Question & Answer (Q&A): Diagnosing and Treating Dementia—Current Best Practices

Webinar participants asked these questions during the July 2019 Diagnosing and Treating Dementia—Current Best Practices 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/

Diagnosing_and_Treating_Dementia

Featured Speakers:

- David Reuben, MD, Chief, Division of Geriatrics at the David Geffen School of Medicine at UCLA; Director, UCLA Alzheimer’s and Dementia Care (ADC) Program
- David Bass, PhD, Senior Vice President and Director, Center for Research and Education, Benjamin Rose Institute on Aging (BRI)
- Michelle Panlilio, MSN, NP, Dementia Care Specialist and Nurse Practitioner, UCLA ADC Program
- Ann Cheslaw, Family Caregiver

Assessment

Q1: How do you approach cognitive assessment for individuals with physical or intellectual disabilities?

Dr. David Reuben: Neuropsychological testing is often useful for persons with physical (e.g., hearing, vision, or prior stroke) or intellectual disabilities, as it expands the available assessment instruments and experts available to interpret results.

Q2: Dr. Reuben, you mentioned assessing memory using questions about common history knowledge. How do you ask questions to assess memory for individuals who come from different backgrounds or for whom English is not their first language?

Dr. David Reuben: This is a challenging issue. To test for memory, both the examiner and the person being tested must have the same experiences; however, this is not always the case. For example, someone being tested may have immigrated here after specific historical events occurred. In a situation like this, I talk to the family to better understand where the individual came from and what information they know. This allows me to ask the individual culturally and personally relevant questions. Other approaches include having a translator available, enlisting the help of a provider who has a more similar cultural background to conduct the assessment, or referring the individual to neuropsychology for assessment.
Treatment
Q3: Dr. Reuben, do you recommend de-prescribing other medications in order to simplify routines or reduce contraindication, as opposed to adding dementia-focused medications, such as cholinesterase inhibitors?

Dr. David Reuben: De-prescribing, or taking away drugs, is an important component of good dementia care for three reasons. First, other medications often have side effects that can actually worsen cognition, such as bladder relaxants. Second, it helps simplify the medication regimen, which can benefit both caregivers, as well as the individuals actually taking the medications, by making their routines easier. Third, there are certain medications that individuals with dementia sometimes do not need. For example, individuals with dementia may not need medications to lower cholesterol considering their limited life span. However, this does not necessarily mean avoiding dementia-focused medications, as some individuals may experience benefits from such medications.

Care Coordination
Q4: Dr. Bass, how do Care Consultants involve an individual’s primary care physician in the action plan and ongoing care for individuals with dementia and their caregivers?

Dr. David Bass: There are a number of ways Care Consultants may involve primary care physicians in the action plan and BRI Care Consultation™. Action plans list all of the practical steps patients, caregivers, and professionals can employ to address problems that are important to families.

With the primary care physician’s agreement, Care Consultants may assign action steps to the primary care physician or to the family for follow up with their doctor. In this way, primary care physicians are directly involved in the action plan process. On follow up calls, Care Consultants review progress on action steps with the family and address any barriers to completion. For example, if there are difficulties in communicating with the primary care physician, additional plans or interventions can be discussed and implemented. Care Consultants may also coach patients or caregivers on how to prepare for a doctor’s visit to ensure that their needs are addressed. This coaching may involve collaborating on questions to ask and role playing to ensure that patients and caregivers feel prepared and comfortable for the visit.

Families may also choose to bring a copy of their action plan to appointments with their primary care physician, which can help the physician gain a more complete picture of the family’s situation, their needs, and how the disease is impacting their daily life. If pre-approved by the primary care physician and preferred by patients and caregivers, Care Consultants may periodically send updated action plan copies to the primary care physician.
Q5: Michelle, how do you involve primary care physicians in the dementia care you provide?

Michelle Panlilio: The primary care physician typically refers the patient for enrollment in our program, which means they are also our partnering physicians. Whenever the Dementia Care Specialist makes any medical, social, or behavioral recommendations, they will send the recommendations to the primary care physician for approval. If there are significant updates to the recommendations (e.g., goals of care, safety, change in caregivers, medications) we also update the primary care physician via electronic medical records.

Q6: Michelle, what technology do you use to facilitate care coordination between your program and community-based organizations (CBOs)?

Michelle Panlilio: We use email and the UCLA Alzheimer’s and Dementia Care (ADC) software. We designed the UCLA ADC software specifically for our program; the software allows us to track referrals and vouchers for CBO services for each individual and caregiver. CBOs can also communicate with us through use of the software. We also ask families to sign a consent form agreeing that they can be contacted by outside facilities and that we may release certain PHI to the CBOs.

Caregiver Support

Q7: Ann, how can providers support family members whose loved ones recently received a dementia diagnosis?

Ann Cheslaw: Finding a doctor who can talk through your options and help navigate the future is critical. The provider fills a role similar to that of an orchestra leader; there has to be one person who can help you find rhythm and synchronize things. It is very critical that this person not only informs you about the disease, but also guides you while trying to determine next steps. Pairing up with a team like UCLA’s ADC team was absolutely critical for me. They helped me identify resources and determine what types of care we needed.

Q8: Ann, do you have any recommendations for family members on how to coordinate care responsibilities with each other?

Ann Cheslaw: Family dynamics are complicated, and this disease brings old sensitivities to the forefront. Success comes when every family member keeps the end goal in mind: the safety, protection, and shared love of the person who is living with dementia. Family members have to get on the same page in this regard. Issues from the past or difficult dynamics can too easily get in the way of doing what is best for the loved one.

From the start, I urge family members to find a local support group, family counselor, or spiritual leader who will help establish distinctive roles for each family member. Coordinating care responsibilities requires each family member to identify their best skill set and offer a realistic view of their own personal needs regarding time, finances, and proximity. This is often difficult and continually calls on family members to be open, vulnerable, and adaptive.
Q9: Dr. Bass, how do you help caregivers balance necessary steps in an action plan without overwhelming them?

Dr. David Bass: The number of action plan steps a family can handle at one time truly depends on the family on any given day. While the steps are meant to guide, help, and support the family, seeing a long list of “to-do’s” can certainly be overwhelming, especially for a family in crisis. Thus, the number of action steps actually “assigned” to a family is based on a conversation between the Care Consultant and the family, and informed by the clinical experience of the Care Consultant.

The software platform used to deliver BRI Care Consultation (CCIS) makes it easy for Care Consultants to decide how many steps are actually included on an Action Checklist, which is the list regularly sent to families. The CCIS allows Care Consultants to record all of the steps that are determined in collaboration with families. Next to each action step, there is a check box: “Include on Action Checklist.” Care Consultants can keep a running list of action steps, but by not clicking the box, an item will not be included on the Checklist. Families only see items on their Checklist that they wish to handle or that their Care Consultant feels are appropriate to address before the next call. In this way, families take on what they can handle and, ideally, are not overwhelmed. On the next call, Care Consultants review the action steps that have been completed and, if relevant, add additional steps to the Checklist. Over time, this regular process of BRI Care Consultation also helps Care Consultants gauge a family’s capacity.

Q10: Dr. Bass, how will providers know when the Best Practice Caregiving resource is available?

Dr. David Bass: The Best Practice Caregiving resource will be available to the public in Fall 2019 and we will have a multi-faceted marketing campaign. The Family Caregiver Alliance website will host the resource. For more information, you can reach out to me at dbass@benrose.org.