Alzheimer's Advisory Council

Meeting Minutes
June 18, 2019
3:00-5:00 pm

Date of meeting: Tuesday, June 18, 2019
Start time: 3:06pm
End time: 4:58 pm
Location: McCormack Building, One Ashburton Place, 21st Floor, Boston, MA

Members present:

- Marylou Sudders – Executive Office of Health and Human Services (Chair)
- Elizabeth Chen —Executive Officer of Elder Affairs
- James Lavery—Department of Public Health
- Andrew Budson, MD—VA Boston Healthcare System
- Robin Callahan—MassHealth
- Rep. Ruth Balser—MA House of Representatives
- Hector Montesino, CDP—Alzheimer's Advocate
- Rhiana Kohl, PhD—Caregiver
- Heather Sawitsky, JD, MPH—Fox Hill Village Homeowners Corp.
- Linda Pellegrini, NP—UMass Memorial Medical Center
- Jonathan Jackson, PhD—CARE Research Center, Mass. General Hospital
- Susan Antkowiak—Alzheimer's Association
- James Wessler—Alzheimer's Association
- Barbara Meehan—Alzheimer's Advocate/Former Caregiver

Members calling-in:

- Maura Brennan, MD—Baystate Medical Center
- Bernice Osborne-Pollar—Caregiver

Members absent:

- Sen. Patricia Jehlen—MA Senate

Proceedings:

Secretary Sudders called the meeting to order at 3:06 pm.

Vote: Rep. Balser introduced a motion to approve the March 19th meeting minutes, which was seconded by Mr. Wessler and unanimously approved, by roll call.

Secretary Sudders thanked the Alzheimer's Association for assembling the panel of individuals living with Alzheimer's and dementia for this meeting. She briefly reviewed the Council's charge and emphasized that this is an extraordinary group of people to advise the Commonwealth, we have an extraordinary opportunity to learn from your wisdom and create a culture of support for people living with Alzheimer's in Massachusetts. She introduced the panelists, **Susan Champigny, Jane Challachan, Mike Belleville,** and **Mitch Evich,** accompanied by his wife **Paula Evich.**

Council members briefly introduced themselves and their relevant affiliations to the panelists.

Ms. Champigny opened her remarks by thanking the Council for inviting her to speak. She proceeded to describe how she was diagnosed with Alzheimer's three years ago; her coworkers confronted her about her changing behavior and "work ethic." She was instructed to see a doctor and was put on medical leave. She described how she was diagnosed via lumbar puncture, and her shock and sadness at this discovery; her father, grandmother, and aunt all had Alzheimer's, and she had witnessed their struggles. She described the progression of her symptoms, including personality changes and symptomatic "sundown" episodes. She noted that the Alzheimer's Association and the programming they provide has been a huge resource for her. She concluded by emphasizing that day programming for people with Alzheimer's should be more widely available.

Ms. Callachan described the journey to her dementia diagnosis five years ago; she began forgetting how to do tasks at work and was struggling to read numbers on her screen. Having been a successful businesswoman, she emphasized how "demoralizing" this loss was, and how it "made [her] feel so small." She expressed to her sister that she was worried that she may have Alzheimer's; her sister believed that she was too young to have the disease. She reached out to the neurology department associated with her primary care provider, Beth Israel, and was placed on a waiting list to see a provider. Her symptoms at work worsened, and she contacted Beth Israel, demanding to see a doctor as soon as possible. She underwent neuropsychological testing, but her insurance wouldn't pay for her PET scan; she was deemed too young for this testing. She paid out of pocket, as she was "desperate for answers." Ms. Callachan described the relief she felt when her doctor diagnosed her with dementia, as she had thought she was "going crazy." She noted that every doctor who diagnoses dementia should tell people about the Alzheimer's Association and noted the importance of having a good relationship with your neurologist. She described her feelings of anger and thoughts of suicide upon her diagnosis, but noted that being in a "community with people who understand the disease" has improved her quality of life. She noted how important her online support group has been to her well-being. She discussed how stigma has impacted her relationship with her husband, who has been struggling to cope with her diagnosis. She emphasized that "everyone's experience is unique," and that there is too much generalization "about what dementia is and who could possibly have it." She described stories of her peers meeting with their political representatives who have responded by saying, "You can't have dementia; you're too well-spoken." She concluded by emphasizing how individual the experience of dementia is and the need to change the cultural understanding of this disease.

Mr. Evich opened his remarks by noting that he was diagnosed in 2016 with early-onset Alzheimer's. He described the blog he started upon his diagnosis, and how crucial this outlet has been for him.

Ms. Evich read some notes that Mr. Evich had prepared. She described how Mitch was diagnosed at almost 52 years old, when their son was in college, and their daughter was in middle school. Mr. Evich had been the primary source of income for the family, and the diagnosis was a "blessing in disguise," as an opportunity for Mr. Evich to stay at home and leave the work environment that had been a source of great anxiety for him. She noted that the most helpful resource for them has been their support group through the Alzheimer's Association, which they have been attending since the fall of 2015. She described the support they have gleaned, both "emotionally and practically" by learning what to expect next and what resources are available. She mentioned the free Charlie pass, which she learned about by researching the Ride program. She also noted that the Health Connector and SHINE have also been useful resources for her. She expressed her hope that early onset legislation will pass, as the current age of eligibility for the Frail Elder Waiver is 60. She concluded by noting that "any age minimum for Alzheimer's related services should be done away with."

Ms. Sawitsky arrived at 3:47.

Mr. Belleville opened his remarks by sharing that he has been happily married for 30 years, has 3 children, 5 grandchildren, and “one on the way.” He described being diagnosed at age 52 and a half with Alzheimer’s; a diagnosis which was later changed to Lewy body dementia. He described his shock at this diagnosis, because he “had the same stereotypes that other people have.” He described being given test results and medication by his doctor, but no referrals to other resources or information. His wife contacted the Alzheimer’s Association’s local chapter, and they were connected to a care consultant, who referred them to some education forums. He explained that it was at these forums that he “realized that I still had a life to live, where I can learn new things, but most importantly, I have a voice.” He emphasized that at the time of his diagnosis, his doctor should have told him that he could “still have a meaningful, purposeful life.” He noted that “the most important prescription they should be giving is social engagement,” asserting that he is “here today,” because of the efforts he and his wife have made to staying engaged. He described how some friends and family have disappeared from their lives, but their “dementia family” is a constant. He noted various ways that he has stayed active: working as a dementia advocate, working as tech support at the senior center, learning to cook, watercolor painting, and teaching himself to code to develop an app for individuals with dementia. He concluded by emphasizing that: “a diagnosis doesn’t mean you have to stop living. We are still part of society. And we deserve the same equal rights and should have a voice in policies being made about us. We are the true experts. Time is a very precious commodity for us. But we also want to help others in our footsteps have a more dignified experience.” He ended with a quote by this friend Steven who passed away a year ago from Alzheimer’s disease.

Secretary Sudders thanked the panelists for their stories, and opened the conversation to questions from Council members.

Dr. Budson described the “window” between the time of diagnosis and the time when an individual needs formal, institutional care, which is usually a span of a few years, during which “there is often not really anything set up for them to do.” He asked the panelists for their thoughts on the Commonwealth establishing some partial employment programming for these individuals. Mr. Belleville enthusiastically supported this idea, but noted that transportation issues may pose a stumbling block. He mentioned purpletables.com (a website that makes reservations at participating restaurants with staff that have been trained to serve those living with Alzheimer’s/dementia and other physical or cognitive conditions); he noted that this model could expand to a program like “purple Uber.”Ms. Evich noted that engagement and continued contribution is very important to those with dementia, and that her philosophy is “to not take things away” from her husband.

Ms. Champigny agreed, noting how difficult it was for her to retire, and how important the engagement she found at the senior center was for her. She also noted the need for education for families, and that her daughter has been struggling to cope.

Ms. Callachan agreed, and emphasized that “it’s important for those of us who have the disease to have support but it’s also important to support the family members who are dismayed and confused and are taking on the burden of managing the household.” She noted that stigma is the biggest barrier, and that she loves attending meetings and any social engagement she can, and that “there are things we can do to make life with dementia wonderful.” Ms. Champigny agreed that the time to pursue other things once an individual stops working can be a “blessing.” Ms. Callachan expressed that it should be easy to teach the community “that we can all live well together.”

Ms. Meehan asked the panelists for their ideas on how to address the stigma of Alzheimer’s/dementia. Mr. Belleville replied that the public sees Alzheimer’s only as a tragedy, as only people in the end stage, and there isn’t visibility around what is meaningful and purposeful about those living with dementia who are leading a full life. He noted the importance of developing programs and services to allow individuals to live in their homes as long as possible.

Mr. Lavery asked the panelists to consider their experience of their initial diagnosis, and if a member of their provider team had been able to articulate the "positive spin" for them, how it would have impacted them. Mr. Belleville replied that such a viewpoint would have saved him "six months of agony." He noted that when someone gets a cancer diagnosis, they are connected with supports and counseling, but that dementia diagnoses do not receive such resources. He emphasized that having a liaison there, someone to connect the family to the next step, would have been very helpful. Ms. Champigny agreed and asked what role social workers could play in this system. Mr. Lavery replied that he believes there could be an avenue here for their involvement, to "have someone there to take you by the hand and tell you it's not a death sentence."

Mr. Wessler mentioned the Dementia Care Coordinator program, a direct referral from the doctor to a social worker at the Alzheimer's Association. He explained that the Association's team contacts the family first, rather than waiting for the family to reach out. He mentioned that one bill hearing he attended earlier in the day would require the six Senior Care Options in the Commonwealth to provide this service.

Ms. Robin Callahan expressed her gratitude to the panelists for sharing their stories and thanked them for their courage in coming to present. She noted that her mother had Alzheimer's and that she struggled as a caretaker to understand what she should be doing next. She asked the panelists if having a care coordinator establish immediate contact, and if having certain materials in place at the time of diagnosis would be helpful. She also noted that regarding stigma, some approaches could examine the education of children, changes to the language used, and widespread acknowledgement that the experience of dementia is so common and that competence around it is crucial. She expressed wanting to "create a conversation that puts all of us in a better place."

Rep. Balser thanked the panelists for their participation, noting that she is "already a beneficiary of your education." She inquired whether there are enough services and programs for those with dementia throughout the state, and whether there is room enough for everyone who wants them. She also asked, if there are not enough services available, if the panelists felt that the Alzheimer's Association or state government should be responsible for expanding them? Ms. Evich replied that she doesn't feel that there is adequate programming. She added that while the Alzheimer's Association has some great meetings, transportation to them can be tricky. She noted that programming at Memory Cafes is on calendars "sporadically." Secretary Sudders added that there are 110 Memory Cafes throughout the Commonwealth. Ms. Evich noted that the senior center in their town doesn't have programming for individuals their age, and that more senior centers catering to a wide age range should be established. Ms. Meehan noted the importance of Memory Cafés and the strength of the relationships they foster; she expressed that more Memory Cafes should be held.

Mr. Montesino mentioned the importance of public awareness and expressed his belief that there should be more Memory Cafes, including those geared towards underserved populations and in different languages. He noted that in his city, while there is a very large population of those over 65, there are only two cafes a month. He thanked the panelists for their contribution.

Dr. Jackson brought up the transition to retirement, noting that this transition is not always "voluntary, graceful, or elegant." He asked the panelists what kinds of support employers need when learning that someone on their team is living with dementia. Mr. Belleville thanked Dr. Jackson for this question, replying that he would love to see more employment of "patients." He elaborated on his experience, explaining that the insurance company who oversaw his long term disability benefit sent him a letter telling him that because of his age, they did not believe that he had dementia, and he was ordered to return to work. He noted that at this point in his disease progression, he was unable to drive, but was still required to go back to work. He had to hire a lawyer to confirm his diagnosis. He described the common pattern that his peers undergo, that a diagnosis is delayed, and their job performance declines and they are fired, find new work, and are fired again. He noted that while he was lucky to have a good lawyer who found prominent neurologists to testify on his behalf, there are other younger people who are losing jobs and benefits that they should be entitled to. He noted that there should be a "grace period" for people who have been given a dementia diagnosis.

Mr. Wessler noted that within the disability framework, there is a notion of "reasonable accommodation." He inquired whether there was something else that Mr. Belleville could have done, such as another job that could have eased the transition. Mr. Belleville responded that his manager did make accommodations for him until he was able to leave on disability. Ms. Evich noted that in the case of her husband, the ADA covers cognitive impairment, but a diagnosis of Alzheimer's takes at least a year, so he had to go in for multiple evaluations to show his functional decline. She explained that during that year, Mr. Evich's employer was kind enough to make accommodations for him as his capabilities changed.

Dr. Kohl shared that her husband was misdiagnosed for 4 years, and that it took 3 months to get an appointment for his neuropsychological testing. She cited that transportation issues were key to her husband's ability to continue to work at the local food pantry and at the senior center, but that they would network with other families at the center to help coordinate transportation for everyone's loved ones. She also noted that the center had a grant to pay volunteers, but that could only apply to individuals 60 and older. She concluded by saying that "so much of Alzheimer's is considered an elderly disease, and that's just not true empirically."

Mr. Belleville agreed, quipping that "this isn't your grandfather's Alzheimer's." He described how for previous generations, conversations about dementia were never brought up in public, but that now, these conversations need to happen in the open. He expressed that if it had not been for his online support groups, he "would not be sitting here," emphasizing how critical "meaningful engagement" has been to him. He also agreed that transportation is the biggest stumbling block. He stated that "we're losing ourselves a little bit every single day, and we know it. I thought the diagnosis would be the worst thing I'd ever go through, but it's the navigation after the fact." He added that he learned while in a waiting room to have genetic testing performed that his insurance would not pay for it, because the lab was out of network (he was told that the only lab in the country that did this testing in his network was in California).

Dr. Kohl added that the only way that her husband could get a PET scan was to enroll in a clinical trial where the scan was part of the study protocol. Mr. Belleville noted that most of the trials that grant patients access to certain tests typically have an age minimum of 65 or 70 years old. Dr. Budson noted that there are some studies that include younger patients, and Mr. Belleville agreed, but emphasized that they are "far and fewer between."

Rep. Balser asked Mr. Belleville to describe how much of the online or in-person social engagements he's found have been through his own discovery or via his friends or the medical community. Mr. Belleville replied that it was 100% from his own search with the help of the Alzheimer's Association, noting that none of it came from the medical community or government services.

Mr. Wessler noted that Mike has been very resourceful in tapping into the Alzheimer's Association's series of engagement programs, but emphasized that these resources alone are not enough. He explained that the Memory Cafes and the Dementia-Friendly movement throughout the state overlaps with their efforts. He noted that the support network is growing, especially in the last two years. He noted that the individuals on this panel are very young and therefore represent "the most neglected part of the dementia community in many ways." He noted that there is an effort in Congress to amend the Older Americans Act, which would create a huge shift in terms of what services are available to those under 60.

Rep. Balser noted that a possible solution to many of the issues raised during this meeting could be to get rid of age cutoffs for many government programs and services.

Ms. Champigny inquired whether there was a way for the Commonwealth to get more information about available resources and supports out to patients. Secretary Sudders replied that that is a key issue that the Council heard throughout the meeting; the need for centralized information that provides a much more “consistent experience.” She echoed that there is a gap from the medical diagnosis and the connection to social services and supports and social engagement. She thanked all the panelists for their grace and honesty, and the extraordinary hope that they imparted to the Council. She noted that she is “awed” by what the panelists shared in order to inform the Council’s deliberation. She acknowledged that there were two scheduled presentations for this meeting that will now take place during the Council’s next meeting. She called upon Council members to consider if there are any additional agenda items that they’d like to add.

Ms. Champigny expressed the desire to assist the Council in future work and meetings, given that she has a medical background and is now high-functioning. She said that she “would love to be of help before it’s too late.”

Vote: Ms. Meehan introduced a motion for the meeting to adjourn, which was seconded by Mr. Wessler and unanimously approved, by roll call.

The meeting was adjourned at 4:58 pm.