

## **Supporting Patients & Caregivers through Comprehensive Dementia Care**

Since 2012, Eskenazi Health's Aging Brain Care (ABC) program has been a model for effective, compassionate dementia care in Indiana. ABC provides a suite of services for adults living with Alzheimer's disease and related dementias in their own homes, including a personal treatment plan that aims to improve the quality of life for both people living with dementia and family caregivers. ABC's success with dissemination has been supported by its ability to adapt the care navigator role to different environments. Originally, care navigation was completed by a clinician. Over time, the ABC demonstrated that effective care navigation can be conducted by a community health worker.

At the core of the ABC program is a care navigator. The care navigator visits people in their home where they assess the person's cognitive, behavioral, psychological and functional health. Working as a liaison to the person's primary care provider (PCP), the care navigator provides insights that help the PCP make informed decisions about patient care and treatment. ABC also provides education and respite services for caregivers, helping to reduce caregivers' stress while improving their ability to support the health needs of their loved one.

With a demonstrated track record of success, ABC has been identified as one of six models that comprise the National Dementia Care Collaborative (NDCC). The NDCC aims to expand access to evidence-based models for comprehensive dementia care. These models have been tested and shown to improve care delivery, reduce healthcare costs while reducing caregiver strain.

### **An Integrated Approach to Health**

Comprehensive dementia care emphasizes collaboration among all clinicians, support persons and family members who aid the person living with dementia. In this way, it provides a different level of service than is typical in a traditional primary care setting.

For example, in a traditional primary care setting, a patient with dementia may see their PCP and be referred to a specialist for a specific health concern, such as cognitive decline or physical rehabilitation services. However, the patient is left to coordinate their own care. This puts tremendous pressure on either individual patients with dementia or their unpaid family caregiver to navigate appointments while making sense of complicated, and sometimes contradictory, recommendations from multiple health care providers.

In a comprehensive dementia care model, much of this coordination is handled by a trained care navigator. Care navigators assist with scheduling appointments with PCPs or specialists, and then serve as an advocate, providing education and tools that empower the person living with dementia and family caregivers to be active members of their care. Care navigators also help with understanding how to adhere to prescribed medication regimens. By collaborating with PCPs, specialists, and the person with dementia and their caregivers, care navigators provide support, advocacy, and education that is often lacking in traditional dementia care.

### **Improving Outcomes through Comprehensive Care**

Lauren Sullivan is one of ABC's care navigators. Last fall, she received a call from a caregiver who was worried about her mother. The mother had Alzheimer's, and although she had been prescribed different medications to take each night to assist with sleeping, she wasn't sleeping well. The stress of managing the situation was beginning to take a toll on the family member. "Can you help?" she asked Sullivan.

Sullivan arranged for a home visit. Upon arriving, she made a discovery: there were several bottles full of the same medication, some past their expiration date. This meant the patient wasn't taking medication at bedtime as prescribed. Sullivan wanted to help the caregiver manage her mother's medication more closely while also reducing her sense of being overwhelmed by the task. So, she dove deep into her care navigation toolbox.

First, Sullivan showed the caregiver how to organize daily medications by using a pillbox.

She also taught her some strategies for making sure her mother was swallowing her daily pills. Sullivan then reached out to other people on the patient's care team. She arranged for a nurse to conduct an in-home visit to help the caregiver better understand the regimen of medications that her mother was taking. She discussed the situation with the pharmacist who was dispensing the medications, too. Finally, Sullivan messaged the patient's primary care physician via Eskenazi's electronic health record system to describe what she had learned and the intervention steps she had taken.

In fact, the patient's PCP had also been concerned about her sleep and medication for a while. Sullivan's advocacy helped the PCP figure out what was occurring and take steps to provide the best possible care.

**“One goal of the ABC model is to focus on the caregiver and reduce their stress, but also to watch out for safety,” says Sullivan. “And in this situation it was safety. That was a big component of what we were focusing on.”**

Sullivan's ability to help coordinate multiple doctors, specialists, and support staff has made a huge difference for the patient and her caregiver. The caregiver is now better able to manage her mother's daily pill regimen, resulting in improved sleep for her mother.

ABC also provided the caregiver with respite services. Now, once a month, a home health aide takes care of the patient for 8 hours, allowing the caregiver to focus on themselves and their own needs. This has helped the caregiver decompress and recharge, which is also essential for strong patient care.

Sullivan notes that while this sleep issue has now been resolved, she will continue to check in with the patient and the caregiver, and that all of ABC's coordination and education services will remain available. This is important, she says, because dementia can be unpredictable—and both patients and caregivers need to know that support is nearby.

**“When new symptoms arise, things can be scary and confusing,” she says. “That's why having us there, having us able to help out as these issues arise, is really a benefit for everyone.”**

The 13-year history of the ABC program at Eskenazi health is evidence of the adaptability, effectiveness, and rightness-of-fit for care navigation to support people living with dementia and their family members and caregivers. The Indiana University and Eskenazi health team members are now building on this success through multiple strategies; they are adding new sites for ABC, demonstrating new ways of identifying people with mild cognitive symptoms, and integrating the ABC model into population health approaches that address dementia as early as possible in the disease course. Through all these approaches, ABC continues to demonstrate its regional and national leadership.

