For about 15 years now I have been advocating for the dementia arena. I have been leaving bread crumbs all over the place with some of the highest levels of people in the world in hopes I can make a small difference for those impacted by this horrible disease.

I started doing this because there were not enough people, actually living with dementia, standing up for others. There was less than a handful of folks doing this from around the world. Today, I am glad to say, there are many out there stepping up to do their part, but sadly I still don’t see the number of minority representatives I would like to see.

When I began this journey, I had a list of about 15 things to be accomplished that would lead to better support for those impacted by dementia. Over the years that list grew and I was very fortunate to get all but two items accomplished, with the help of many great people and organizations out there.

I believe we are living in exciting times as so many advancements have occurred in the last 5 years. People with cognitive issues will benefit greatly, and the possibility even exists that some living with dementia today will see a cure, or at least a way to slow it down within the next 10 years.

Currently there are some great programs being designed and considered to keep people living in their homes longer and being paid so they are not forced into seeking an assisted living facility or memory care unit.

There is a great deal of new education programs around dementia for hospitals and medical staff that did not exist a few years ago. Perhaps, early training and awareness is the answer? Yet, medical schools today are overburdened with meeting high accreditation standards for qualifying exams and less concerned with graduating doctors educated to address complex care pathways like dementia and cognitive disabilities. This includes places like Harvard, where I had the opportunity to speak with a class of students soon to graduate. It is sad to see our future physicians being trained as expert scientists rather than patient care stewards.
So how do we resolve some of these issues? I personally know that most medical staff is eager to learn more about dementia. But that comes at a cost to the institutions for which they work. I have been fortunate to speak to people at the highest level in government, related to healthcare, and they all agree we need to see changes for the better, especially in hospital systems.

While we have advanced in the last few years how do we ensure that people get this dementia training that has been designed and is ready for implementation? Hospital system management refuse to pay for this education and organizations, like The Joint Commission, refuse to create an accreditation requirement, or even a certification process which hospitals can apply for if they meet the education criteria.

What I find amazing is they already enforce an educational requirement for staff working in Assisted Living facilities but they don't feel it is needed in acute care hospitals. Not only do those living in Assisted Living facilities require acute hospital care, but also many with dementia still living at home. I have been working on this for 10 years without success and I know many others who have also failed.

Another issue that must be addressed concurrently is how to identify which hospital patients are living with dementia. Facing stigma in society is a huge problem and sadly leads to many not disclosing their dementia diagnosis to others. Also, about 50 percent of those living with some type of dementia don’t even know they have it, as that is part of the problem with this condition. There are also many people with cognitive issues that could be reversed if they were able to seek a diagnosis. Not all cognitive issues are progressive so we must ensure quick diagnosis. Sadly, today many still feel cognitive decline is a normal result of aging. This is not true.

While everyone I have spoken with insists my idea of having a certification program for dementia in hospitals is the right thing to do, most feel it cannot be accomplished. They feel that the cost and time required will not be accepted by senior hospital management. To meet managers and administrators where they are, perhaps the answer is showing how certification can reduce cost and improve patient outcomes overtime. Yet, unless administrators are willing to think outside the traditional care pathways, systems will continue to sacrifice people’s lives to avoid additional cost. I cannot stand idly by while knowing that some of the most important advances in hospital care required changes and management approvals. Just think many of the standards we have today would not exist if we thought that way all the time.

If hospitals had these certifications programs, they could easily close the final gap that is needed to fix the entire system as it relates to patients with cognitive issues. I am not saying that hospitals should be mandated to get this certification. I believe, as we have seen in the past, that when certification programs exist, hospitals seek them out to show their community they offer high quality healthcare. I also believe this will create more competition among hospitals. Just as they do today for other certification programs that are tracked.

So, let’s assume the hospital has a Certification program for dementia. Their admission work-up would include a 3-minute cognitive test. This will identify the patients that may need additional help while they are in the hospital. It will also determine if the patient needs further follow-up upon discharge to get the advanced care they need and deserve. Addressing patient needs upfront and early in the admission process will guide care planning as well as provide an appropriate pathway to discharge and advanced care planning if necessary.

Today we do not know when most people admitted to the hospital need additional help, which can contribute to medication errors, unnecessary or suboptimal treatments, increased stress and an unhappy patient. There are also financial implications from lawsuits and penalization in bill payment for hospital readmissions.

By instituting this quick test, hospitals may even increase volumes as they identify patients that may have an issue and require further work-up. This also benefits the patient who may have been unaware of their deficit. I hear from others often that they know something is wrong but are afraid to say something to their loved one for fear of causing an argument.

I have always been a visionary and out of the box thinker. While this idea came to me from my own hospital experience, over 12 years ago, I believe now is the time to close the loop and make the hospital system safer. I know hospitals that would seek out this certification if available.

There is a program that came out a few years ago gaining traction, but it only places a band aid on the problem and fails
those living with dementia. It’s called the “4Ms”. The focus is on What Matters, Medication, Mentation, and Mobility. But it fails to identify the patients in need. What is the benefit of having a procedure in place if you can’t identify when to implement it? Here is where a certification can guide clinics and hospitals through training on screening and new techniques for engaging people in conversations about cognitive health.

I am not one to reinvent the wheel and do not care where the credit will lie, but we must do something now and must hold our hospitals accountable for the safety of our patients. Let’s stop talking about it and do the work that we know will be successful, not just another program that sounds good. The existing systems fail our seniors and others living with cognitive challenges. People with cognitive issues deserve to be treated with respect and to receive the highest quality care possible.

Michael Ellenbogen - living life to the fullest with dementia

Comments from the experts:

I am fully on board with this. Especially now that there are treatments slowing Alzheimer’s, the need for more people being diagnosed and earlier in the disease process is imperative. Half a million Americans die each year with significant cognitive impairment but most lack a diagnosis. We must do more, especially to raise awareness of health care providers.

David Morgan, PhD, MSU Foundation Professor of Translational Neuroscience, Director Alzheimer’s Alliance, Michigan State University College of Human Medicine, Grand Rapids MI.

I fully support the need for more dementia-capable care for people living with dementia in the hospital, and the need for expanded training for hospital-based professionals.

Joseph E. Gaugler, PhD | Robert L. Kane Endowed Chair in LTC & Aging | Director, Center for Healthy Aging and Innovation | Distinguished McKnight University Professor | Director, BOLD Public Health Center of Excellence on Dementia Caregiving | Editor-in-Chief, the Gerontologist | Division of Health Policy and Management | School of Public Health | University of Minnesota.

The underdiagnosis and non-disclosure of Alzheimer’s disease and other dementias is a big problem. Rewarding hospitals who do a good job identifying cognitive disorders that impact care is a good first step towards a solution.

David Weisman, MD. Director, ANA Clinical Research Center.

Michael has indeed identified two of the primary stumbling blocks to providing the necessary support and care when someone is living with the brain changes of a developing dementia: the lack of recognition that dementia has an active role in the situation, and the lack of training that involves both knowledge acquisition and skill demonstration. The current lack of any dementia recognition or training requirements for all personnel in hospital settings makes them some of the most dangerous and ill-informed places for someone who is living with this condition. As the numbers of individuals who are likely to experience some form of dementia in their lives is increasing, the ability to provide effective support and care is not keeping pace.

Improvement of dementia recognition and training are essential for providing quality interactions, treatment, and outcomes in our hospital systems. It is time to acknowledge the need for all health care settings, hospitals included, to participate in the recognition and support of early indications, mid-state changes, and late state challenges of dementia and other neurodegenerative conditions.

Teepa Snow, MS, OTR/L, FAOTA, Founder and CEO of Positive Approach to Care®.

Michael describes in detail the sentiment I’ve heard from patients and families across the country. Cognitive health is not a priority in hospitals or in primary care. As he explains, this is not a result of bad physicians; rather, this is the result of a bad system of care. It is clear that the biomedical model rules medical school training. We also know that hospitals are guided by systems of payment and reimbursement. Levels of burnout across the U.S. demonstrate how systems focused on financial outcomes rather than the care or treatment of patients demoralizes physicians and the nurses on the front lines. Patients with cognitive health concerns are at the forefront of this imbalanced system. They are there because treatment costs time and attention. It requires compassion from a system that is inherently dispassionate. As a result hospitals are letting go of their responsibility to care for this population because they simply can’t justify the
costs. To meet this head on, we all must rethink our approach and argue with evidence that intentional and kind care saves money, lives, and improves outcomes.

**Stuart W. Grande**, Residential (MPH) Program Director, Public Health Administration Policy, Division of Health Policy and Management, The University of Minnesota, Twin Cities.

I agree whole heartily with your basic assessment of the dire need in hospital systems to do more awareness training, some kind of certification, provide short screenings to all those 50+ entering their care, and a wristband for staff awareness when needed. The real key is, if they perform an abridged mini screener, and find that there is a possible impairment, what steps they take with that knowledge. There is a lot to roadmap, unpack, and work through, but well worth the effort, and I am more than willing to lend my support.

**Kevin Jameson**, Volunteer, Founder, CEO, Dementia Society of America®.

**ACKNOWLEDGMENTS**

None.

**CONFLICTS OF INTEREST**

Author declares there are no conflicts of interest.

**FUNDING**

None.