

Question & Answer (Q&A): Delivering Dementia Capable Care within Health Plans: Why and How?

Webinar participants asked these questions during the June 2019 Delivering Dementia Capable Care within Health Plans: Why and How? webinar. We have edited speakers' responses for clarity. The webinar recording, slides, and transcript can be found on the Resources for Integrated Care website:

[https://www.resourcesforintegratedcare.com/GeriatricCompetentCare/2019 GCC Webinar/Delivering Dementia Capable Care Within Health Plans](https://www.resourcesforintegratedcare.com/GeriatricCompetentCare/2019_GCC_Webinar/Delivering_Dementia_Capable_Care_Within_Health_Plans)

Featured Speakers:

- Christopher M. Callahan, MD, MACP, Cornelius and Yvonne Pettinga Professor, Director, Indiana University Center for Aging Research
- Debra Cherry, Executive Vice President, Alzheimer's Los Angeles
- Megan Dankmyer, Associate Vice President of Case Management, Molina Healthcare of California
- Katie Scott, MPH, Sr. Director of Dementia and Caregiver Support Services, BakerRipley Senior Services Division

Family Caregivers

Q1: How does culture impact caregiving?

Dr. Christopher Callahan: The importance of culture in caregiving is often under-recognized. Culture can play a role in whether someone embraces the caregiving role or whether someone embraces the care recipient role, and how people want to receive care. In my own practice, the best way we can get to these issues is by asking care recipients and their caregivers directly, rather than making assumptions about someone's cultural preferences or approach. Perhaps the most important first step for any of us is to simply recognize and respect that culture matters so we need to have a conversation. Eliciting the care recipient's and caregiver's perspectives, which is a pathway to understanding cultural preferences as well as preferences across multiple other domains, simply starts by asking them how they view their symptoms and their causes. For additional information, you can review this resource (example questions are included on page 9): https://www.careinnovations.org/wp-content/uploads/2016/03/four-habits-monograph_new-agenda.pdf

Dr. Debra Cherry: We find that working with individuals from different cultures often means learning from them about how they view the disease and the caregiving role. Sometimes we use the word "caregiver" and people look at us with a great deal of confusion because they do not see that as a role. They may think that this is simply what family members should do for one another. Most caregivers in this country are spouses or adult daughters. Yet in some

cultures, there is a division and people take on different roles of caregiving. For example the daughter-in-law might be the most common caregiver or the oldest son might make the most decisions about care. Also, it is important to assess language preferences before providing information to the caregiver.

Q2: What resources are available for family caregivers in order to reduce the stress associated with caring for loved ones with dementia?

Katie Scott: There are a variety of resources available for caregivers. Through our project, “Texas Takes on Dementia,” the *Benjamin Rose Institute 1-1 Care Consultation Program* offers individual coaching with caregivers and teaches them how to manage behavioral symptoms and care, and how to action plan for their caregiving role. We offer classes such as the *Stress Busting* class and REACH, which are evidence-based stress management programs. There are other resources such as *Powerful Tools for Caregivers*, which is another class that helps individuals manage their caregiving role.

Resources for Integrated Care: For more resources for caregivers, you can download a caregiver-specific resource guide [here](#).

Q3: Do you have any tips for navigating Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements for caregivers?

Katie Scott: We work with each referring entity to ensure we abide by all HIPAA requirements for data sharing. Often, we ask the referring party to identify a caregiver that we can contact in addition to the client. When working directly with the client or caregiver, we first ensure we receive consent from the client to share information with their identified caregiver. From there, we try to find out if the individual identifying as a caregiver has any legal authority to represent the individual with cognitive impairment. Legal relationships can include durable power of attorney (POA), medical POA, or guardianship. If they do not have any of these relationships, we work with the client and the caregiver to set up advanced directives. If the client still has mental capacity, we try to set up POAs instead of pursuing guardianship.

Dementia Diagnosis and Screening

Q4: Dr. Callahan mentioned that there is a trend toward earlier diagnosis and recognition of Alzheimer's and other dementias. Given this trend, do you see the issue of stigma growing or changing?

Dr. Debra Cherry: We have seen the issue of stigma change with the trend toward earlier diagnosis. People are often surprised to see individuals with dementia who are articulate, able to speak up about their own desires, and able to plan for their own futures. This has challenged the views of some professionals who may think of an individual with dementia as a very elderly person in a wheelchair, sitting near a television set in a long-term care facility. Individuals with

early stage dementia often speak up and act as advocates for themselves and that changes the way people look at the disease.

Dr. Christopher Callahan: I think one of the difficulties that we face with stigma is that sometimes providers do not always know how much individuals with early dementia can do—that with a little assistance they can live independently. Also, providers may be pessimistic about what they can offer to the individual and their family. Individuals with dementia may try to avoid the diagnosis for fear that they will lose access to their car, their checkbook, or even their home. Even family members will sometimes try to avoid the diagnosis because of their circumstances—for example, if you do not drive, and your spouse with dementia can no longer drive, you may end up socially isolated. I think providers can reduce stigma by communicating the person’s strengths and the provider’s access to resources to support those strengths. I think it is important to make it clear to individuals and their families that we understand that many individuals with dementia can successfully live independently at home for a long period of time and manage their own affairs. I think that is an important first step in reducing stigma, because we need to acknowledge more that there are resources we can offer.

Katie Scott: I find that the biggest issue with stigma affecting dementia care is that service providers are sometimes afraid and may not know how to act around individuals with dementia. As service providers, we need to ask ourselves, “Are we treating individuals with respect and with knowledge of their own capacity to make decisions?”

Q5: Dr. Cherry, you mentioned that many health plans in California have opted to adopt validated screening tools that can be administered by telephone. Which member of the care team is typically responsible for completing these phone assessments?

Dr. Debra Cherry: In California there are two levels of phone assessments: health risk assessments and validated cognitive screens, like the [AD8](#). Health plans often outsource health risk assessments (health and functional status screenings given to all plan members) to external organizations. Screening staff are not necessarily licensed professionals. In contrast, care managers (mostly nurses and social workers) typically administer validated cognitive screens.

Q6: Dr. Callahan, what recommendations do you have for training providers to increase their ability to diagnose dementia?

Dr. Christopher Callahan: Training providers is not especially difficult and providers are perfectly capable of learning these skills. Training is of course necessary, but it is almost never sufficient to increase the rates of diagnosis and treatment. The more complex issue is putting the systems and supports in place to assist providers in making a diagnosis or completing a referral and then supporting the development and implementation of a care plan. These activities are difficult to accomplish in the constraints of a typical primary care office and providers perceive barriers to redesigning their practices to overcome these barriers. A large

research effort now focuses on how to help providers and their patients overcome these barriers.

Dementia Care and Services

Q7: Katie, can you share more about your dementia day center?

Katie Scott: We started our dementia day center in 1987. It was the first in Houston, and we are still only one of two centers in the greater Houston area that specializes in dementia day care, meaning that the eligibility criteria includes having some type of dementia diagnosis. We operate our program primarily through private-pay and some contracts with our local Area Agency on Aging as well as our VA program. Our day center operations are similar to a lot of other day centers across the state and country. We are open multiple days a week and individuals can come during the day; there is no residential option.

We tailor programming to the needs of individuals with dementia. For example, our activities typically last from 30 to 45 minutes, as we understand that individuals with dementia may not be able to concentrate for an extended period of time. We also alternate between physically and cognitively stimulating activities so that individuals do not get physically or mentally exhausted. In addition, we offer activities that can be adapted based on the individual's current cognitive abilities. For example, our cooking class allows independent (i.e., high functioning) individuals to participate in all aspects of the project, including the selection of ingredients and the final preparation of the food. Other individuals with lower cognitive functioning participate in only one or two steps of the process, like mixing or taste testing. We also tailor our programming to the specific interests of the individuals, improving the likelihood of participation in the program and creating a sense of community for the individual.

Q8: Some studies show that language pathologists have been very helpful in dementia treatment. When do you include speech in the member's plan?

Megan Dankmyer: That's a great point. If this is an issue that the member or caregiver identifies as a need, they can work with their primary care physician (PCP) to add it to their care plan and get authorization for those services.

Q9: Dr. Callahan mentioned in his presentation that an increasing number of individuals living with dementia are receiving community-based services provided in their own home. How can health plans encourage more PCPs to refer patients to community-based organizations (CBOs) for services?

Dr. Christopher Callahan: There are a couple of barriers to PCP referrals. One is that PCPs may not know what services the CBOs can offer. In addition, CBOs may experience frustration with low rates of referral, and sometimes an individual cannot access these types of services without a referral from a PCP. In order to combat these challenges, I believe we need to focus on increased relationship building and then improvement in communication technology.

Katie Scott: We have found that the easier the CBOs make it on the primary care team, the more likely these referrals will occur. CBOs can do this by working with partners to develop a clear set of guidelines on what should be included in the referral and how they want to communicate. The other thing that we heard across our project is that people want a centralized place to access multiple resources. For instance, having one centralized email address to send all requests to streamlines the process. In our case, referring parties can send an email to dementia@bakerripley.org to access any of the community-based resources tied to our network. The triage is then on the CBO side, which we believe has helped with our referrals.

Dr. Debra Cherry: When we started doing the work with the Cal MediConnect health plans, we were hardly getting any referrals. Over the last three years we have built up to 900 referrals per year, and we did this by providing the health plans with a tool that allowed them to connect families to resources mostly through care managers rather than primary care doctors. Care managers promote this confidential e-referral to members and families and this has resulted in growing numbers of referrals. At some point, there may actually be too many for us to manage. I think it would be possible to adapt a tool like this for other communities.

Megan Dankmyer: At Molina we have educated our PCPs and physician groups on the resources and education available through Alzheimer's Los Angeles so they can make referrals. I think sometimes all the different types of resources for the different types of conditions can be overwhelming. It is much easier for them to make that referral to case management and have the case manager assess the need and make that appropriate linkage.