰ NYUCI has successfully been replicated in a number of states, including California, Florida, Georgia, and Utah. See the [NYUCI Implementation Guide](#) published by the Rosalynn Carter Institute for Caregiving for information about how to replicate this program.

Resources for Enhancing Alzheimer's Caregiver Health II

Resources for Enhancing Alzheimer's Caregiver Health II ([REACH II](#)) is a multicomponent intervention for caregivers of people living with dementia that has been replicated in multiple settings, including the Department of Veteran's Affairs's ([REACH VA](#)) model. The intervention involves caregiver participation in nine in-home and three telephonic sessions for education and skill building, as well as five telephonic support group sessions over six months. The sessions provide educational materials on dementia, caregiving, caregiving stress, and information on local resources. They also involve role-playing exercises to practice managing behavioral symptoms of dementia, and skills training for managing caregiver burden, emotional well-being, and social support. Caregivers enrolled in the intervention reported significantly decreased burden, depression, and frustration, and reduced frequency of dementia-related behaviors.³¹

Measuring Progress

Measuring the effectiveness of new services and care processes is critical to improving quality, justifying growth, demonstrating impact to stakeholders, and garnering necessary resources. Different measures are appropriate for different interventions and settings. Use the needs revealed in your gap analysis as a starting place for identifying appropriate measures and quality goals.

1. Align program measures with national quality standards for dementia care.

Select measures that are actionable, feasible to collect, and aligned with the program's goals. Nationally recognized sources for dementia care best practices and quality measurement include the following:

- National Quality Forum's [Addressing Performance Measure Gaps for Dementia](#) report
- [National Plan to Address Alzheimer's Disease](#) 2017 report
- [American Academy of Neurology and American Psychiatric Association's measure set](#) developed as part of the Physician Consortium for Performance Improvement
- Alzheimer's Association [2018 Dementia Care Practice Recommendations](#)
- [Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners](#) developed by Family Caregiver Alliance and Benjamin Rose Institute on Aging

2. Align program measures to organizational goals and stakeholder priorities uncovered in the gap analysis.

Recall your gap analysis: which measures matter most to your stakeholders? Are your improvements to dementia care being tied to another organizational initiative—and, if so, by what measures is that initiative being evaluated?



The quality of life for people living with dementia and their caregivers is the ultimate goal of any intervention, so select measures that effectively demonstrate improvement in quality of life for both groups. Other stakeholders at your institution will likely require additional measures, including cost effectiveness and utilization metrics. Using your gap analysis, consider which of these measures your program or organization has the capacity to collect and which are highest priority both to the patients and caregivers you serve, as well as to your organizational decision makers.

3. Identify potential structure, process, and outcome measures.

STRUCTURE MEASURES

Structure metrics measure program characteristics such as team composition, payment structure, infrastructure, service locations, and organizational characteristics. Potential structure measures include:

- Presence of a dementia care program in the appropriate setting
- EHR templates for dementia diagnosis and caregiver information
- Staff training in evidence-based dementia care practices
- Partnership with community-based organizations in your service area

PROCESS MEASURES

Process metrics measure what services were provided to whom, and where, when, and how services were provided. Potential process measures include:

- Routine memory and functional status testing
- Documentation of dementia diagnosis and disclosure
- Identification of caregivers and documentation of contact information
- Assessment of caregiver and patient needs over time
- Provision of caregiver education and support
- Screening for behavioral, psychiatric, pain, and other symptoms
- Screening for driving and other safety concerns
- Advance care planning conversations and documentation
- Number of referrals to CBOs from your organization's providers
- Increase in cognitive impairment screens among relevant population
- Addition of a dedicated field in the EHR for recording caregiver information, and increase in documentation of caregiver information in patient's record
- Increase in documentation of formal caregiver assessment
- Increase in documentation of goals-of-care conversations



OUTCOME MEASURES:

Outcome measures demonstrate the impact of the intervention on patients, family and other caregivers, organizations, and payers. Outcome measures should be linked to specific structures and process measures that influence the outcome measures. Many of the sample patient and caregiver outcome measures listed below are also outcome measures relevant to organizations and payers, such as reduction of 30-day readmissions, hospital mortality, or avoidable ED visits and hospitalizations.

Note: Establish baseline levels for the outcomes listed below in order to monitor change over time.

Potential indicators of patient outcomes include:

- Improvement in scores of patient depression, pain, and other symptom assessments (e.g., Cornell Assessment scale, PAINAD)
- Reduction in avoidable emergency department visits and hospitalizations
- Reduction of 30-day readmissions
- Reduction in number of patients entering long-term care facilities
- Concordance between patient preferences and services received
- Days spent at home before and after intervention

Potential indicators of caregiver health outcomes include:

- Improvement in scores of caregiver strain assessments (e.g., PHQ-9, Zarit Burden Interview, Geriatric Depression Scale, Caregiver Self-Assessment Questionnaire)
- Increase in caregiver self-reported confidence in their role
- Increased number of caregivers utilizing community-based services
- Decreased reports of behavioral symptoms of dementia
- Improved patient experience and satisfaction scores
- Changes in utilization of emergency, hospital, and post-acute care services and total cost of care per patient
- Days spent at home

Utilization measures to evaluate dementia care processes and workflow changes may include:

- Number of ED visits
- Number of hospitalizations and lengths of hospital stays
- Days at home
- Post-acute utilization, including sub-acute rehabilitation stays and duration, and use of certified home health agency services



Quality improvement surveys are a useful tool for measuring impact and identifying opportunities for improvement.

The organization **Next Step in Care** has designed a set of **quality improvement surveys** for both staff and family members in a variety of settings, available in multiple languages.

See the following examples of evaluation efforts by model dementia care programs for ideas about how to evaluate the effectiveness of your intervention.

Examples of Measurement in Action

UCLA Alzheimer's and Dementia Care (ADC) Program

The program tracks processes of care, health indicators, and health care utilization.¹⁵

Patients and caregivers are given a pre-visit questionnaire that collects information on dementia-related health issues. The program tracks neuropsychiatric symptoms and symptom-related caregiver distress using the **Neuropsychiatric Inventory Questionnaire (NPI-Q)** and the Cornell Scale for Depression in Dementia and tracks cognition using the **Mini-Mental State Evaluation (MMSE)** and **Montreal Cognitive Assessment (MoCA)**.

It tracks caregiver strain using the **Modified Caregiver Strain Index (MCSI)** and caregiver

depression using the **Patient Health Questionnaire-9 (PHQ-9)**. The program also tracks services provided, including percentage of enrollees and/or caregivers referred to support groups, CBOs, or the Safe Return program. The program evaluates its impact on utilization by tracking ED visits, hospitalizations, and nursing home placement of enrollees. Recent evaluation results found that program participants were less likely to be admitted to a long-term care facility than those not participating. The program was also found to be cost neutral for Medicare.³³

Hospice of the Valley

Initial evaluation finds that the program delays placement into long-term care and skilled nursing facilities and reduces the need for ED visits and hospitalization. After three months of care from dementia educators working in the field, Zarit Burden Interviews demonstrate a significant reduction in caregiver strain, with caregivers reporting that they felt more equipped to meet challenges as they arose.





Dementia Cal MediConnect Project

The **Dementia Cal MediConnect Project** involves technical assistance, training, and advocacy within ten dual-eligible health plans.³²

The program offers **two tiers of training to care managers** to build dementia-specific skills and establish Dementia Care Managers and Dementia Care Specialists in each of the participating health plans. Program leaders measure patient outcomes, utilization of services, and alignment of care processes to national guidelines.

In pre-, post-, and six-month surveys, care managers reported being more likely to screen for dementia, encourage a formal diagnosis, identify caregivers and involve them in care planning, provide or arrange for support for caregivers, and refer to CBOs. Dementia Care Managers and Dementia Care Specialists reported being more likely to conduct formal dementia screening as part of their client's needs assessment. Their self-reported knowledge of dementia, screening, and

identification increased after training and was sustained at six months.

Program leaders also interviewed health plan stakeholders about implementation of appropriate dementia care processes. Interviews revealed significant changes in both care managers' self-reported behaviors and reported systems change. All ten health plans have at least one question in their health risk assessment regarding cognitive issues; six have adopted a validated cognitive screening tool and have integrated results in the EHR; and ten plans report sharing information about cognitive impairment with providers through care plans. All plans report identifying a caregiver, and eight plans report documenting the caregiver in the EHR and sharing with providers through care plans; three plans have adopted a validated caregiver assessment tool and have incorporated results in the EHR; and all plans make referrals to local Alzheimer's organizations for education, support, and/or respite.





Eskenazi Health Aging Brain Care (ABC) Program

The ABC program provides support to people with cognitive impairment and their caregivers through collaboration with the patient's primary care provider. The dementia care model, initially piloted as the ABC Medical Home Program, monitors its impact on Medicare beneficiaries with dementia using the MMSE, PHQ-9, HABC Caregiver Monitor³⁴ (a composite measure of cognitive issues, affect or emotion), and presence of behavioral symptoms.²² The program tracks use of anticholinergic medications as a quality metric because of their association with adverse effects, including worsened confusion, falls, urinary retention, constipation, more rapid decline, and delirium. The program also tracks process measures, including note audits of RNs, social workers, and care coordinator assistants, as well as annual assessments of staff competency in using measurement tools and delivering standard protocols. Clinicians receive monthly reports of patient and family/caregiver need based on the results of the HABC Caregiver Monitor and the PHQ-9. Finally, the program tracks health care utilization with an emphasis on reducing emergency department and hospital admissions.

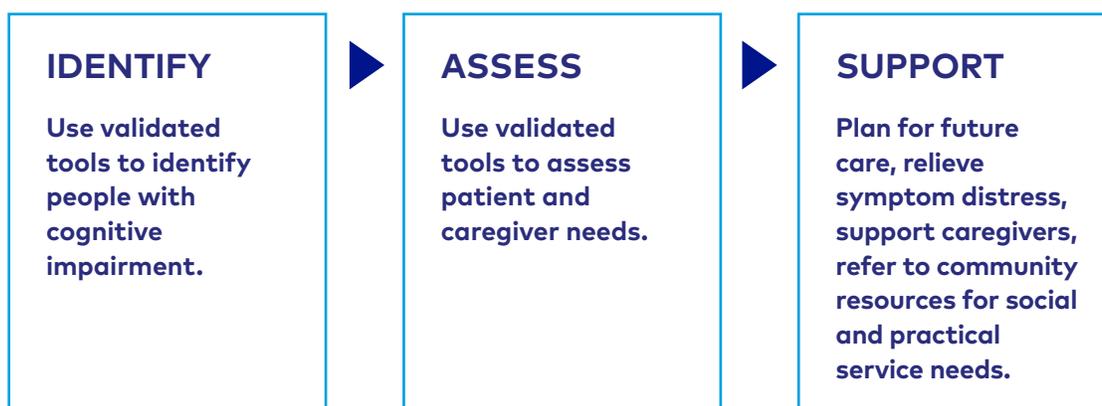
The ABC Medical Home, which integrated with the Healthy Aging Brain Center (HABC) to form the Eskenazi Health Aging Brain Care program, successfully **demonstrated reduction in depressive symptoms for 66% of participants after 18 months.**²³ 51% of the caregivers of individuals enrolled in the program showed at least a **50% reduction in caregiver stress symptoms**, as measured by the HABC Caregiver Monitor. **Cost analysis of the HABC clinic found a net annual savings of between \$980 and \$2,856 per patient.**¹⁶



Putting it Together

This guide identifies key principles of dementia care and caregiver support, outlines core capabilities of dementia support programs, and describes the steps needed to improve care for people living with dementia and their caregivers.

No matter your care setting or organization, improving quality of care for people living with dementia and their caregivers involves these processes:



Keep the following strategies in mind:

- **Dementia care initiatives align with major organizational goals** around value-based care, improved quality, staff training, addressing the social determinants of health, and reduced unnecessary utilization. Engage leadership to match dementia care improvement efforts to their priorities.
- **Start small.** Set realistic short-term and achievable goals, such as identifying community-based dementia resources in your area, or scheduling an initial set of meetings with organizational leadership and clinical leads by a certain date.
- **Support for caregivers is support for the patient.** People with dementia rely heavily on their caregivers. Providing caregivers with education and training and meeting their physical, practical, and emotional needs are essential supports to maintaining the health and well-being of people living with dementia. Design your services with this fact in mind.



- **Role clarity** is critical for efficiency and effectiveness among teams caring for patients with dementia. There are many services that can (or should) be delivered by non-physicians, but responsibilities have to be clearly defined and staff must be equipped with the training and time required to carry out these responsibilities.
- **Electronic health records** can be a powerful tool for care coordination, clinical management, caregiver support, and care planning. Routine addition of fields such as caregiver name, caregiver contact information, and cognitive/functional assessment results improves quality of care for people living with dementia. The EHR will also be critical for measuring the effectiveness of your interventions.
- **Educate clinical teams** about how to better support people living with dementia and their caregivers. Clinical teams must be trained in the clinical assessment tools required for both patients and caregivers, the communication skills necessary to engage in meaningful conversations about the diagnosis and care planning, strategies for understanding and mitigating behavioral symptoms of dementia, and referral to available support resources. See Appendix A for CAPC online courses that cover these topics.
- **Utilize community resources and partners.** Health care organizations cannot do it all. Work closely with CBOs, either through formal partnership agreements or through warm handoffs (person-to-person), to meet the needs of people living with dementia and their caregivers where they live. Clinical staff must receive training about available resources in order to make referrals.

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Appendices

APPENDIX A: Staff Training and Role Definition

Navigating the CAPC Online Curriculum

Staff Training

Interdisciplinary Roles and Responsibilities in Dementia Care

APPENDIX B: Patient Identification Tools

Cognitive Assessment Tools

APPENDIX C: Patient and Caregiver Assessment Tools

Assessing Needs of People Living with Dementia

Caring for the Caregiver

APPENDIX D: Patient and Caregiver Support Resources

Referral to Community Resources

Dementia Care Resources for Caregivers

Dementia Support Resources in our Community Worksheet

NAVIGATING THE CAPC ONLINE CURRICULUM:

A Guide for Improving Dementia Care and Caregiver Support

The following CAPC courses and tools are recommended for all clinicians seeking to improve quality of life for people living with dementia and their caregivers. The majority of the CAPC courses listed are approved for ABIM Maintenance of Certification (MOC) points for physicians, and all courses provide **free continuing education credits** for physicians, nurses, social workers, case managers, and licensed professional counselors who are part of CAPC member organizations.

Care Practice	Online CE Courses	Tools
<p>Identify people living with dementia and their caregivers.</p>	<p>Dementia Care</p> <ul style="list-style-type: none"> → Dementia: Relieving Suffering for Patients and Families → Discussing Your Patient's Dementia Diagnosis 	<p>Cognitive Assessment Tools</p> <ul style="list-style-type: none"> → General Practitioner Assessment of Cognition (GPCOG) → Memory Impairment Screen (MIS) → Mini-Cog® → AD8 Dementia Screening Tool → Montreal Cognitive Assessment (MoCA) → Short Form Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE)
<p>Assess the well-being of both patients and caregivers and identify unmet needs.</p>	<p>Dementia Care</p> <ul style="list-style-type: none"> → Dementia: Relieving Suffering for Patients and Families → Supporting the Caregivers of People Living with Dementia (open to non-members) 	<p>Patient Symptom Assessment Tools</p> <ul style="list-style-type: none"> → Pain Assessment in Advanced Dementia (PAINAD) Scale → Pain Assessment and Documentation Tool (PADT) → Cornell Scale for Depression in Dementia <p>Caregiver Strain Assessment Tools</p> <ul style="list-style-type: none"> → Zarit Burden Interview (ZBI) → Caregiver Self-Assessment Questionnaire → "What Do I Need as a Family Caregiver?" Assessment Survey → REACH III Risk Appraisal <p>Anxiety and Depression Assessments that Can be Used with Either Patient or Caregiver</p> <ul style="list-style-type: none"> → Hamilton Depression Rating Scale (HDRS) → Validated Screening Tools for Depression and Anxiety (PHQ-9 and PHQ-4) → Geriatric Depression Scale (GDS) → GAD-7 Anxiety Scale

Care Practice	Online CE Courses	Tools
<p>Communicate with patients and caregivers to understand care goals and priorities, and help plan for the future.</p>	<p>Dementia Care</p> <ul style="list-style-type: none"> → Discussing Your Patient's Dementia Diagnosis → Communicating About What to Expect as Dementia Progresses → Planning for the Future with People Living with Dementia and Their Caregivers <p>Communication Skills</p> <ul style="list-style-type: none"> → Clarifying Goals of Care → Advance Care Planning Conversations 	<p>Advance Care Planning Tools</p> <ul style="list-style-type: none"> → PREPARE For Your Care → Decision Aid about Goals of Care for Patients with Dementia → Dementia Directive <p>Billing for Care Planning</p> <ul style="list-style-type: none"> → Billing the Physician Fee Schedule for Advance Care Planning Services one-pager → Cognitive Assessment and Care Planning Services guidance from Alzheimer's Association
<p>Manage pain and symptoms.</p>	<p>Dementia Care</p> <ul style="list-style-type: none"> → Understanding and Responding to Behavioral and Psychological Symptoms of Dementia → Addressing Mood and Sleep Disturbances for People Living with Dementia → Addressing Swallowing Disorders, Pain, and Medical Decision-Making for People Living with Advanced Dementia <p>Pain Management</p> <ul style="list-style-type: none"> → Comprehensive Pain Assessment → Matching the Drug Class to the Pain → Opioid Trials: Determining Design, Efficacy, and Safety → Pain Management: Putting It All Together <p>Symptom Management</p> <ul style="list-style-type: none"> → Dyspnea → Constipation 	<p>Symptom Assessment and Management Tools</p> <ul style="list-style-type: none"> → Pain Assessment in Advanced Dementia (PAINAD) Scale → Prescribing Opioids Pocket Card → Medication Management Form from Next Step in Care → Cornell Scale for Depression in Dementia → Assessing Needs of People Living with Dementia handout
<p>Refer patients and caregivers for appropriate services.</p>	<p>Dementia Care</p> <ul style="list-style-type: none"> → Supporting the Caregivers of People Living with Dementia (open to non-members) <p>Preventing Crises Through Whole-Patient Care</p> <ul style="list-style-type: none"> → Care Coordination <p>Managing Gaps in Care</p> <ul style="list-style-type: none"> → Care Management for Seriously Ill Patients: Addressing Gaps in Care → A Palliative Approach to Care for Direct Care Workers 	<p>Referral to Community Resources</p> <ul style="list-style-type: none"> → Alzheimer's Association Direct Referral → Discharge Checklist from Next Step in Care → Local resource directories from Alzheimer's Association and Family Caregiver Alliance → Respite locator from Arch National Respite Network → Support group directory from Alzheimer's Association → Adult day center directory from Eldercare Locator → Referral to Community Resources handout

Additional information and links to these tools and other resources can be found online in the **Implementing Best Practices in Dementia Care toolkit**. cappc.org/dementiatoolkit

Staff Training

Educate health professionals who work with people living with dementia and their caregivers on the following topics:

- Skillful communication about the diagnosis, what to expect as dementia progresses, and how to plan for the future
- Using cognitive and functional assessment and caregiver needs assessment tools and procedures
- Understanding that dementia-related behaviors are communication
- Assessing and managing the causes of behavioral and psychological symptoms of dementia
- Managing pain, symptom distress, and comorbidities that are common causes of dementia behaviors
- Acknowledging and supporting the patients' caregivers
- Connecting patients and caregivers to community-based resources

Ongoing education of clinical staff increases their comfort and integrates best practices into the routine care processes of clinical teams.

Opportunities for staff training in dementia care are listed below.

- CAPC's Curriculum Best Practices in Dementia Care and Caregiver Support: provides training that clinicians can use to make a meaningful difference in the lives of their patients and caregivers at all stages of dementia. This seven-course curriculum offers continuing education credits for physicians, nurses, APRNs, PAs, social workers, case managers, and licensed professional counselors, as well as ABIM Maintenance of Certification (MOC) points for physicians. Courses include:
 - Discussing Your Patient's Dementia Diagnosis
 - Communicating About What to Expect as Dementia Progresses
 - Planning for the Future with People Living with Dementia and Their Caregivers
 - Supporting the Caregivers of People Living with Dementia
 - Understanding and Responding to Behavioral Symptoms of Dementia
 - Mood and Sleep Disturbances in People Living with Dementia
 - Critical Decisions in Advanced Dementia
- **Alzheimer's Los Angeles**: offers both **in-person** and **web-based** training programs for health care professionals on a number of dementia care topics, including coping with a new diagnosis and compassionate communication for people with memory loss. For programs planning to replicate the care manager training conducted by the Dementia CalMediconnect Project, **Alzheimer's Los Angeles Dementia Care**

Manager Toolkit guides programs in training care managers and other health care professionals supporting people with dementia and their caregivers.

- **Comfort Matters**: provides an approach to dementia care focused on prioritizing comfort for the individual living with dementia through relief of symptoms, pain, and stress. Comfort Matters education is intended for all staff who provide care for people living with dementia, including clinicians of all disciplines, spiritual care providers, and housekeeping staff. Comfort Matters education is offered through both in-person and web-based instruction. **Accreditation is available** for completion of staff training and systems change. The Comfort Matters approach has been successfully replicated by hundreds of health care organizations, and has been shown to reduce use of chemical and physical restraints, unnecessary medications, emergency department visits, hospitalizations, and sundowning.
- **KAER Toolkit**: outlines a four-step process developed by the Gerontological Society of America's Workgroup on Cognitive Impairment Detection and Earlier Diagnosis. The toolkit offers processes and tools to help primary care providers **K**ickstart the cognition conversation, **A**ssess for cognitive impairment, **E**valuate for dementia, and **R**efers to community resources.
- **Health Resources and Services Administration (HRSA)**: offers a 16-module curriculum for the primary care workforce about care for people living with dementia and their caregivers. Modules include a PowerPoint presentation with detailed notes and references. One of the modules currently offers CE credit.
- **Alzheimer's Association**: offers one free CME course, Challenging Conversations about Dementia, as well as other 15-minute modules. In addition, they offer an array of **tools and resources for health care professionals** about cognitive assessment, dementia diagnosis, care planning, and caregiver resources.

Interdisciplinary Roles and Responsibilities in Dementia Care

An interdisciplinary approach is most effective for patients with long-term complex medical and social needs and their caregivers. Successful models typically involve collaboration between primary care providers and clinicians who see the patient in other hospital and community settings. Collaborative care models have been shown to increase use of community-based services,²¹ decrease caregiver strain and depression in people living with dementia,²² and decrease behavioral and psychological symptoms²⁴ of dementia.

An interdisciplinary approach allows teams to designate the many and complex tasks involved in dementia care to the clinician best suited for the undertaking. Though physicians and advance practice providers collaboratively assess and make the formal diagnosis of dementia, many support interventions for patients with dementia can be managed by other team members. For example, social workers may be best equipped to connect caregivers to local support groups and CBOs. Training caregivers in strategies for mitigating behavioral symptoms of dementia may be a task best suited for nurses, social workers, or care managers. The following table, originally published in *Neurodegenerative Disease Management*,³⁵ outlines potential roles for different team members involved in dementia care and caregiver support.

Potential responsibilities of different team members in a collaborative care model	
Physician	<ul style="list-style-type: none">→ Diagnosis of memory disorder and initiation of care plan→ Review of brain imaging and laboratory tests, if indicated→ Evaluation of patients with unexpected change in condition, atypical or unusual presentations→ Available for patient emergencies→ Referral to Medicare Part A services (home care, hospice) depending on state regulations
Nurse Practitioner or Physician Assistant	<ul style="list-style-type: none">→ Re-evaluate plan of care and provide ongoing assessment of cognition and associated symptoms→ Coordination of care with other disciplines and medical providers→ In some collaborative models, the NP may be the clinician making the initial diagnosis, completing the initial assessment, and identifying a plan of care→ Referral for outpatient services (i.e., physical therapy/occupational therapy)→ Follow-up of all imaging and testing results→ Patient and family education on pharmacologic and nonpharmacologic interventions

INTERDISCIPLINARY ROLES AND RESPONSIBILITIES IN DEMENTIA CARE

<p>Registered Nurse</p>	<ul style="list-style-type: none"> → In some collaborative models, the RN may serve as the care coordinator and manager, particularly if there is not an NP or physician assistant as part of the team → Performs routine vital signs on patients in the office → Perform memory and functional screening and conduct objective reevaluation of change in cognitive performance and/or function over time → Patient and caregiver regular phone follow-up and support, to identify rising risk early, ensure caregiver capacity, clarify instructions and prevent or correct any medication errors → Assists with outpatient referrals to disease-specific organizations, community-based resources, MedicAlert+ SafeReturn, and similar useful patient and caregiver resources
<p>Social Worker</p>	<ul style="list-style-type: none"> → Varies by state depending on licensure (LMSW/MSW and LCSW) → Educates about memory loss and caregiver issues → Offers referral for concrete services (transportation services, housing, assistance in the home, meal delivery and adult day programs) → Assists with transition to alternate care settings → Provide psychotherapy and counseling services (billable service) → Refer to or lead support programs for patients and/or caregivers → Collaborates with local agencies and organizations → Provides educational resources and materials
<p>Medical Assistant</p>	<ul style="list-style-type: none"> → Coordinate paperwork for office visits to complete in the waiting area or at home → Assist with completion of documentation (long-term care insurance, adult day program paperwork, referrals) → Coordination with caregivers, family, and friends → Provide feedback on patient's ability to manage appointments and compliance → May complete simple screenings (cognition, fall risk assessment)
<p>Neuropsychologist</p>	<ul style="list-style-type: none"> → Trained to perform and interpret neuropsychological testing → May play key role in diagnosis and monitoring of patients → In role of a psychologist, may provide counseling and therapeutic services → May lead cognitive remediation or retraining programs
<p>Health Educator</p>	<ul style="list-style-type: none"> → Trained to perform neuropsychological testing, with interpretation of tests performed by MD or psychologist → Complete surveys with patient and families → Maintains print and electronic library of resources and health information → Coordinate distribution of health information materials consistent with MD, NP, and recommendations
<p>Occupational and Physical Therapists</p>	<ul style="list-style-type: none"> → Home safety assessment and interventions → Cognitive skills training → Fall prevention and balance training → Activities of daily living (ADL) evaluation and remediation → Caregiver education → Driving evaluation

Cognitive Assessment Tools

Timely diagnosis of dementia enables people living with the disease and their caregivers to:

- Know and prepare for what to expect
- Plan for the future
- Engage in care planning based on their needs, values, and preferences
- Access supportive services in the community

When the diagnosis is identified, clinicians can act to prevent the health crises and caregiver exhaustion that result in ED visits and hospitalizations.

The Medicare Annual Wellness Visit (AWV) requires cognitive assessment. There are a number of simple, effective cognitive assessment tools to use during the AWV or whenever a concern arises about memory loss from either the patient or an informant.

Validated assessment tools for cognitive impairment are essential and listed below. Use in conjunction with patient history, clinical observation, and reports from the patient and their family or caregiver(s). All of the tools below are free for clinical use. **The Mini-Cog®, MIS, and AD8 are recommended for their brevity and validity in primary care or community settings.**

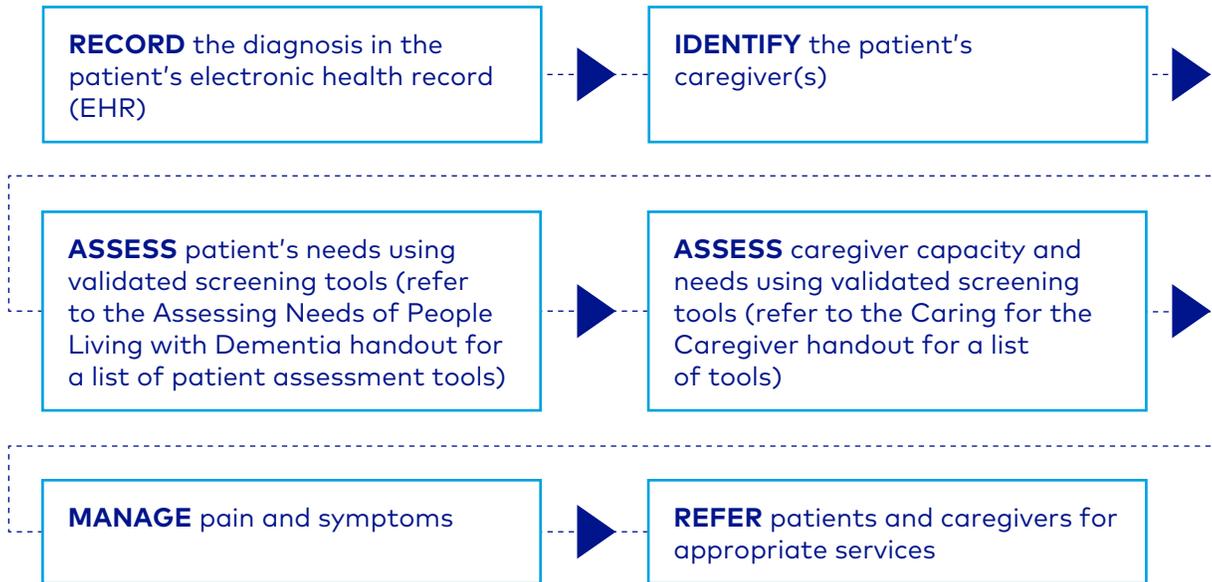
Cognitive Assessment Tools

Tool	Components
For Patient	
Mini-Cog®	<ul style="list-style-type: none"> → Clock-drawing test, 3-word recall test → Requires the ability to write/draw → Can be administered in 5 minutes or less
Memory Impairment Screen (MIS)	<ul style="list-style-type: none"> → Word recall and categorization exercises → Does not require ability to write/draw → May be administered by telephone using MIS-T version of tool → Can be administered in 5 minutes or less

Montreal Cognitive Assessment (MoCA)	<ul style="list-style-type: none"> → 30-question test that covers 11 tasks, including drawing a cube and a clock face, word recall, naming animals shown in drawings, repeating sentences, and four attention tests → Test includes assessment of executive function → Available in many languages → Requires 10–15 minutes to complete
For Patient and/or Informant	
General Practitioner Assessment of Cognition (GPCOG)	<ul style="list-style-type: none"> → 4-minute assessment of patient: remembering a name and address; stating today's date; drawing a clock face; stating something that has been in the news in the last week → 2-minute interview with caregiver: questions for the informant comparing the status of the patient now to their functional abilities 5 or 10 years ago → Requires the ability to write/draw
For Informant	
AD8 Dementia Screening Tool	<ul style="list-style-type: none"> → 8-question interview about cognitive changes detected in the patient in the last several years → May be administered by telephone → Informant is preferred, but can be administered to patient → Requires an average of 3 minutes to complete
Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE)	<ul style="list-style-type: none"> → 16 questions for the informant comparing the status of the patient now to their functional abilities 10 years ago → May be administered by telephone → Requires an average of 5-7 minutes to complete

Other Cognitive Assessment Resources

- **Alzheimer's Association's Cognitive Assessment Toolkit:** provides a comprehensive guide for detecting cognitive impairment during the Medicare Annual Wellness Visit, including screening tools (GPCOG, MIS, and Mini-Cog©) and a sample informant interview
- National Institute on Aging: **Memory Loss and Forgetfulness Resources**
- **Global Deterioration Scale and FAST Scale** for staging and prognosis after diagnosis

WHAT TO DO WHEN COGNITIVE IMPAIRMENT IS DIAGNOSED:

See CAPC's [Best Practices in Dementia Care and Caregiver Support](#) curriculum for more information about diagnosis, assessment, and support.

Assessing Needs of People Living with Dementia

Comorbid conditions result in **more than twice as many hospitalizations** for people living with dementia than for those without cognitive impairment. The most common causes of hospitalizations among people living with Alzheimer’s and other dementias are:

- Syncope and falls
- Ischemic heart disease
- Gastrointestinal disease
- Pneumonia
- Delirium (Note: Hospitalization can often induce or worsen delirium in individuals with dementia, and it often goes undiagnosed because it is attributed to progression of dementia.)

If comorbid conditions have been identified, document those conditions and the results of assessments in the EHR to ensure effective care coordination.

The following are validated assessment tools for common clinical issues that arise for people living with dementia:

Patient Assessment Tools for People Living with Dementia

Depression	
Patient Health Questionnaire (PHQ-9)	<ul style="list-style-type: none"> → Nine-item scale based on the 9 diagnostic criteria for major depressive disorder → Can be administered in person by a clinician, by telephone, or self-administered
Geriatric Depression Scale (GDS)	<ul style="list-style-type: none"> → Short-form version (15 questions) screens for depression in the elderly population → Reliability diminishes with increasing cognitive impairment
Cornell Scale for Depression in Dementia (CSDD)	<ul style="list-style-type: none"> → Diagnostic scale for detecting depression in dementia → Requires ~20 minutes to administer via independent interview with the patient and an informant

Functional Status	
Global Deterioration Scale and FAST Scale	→ For staging and prognosis after a dementia diagnosis
Katz Basic Activities of Daily Living Scale (Katz ADL)	→ Assess function in bathing, dressing, toileting, transferring, continence, and feeding
Functional Activities Questionnaire (FAQ)	→ Rate the patient's functional abilities in 10 instrumental areas of daily living (e.g., paying bills)
Pain	
Pain Assessment in Advanced Dementia (PAINAD) Scale	→ Assess the presence of pain in patients who are unable to report
Wong-Baker FACES Scale	→ Self-report pain measure of pain intensity based on 6 facial expressions ranging from no pain to worst pain
Symptom Distress	
Edmonton Symptom Assessment Scale (ESAS)	→ Assess levels of pain, activity, nausea, depression, anxiety, drowsiness, appetite, and sense of well-being → Completed by patient, if able, or caregiver
Fall Risk	
Tinetti Balance Assessment Tool	→ Measures gait and balance, based on the person's ability to perform specific tasks
Timed Up and Go (TUG) Test	→ Assesses mobility, balance, walking ability, and fall risk in older adults → Can administer in ~3 minutes
Delirium	
Confusion Assessment Method (CAM)	→ Assess confusion to distinguish delirium from other types of cognitive impairment
Sleep	
Sleep Diary from National Sleep Foundation	→ Sleep diary for patients or caregivers to identify potential causes of sleep disturbances
Behavioral Symptoms of Dementia	
DICE Approach	→ D escribe I nvestigate C reate E valuate approach: identify and manage the root causes of behavioral symptoms of dementia

After assessing the well-being of both the person living with dementia and their caregiver(s), the next step is matching services to identified needs and providing referrals to community-based support services. See the Referral to Community Resources handout for suggested sources of support.

Caring for the Caregiver

Care for the caregiver is a critical intervention in dementia care. Caregivers offer essential reports about the cognitively impaired care recipient, and caregiver well-being is a predictor of how long individuals with dementia are able to live in the community before moving to a long-term care facility.

Caregiver statistics at a glance:

- Fewer than half of dementia caregivers report ever having a clinician ask them what they need to care for their loved one
- Only a quarter of dementia caregivers report a clinician ever asking them about their own self-care needs
- More than half of dementia caregivers say they need more help managing their own emotional and physical stress

THERE ARE 4 STEPS THAT ANY CLINICIAN IN ANY SETTING CAN TAKE TO SUPPORT CAREGIVERS:

1. Include caregivers as a member of the care team by identifying who they are, including them in appointments and conversations with the patient, and documenting their information in the patient's medical record.
2. Assess the caregiver's health, well-being, capacity and willingness to be a caregiver, and any unmet needs.
3. Create care plans for both patient and caregiver that are matched to their needs and reflect goals of care and advance care planning.
4. Address caregiver needs via referral to appropriate services, including medical consultation, disease education resources, and online and community resources.

If caregiver needs are unmet, chances are much higher that your patient's needs will be unmet as well. Caregiver assessment may be conducted by a range of health professionals, including physicians, nurses, social workers, or care managers.

The following are validated assessment tools and resources for assessing caregiver well-being. Take CAPC's course [Supporting the Caregivers of People Living with Dementia](#) to learn more.

Caregiver Assessment Tools

Zarit Burden Interview (ZBI)	Assesses distress, perceptions of social and physical health, and financial and emotional burden; providers can also use the short-form version
Geriatric Depression Scale (GDS)	Short-form version (15 questions) screens for depression in the elderly population
Benjamin Rose Institute Caregiver Strain Instrument	Assesses caregiver feelings about caregiving, relationship strain, health, and social isolation
Caregiver Self-Assessment Questionnaire	Developed by the American Medical Association, caregivers indicate specific episodes of physical and emotional strain
"What Do I Need as a Family Caregiver?"	Developed by Next Step in Care , asks caregivers about their living situation, caregiving responsibilities, worries, and sources of support
REACH II Risk Appraisal (RAM)	Developed and validated by REACH II data, identifies risk for depression, social support, and safety

After assessing the needs of both the person living with dementia and their caregiver(s), the next step is matching services to identified needs and providing referrals to community-based support services. See the Referral to Community Resources handout for suggested sources of support.

Referral to Community Resources

Effective care for patients with dementia requires partnership with community service providers who have specialized expertise and can meet needs where patients live.

In many cases, caregivers and people living with dementia are too overwhelmed to seek out these resources on their own. Direct clinician referral to community-based organizations (CBOs) can help. These referrals should be standard interventions for patients with dementia and their caregivers.

QUICK TIP: Write referrals to community supports on a prescription pad to increase the likelihood that caregivers will actually connect with the services.

3 STEPS FOR CONNECTING PATIENTS AND CAREGIVERS TO COMMUNITY RESOURCES:

1. After needs assessment, refer to the Alzheimer's Association.
2. Print or email CAPC's Dementia Care Resources for Caregivers handout to help caregivers locate resources.
3. Use the resources listed below to locate services in your area that meet the specific needs of the patient and caregiver, and refer them to the resource(s) via a prescription.

The Alzheimer's Association is a nationwide source of evidence-based and practical information about all aspects of care for people living with dementia and their caregivers. The local Alzheimer's organizations provide care consultation, support groups, 24/7 support line services, connection to other local services, education, and safe return programs. **Always write caregivers a prescription to call the Alzheimer's Association's 24/7 national helpline at 1-800-272-3900 or visit their support web pages.** Providers can **order referral pads** or download the Alzheimer's Association **Pocketcard App** online. Use the **ALZ Direct Connect Referral Form**, developed by Alzheimer's Los Angeles, as an example of how health care providers can link patients and families to local Alzheimer's organizations.

Potential Community Partners

Online Directories of Local Resources	
Alzheimer's Association's Local Chapter Directory	Online search tool to locate your community's local Alzheimer's Association Chapter
Family Caregiver Alliance's Family Care Navigator	Helps caregivers locate public, nonprofit, and private programs, services, and resources
Aunt Bertha	Social services locator by zip code, connecting people to local services for food, housing, transit, health care, and more
Eldercare Locator	Community service locator provided by the U.S. Administration on Aging; offers a search function for resources based on zip code or city and a toll free support number, 1-800-677-1116
Caregiver Education and Training	
NIA Alzheimer's Caregiving	Tip sheets for caregivers to help with communication, behavioral symptoms, legal and financial issues, safety, and caregiver well-being
Home Alone Alliance	Video series to support caregivers at home, available in English and Spanish and covering a variety of clinical topics including falls, wound care, and medication management; offered via a public-private partnership led by AARP, Family Caregiver Alliance, United Hospital Fund (UHF), and the Betty Irene Moore School of Nursing at UC Davis
United Hospital Fund's Next Step in Care	Resources for clinicians to support discharge planning, community partnership, and caregiver support
Alzheimer's Association's 10 Signs Brochure	For patients, families, and clinicians on the 10 warning signs of Alzheimer's
Alzheimer's Association's Caregiver Resources	Handouts on common challenges in dementia caregiving, and a support group locator
Family Caregiver Alliance's Disease-Specific Tip Sheets	A wealth of resources for caregivers that includes skill building, coping, and psychosocial support; resources available for many types of dementia
UCLA Alzheimer's and Dementia Care Program	Training videos and webinars for caregivers on common behavioral, psychological, and physical symptoms of dementia, and common challenges in dementia caregiving
Alzheimer's Los Angeles' Caregiver Tip Sheets	Tip sheets for caregivers on 15 topics, including bathing, driving, medications, and sundowning; available in English, Spanish, Chinese, and Japanese
Emotional and Psychosocial Support	
Alzheimer's Association's Support Groups	Online directory for local and virtual support groups; local Alzheimer's organizations often offer support groups as well
Family Caregiver Alliance's Support Groups	Online support groups for caregivers of those with any chronic conditions or disease; not dementia specific

Smart Patients	Free, online discussion forums for patients and caregivers divided into different communities based on diagnosis; offers specific threads on Alzheimer's Disease, Lewy Body Dementia, and more
Department of Veterans Affairs Caregiver Support	For caregivers of veterans, the VA offers a caregiver support hotline (1-855-260-3274) and an online search to find local support
Respite Care and Adult Day Services	
Arch National Respite Network	Online directory of respite providers and programs (Note: Medicare only covers respite through the hospice benefit)
National Adult Day Services Association	Online database of adult day center locations (Note: Medicare does not pay for any form of adult day care, but Medicaid and other non-Medicaid assistance programs may help defray costs)
Other Resources	
Legal Aid	Help finding legal aid for advance health care directives, wills, Medicaid and Medicare benefits and asset protection, housing issues, and other legal needs such as discrimination or using the Family and Medical Leave Act (FMLA)
National Academy of Elder Law Attorneys	Help finding legal aid, as well as educational resources for older adults
Meals on Wheels	Available in many communities to bring hot meals to the homes of older adults; depending on individual circumstances, meals may be provided along a sliding fee scale, from no cost to full price; local Alzheimer's organizations, senior centers, and churches may also offer meal delivery services
Financial Power of Attorney	Tips from the AARP for discussing advance financial planning

Follow up with patients and caregivers to determine if they were able to access the services you referred them to, and whether the services met their needs. Regular re-assessment of their needs is essential for effective care for people living with dementia and their caregivers.

Clinicians can serve as a lifeline to caregivers by including them as part of the care team, assessing their health and well-being, and addressing their needs through communication, psychosocial support, medical care, and direct referrals to community resources.

Dementia Care Resources for Caregivers

Taking care of a family member or friend living with dementia can be overwhelming. *You are not alone.* Along with your medical team, there are many resources available to you for support throughout the course of the disease. See the resources below for online education about dementia, and information about support groups, respite care, and more.

Online Caregiver Education

- Visit **Alzheimer's Association** for caregiver support groups, online community message boards to connect with other caregivers, and access to local resources.
alz.org/help-support/caregiving
- **Alzheimer's Association** also offers information for caregivers about the stages of dementia and how to respond to behavioral symptoms of dementia, such as aggression or repetition.
alz.org/help-support/caregiving/stages-behaviors
- The **National Institute of Aging** offers support, including how to respond to behavioral symptoms of dementia, legal and financial planning information, tips for home safety, and resources for caregiver stress relief and self-care.
nia.nih.gov/health/alzheimers/caregiving
- The **UCLA Alzheimer's and Dementia Care Program** offers videos to help understand how to care for people living with dementia. Topics include home safety, responding to aggressive language, depression and apathy, repetitive behaviors, sleep disturbances, and wandering.
uclahealth.org/dementia/caregiver-education
- Find resources specific to different types of dementia from the **Family Caregiver Alliance**.
caregiver.org/resources-health-issue-or-condition
- No matter your location, **Alzheimer's of Greater Los Angeles** offers a series of tip sheets for caregivers in both English and Spanish on a variety of topics, including medications, toileting, and behavioral symptoms of dementia.
alzgla.org/professionals/caregiver-tip-sheets
- The **AARP's Home Alone Alliance** offers educational videos and tip sheets in English and Spanish on wound care, mobility, and managing medications.
aarp.org/ppi/initiatives/home-alone-alliance.html

You are not alone. Call Alzheimer's Association 24/7 Helpline for around-the-clock support for all types of dementia. 800-272-3900

Dementia Care Resources for Caregivers

Finding Local Resources

- Use [Alzheimer's Association's Community Resource Finder](#) to identify local organizations that offer support groups, training, respite care, and other forms of support for caregivers.
communityresourcefinder.org
- Use the 'Family Care Navigator' from the [Family Caregiver Alliance](#) to identify local support resources.
caregiver.org/family-care-navigator
- Visit the [National Area on Aging](#) website to look up your local agency for a variety of resources, including long-term support services and food assistance.
n4a.org
- The [National Respite Network](#) resource locator can help you find local respite care, a service that provides temporary breaks for caregivers.
archrespite.org/respitelocator
- The [National Adult Day Services Association](#) assists caregivers in locating local adult day services.
nadsa.org/consumers/choosing-a-center

Connecting with Other Caregivers

- [Alzheimer's Association](#) offers online support communities and a search tool to find in-person support groups.
alz.org/help-support/community
- [Access Smart Patients](#), a website consisting of free, online discussion forums for patients and caregivers. Divided into different communities based on diagnosis, Smart Patients offers discussion threads specific to disease, including Alzheimer's Disease, Lewy Body Dementia, and more (including general forums for caregivers).
smartpatients.com

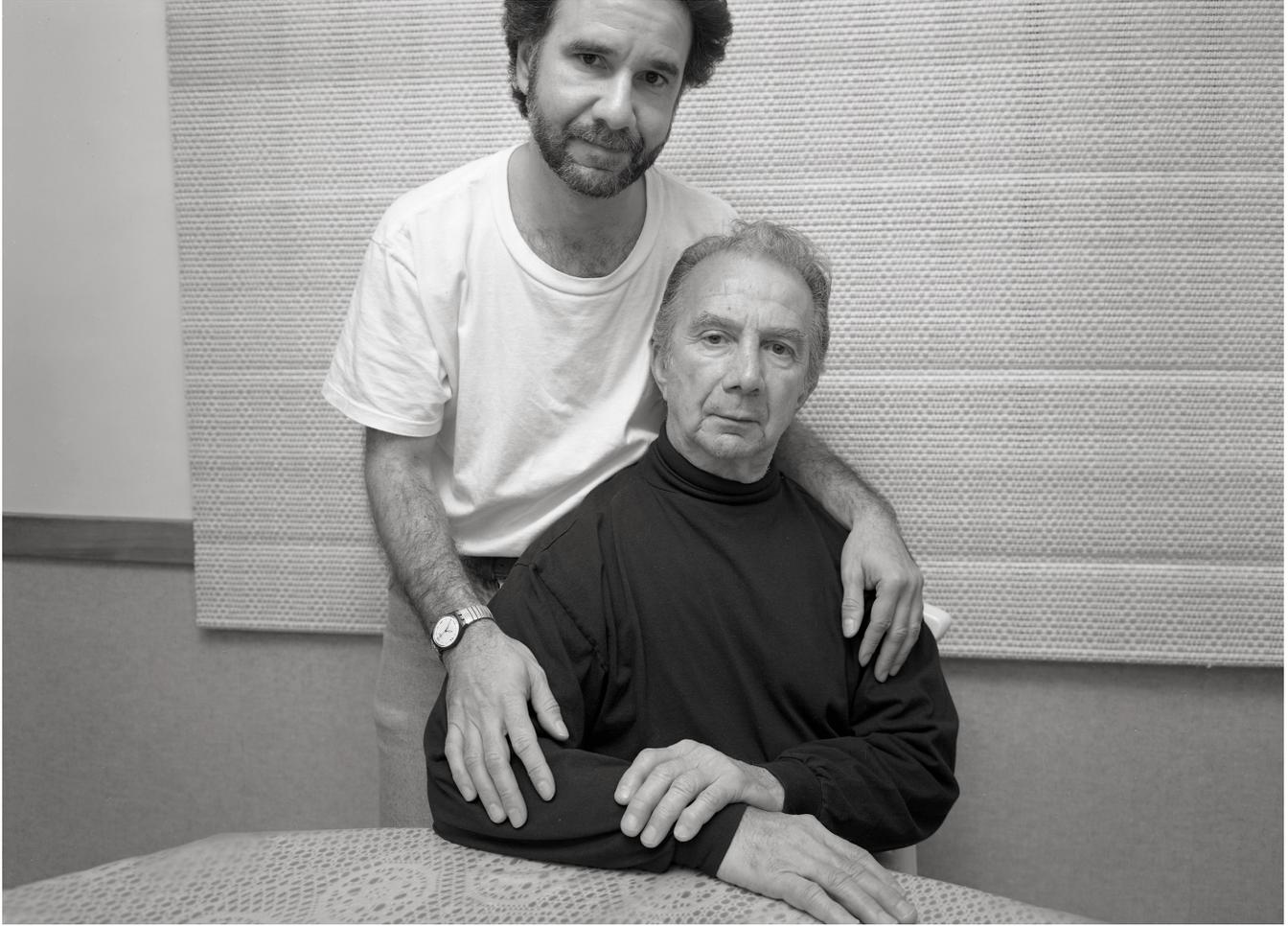
Support for Specific Interest Groups

- [Daughterhood Circles](#) are small communities of women who gather for support and community while caring for elderly parents.
daughterhood.org/circles
- The [Department of Veterans Affairs Caregiver Support](#) program offers veterans and their caregivers training, support groups, tip sheets, and other resources. Visit the website, or call the caregiver support line at 855-260-3274.
caregiver.va.gov
- [Smart Patients](#) offers LGBT caregivers a free, online support community. Search for the LGBT sub-thread on the website.
smartpatients.com/communities

Dementia Support Resources in Our Community

The following services and/or resources support people living with dementia and their caregivers in our area. Use the contact information listed below to connect to these critical supports.

Service/ Resource	Name of Service Provider	Website	Contact Information	Notes
Local Alzheimer's Association Chapter				
Local Area Agency on Aging				
Respite Care				
Adult Day Services				
Support Groups				
Legal Aid				
Meal Delivery				
Caregiver Education and Training				



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55 West 125th Street, Suite 1302 | New York, NY 10027 | 212-201-2670 | capc.org