

Alzheimer's Advisory Council

Meeting Minutes
October 7, 2019
3:00-5:00 pm

Date of meeting: Monday, October 7, 2019

Start time: 3:03pm

End time: 5:01pm

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
- Bernice Osborne-Pollar—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
- Sen. Patricia Jehlen—MA Senate

Members calling-in:

- Maura Brennan, MD—Baystate Medical Center

Proceedings:

Secretary Sudders called the meeting to order at 3:03pm.

Vote: Dr. Kohl introduced a motion to approve the June 18th meeting minutes, which was seconded by Dr. Budson and unanimously approved, by roll call.

The Secretary welcomed the panelists, **Judy Johanson, Margie Levin, Phillip Davis, and Robin Callahan.**

Ms. Johanson explained that she was a caregiver to her husband Steve who passed one-and-a-half years ago from younger-onset Alzheimer's, and that both of his parents have passed from Alzheimer's since. She noted that she is a research ambassador and is collaborating with a variety of dementia care initiatives in local hospitals.

Ms. Levin introduced herself as a caregiver for her two parents; her father passed in the spring from Alzheimer's, while her mother is living and was diagnosed about six years ago. Both of her parents lived in a nursing facility in

Wellesley, her mother still resides there. Both parents spoke Spanish, which posed some challenges in their care. She noted that she is very happy to have her mother living only seven minutes from her.

Ms. Johanson added that both she and Ms. Levin are on the Board of Directors for the Alzheimer's Association.

Mr. Davis thanked the Council for inviting him to participate. He explained that he was the primary caregiver and healthcare proxy for his aunt, who was diagnosed with Alzheimer's in 2014 and passed away in June.

Ms. Callahan stated that her mother passed away "a while ago" from Alzheimer's. She explained that she was living in Boston, while her mother lived in Philadelphia. She had to work with her mother's husband to provide care together; for a number of years she served as respite for him. She emphasized that providing respite allowed her mother to stay at home, her husband had to have some "relief." When her mother got really sick, Ms. Callahan took a leave of absence and went to Philadelphia for seven months. She described that it was during this time that she came to understand what it was like for her mother's husband to take care of her around the clock. She closed by stating an interest in what the Council can do "to support those caring for others. It's a very difficult job."

Bernice Osborne-Pollar entered at 3:11pm.

The Secretary noted that one of the Council's charges is to provide information and recommendations for Alzheimer's disease policy. She asked the panelists to consider this as they answered: "What parts of your journey as a caregiver made it easier for you to be a caregiver? And what things, if they had been available, would have facilitated it? In looking back, what would you have needed to take care of yourself as well as your loved one?"

Mr. Davis answered that one thing that helped him in caregiving for his aunt is that he was able to find a facility only seven minutes away from him for his aunt to live. He explained that having her nearby was something he initially took for granted, but that "it became a godsend," because if something happened he could be there quickly, and he was able to see her at least four times a week. He also explained that it was important to him to "be visible to the staff" of his aunt's nursing home, so that they knew he was nearby.

Ms. Levin answered that the Alzheimer's Association was a great resource for her family. She noted the difficulty of finding placement for both of her parents together, who were on MassHealth. She added that while the support from her friends and community was invaluable, that it would be helpful to have some kind of resource line specifically for caregivers. She cited that her friends who aren't caregivers may not be able to understand the feeling of urgency that comes with getting a call from your parents' nursing facility: "You drop everything." She noted that podcasts were helpful in helping her stay positive.

Ms. Johanson explained that having a husband with younger-onset Alzheimer's "presents a whole different set of issues." She went to the Alzheimer's Association, who helped her build a circle of caregivers, with whom she can compare notes and do "virtual screams." She highlighted the social opportunities that the Association provided, and that they attended forums in DC, which made a big difference to her husband Steve, to feel that he had a voice. She also noted that the community they found through the Association meant that Steve knew that he would be "leaving [her] in a place where [she] wouldn't be alone." She also mentioned how important the support of her family and community was; there was a full meal in a cooler on her front porch every night.

On the flip side, her husband was the primary earner of their family, and he was removed from the workforce 10 years early--Ms. Johanson is not entitled to her husband's Social Security until she turns 60, which she describes as the difference between making her mortgage each month, or not. She also noted that when Steve got to "a catastrophic state," and they had to go to the ER, they "were handled horrifically by the kindest and most knowledgeable people, but not in terms of dementia"-- Steve's wrists were tied to a bedrail. She added that

there's a lot of help that can be given on a state level. She described using Springwell services, an assistance program that entitled them to help once a week to clean the house or spend time with Steve. Unfortunately, this program didn't work well for them. However, the community adult program that Steve attended three days a week in Arlington was positive; she noted that day programs are wonderful, as they allow caregivers to rest.

Ms. Callahan shared that when she was caregiving, she had never heard of the Alzheimer's Association, and that in her seven years "going through it," no one ever mentioned it to her. She noted that this may be due to cultural norms, and that "stuff like this" isn't spoken about. She described that among her family and friends, "those who could opt out, did...it was a very lonely life." Regarding programs, she noted that it is very important to "create flexibility...It's not a disease you can get in a routine about; that person is changing constantly. The things you get used to are always changing."

Ms. Callahan also described taking her mother to Einstein Medical Center in Philadelphia to see an expert, who was "an old school guy." As her mother was put through a variety of tests and puzzles, Ms. Callahan described her heart sinking; her mother thought that Eisenhower was President. She noted that after the exam, the doctor had Ms. Callahan sit in the room while he narrated the findings into a tape recorder to send to her mother's primary care physician. Ms. Callahan described the experience as "excruciating," and that at the end she was shell-shocked. She described how the doctor gave her medications and when she asked how to administer them to her mother, he replied that "it doesn't matter. They don't work, there's nothing we can do." Today, she reflects on this experience and considers it malpractice.

Ms. Callahan noted that the field has come a long way since that time, and that families are given connection and referrals to supports, but that there is more to be done in giving caregivers respite, either via "drop-ins" during the day or day programs. She emphasized that "people with Alzheimer's are emotionally difficult, and they can be hard on their caregivers. And caregivers don't share that because they're trying to protect [their loved one's] dignity, because they can't do that for themselves anymore." She added that sometimes individuals with Alzheimer's don't let their caregiver's sleep and that it's important to "remember that caregivers aren't just caregivers: they have a life, and they have breaking points. They need to be lifted up and to understand that they are going to live through this and they are doing a good job."

Ms. Johanson noted how helpful it was that Steve's neurologist knew that "Steve's body housed the disease, but we both had Alzheimer's."

Ms. Levin agreed that education for health professionals is very important, and advocated for recurring training. She added that there are particular issues when individuals speak a language other than English, particularly during the night shift in nursing facilities, when fewer people are working.

Mr. Davis noted that one thing that left an impression on him while caregiving was how many people living with dementia or Alzheimer's didn't have any supports. He described going to the nursing home and being "everybody's nephew." He added that one day he got a call that his aunt had been admitted to the hospital and that when he arrived, the doctor produced a DNR that Mr. Davis knew had been signed by his aunt after she had been diagnosed. He described what felt like an "interrogation," during which he was pressured to not overturn the DNR. He worried about what happens to individuals who don't have an advocate, and urged the Council to consider identifying services and protections for those who don't have caregivers.

Ms. Johanson noted the importance of social engagement for her husband, and how there was a very well-run Memory Café in Waltham that they attended. She described how this program helped her "re-adjust [her] lens," and how the improv activities were particularly helpful for her husband.

Mr. Lavery inquired whether there was any training available regarding language barriers in those with dementia. He wondered whether there was an opportunity to provide non-verbal training for caregivers. Ms. Antkowiak replied that there is a section of the Alzheimer's Association's curriculum to address language barriers when behavior becomes part of the communication. Dr. Budson added that it is very "hit or miss" regarding whether facilities are skilled at handling such communication barriers.

Dr. Kohl noted that in her experience, the support group via the Alzheimer's Association was helpful not only in terms of venting, but also for receiving practical advice. She added that despite the supports she has, navigating the system is still unbelievably challenging, and that the guidance she did receive came exclusively from her caregiving peers. She added that managing finances, such as navigating Social Security and MassHealth, is very challenging and is an area that needs major attention in terms of caregiver supports. Ms. Levin agreed, recalling how difficult, exhausting, and overwhelming it was for her to try to find placement for both of her parents.

Ms. Callahan added that as she was concluding her tenure working at MassHealth, ACOs were beginning to take hold, and that there was a program called Community Partners for individuals who have long term care of behavioral health needs. She noted a connection to dementia, and that there are "touch points in the system," such as the hospital and the police, where people find themselves when no one else is paying attention to them. She mentioned the need for intervention alerts at these junctures to get the individual connected to services.

Mr. Montesino noted that the Council had heard a lot from the panel around respite, and that the majority of people with Alzheimer's don't have the resources to support private care, and that nursing facilities seem to be the only place where a person can be dropped off and be safe. He asked whether the panelists felt that more day programs would have been helpful for them. Ms. Johanson replied that training communities to be dementia friendly is the first step.

Dr. Jackson added that he would like to understand where there are gaps: "where some people got lucky and were well connected, and others slip between the cracks. What kind of people tend to slip between the cracks? People out west, who don't have a lot of resources, people who don't have a chance to be diagnosed, who aren't in primary care? Who struggles the most when living with dementia?"

Ms. Johanson replied that her mother-in-law was in a nursing home for nearly six years, and that her father-in-law visited her frequently. He lived with dementia for a long time before he was diagnosed, even though trained staff saw him every day. She questioned: "Who's watching the caregivers?"

Ms. Meehan thanked the panelists for their participation. She shared that when her partner had Alzheimer's, no one told them about the Association until four years into her partner's illness. She asserted that the LGBTQ population is one that must be taken into consideration; especially in an older generation when individuals are likely to be alienated from their families. She described the difficulty she encountered navigating the system alone.

Senator Jehlen inquired whether any of the panelists had found the Councils on Aging helpful. Ms. Johanson replied that in her town, it was not helpful---there was staffing turnover at the time, and it was hard to get supports for a 59 year old. Dr. Kohl echoed this, stating that at the time, her husband was 47, and services weren't available for individuals that young. She described going to a Council on Aging senior center to fill out MassHealth forms, and that the staff was unhelpful. Ms. Johanson noted that she and Dr. Kohl are in the same town, and added that her husband was approved for MassHealth three months after he passed, after being denied thrice. Ms. Callahan recalled that she noticed that an acquaintance who lived alone seemed to be "having trouble," so she called an ASAP. Staff members went to visit this acquaintance twice, and both times she denied them entry.

She asked the Council, in this instance, what do people do? She noted that some people fall through the cracks and others “get lucky.”

Senator Jehlen suggested that a clearinghouse of information, best practices, instructions for how to fill out paperwork, and resources for younger-onset Alzheimer’s would be extremely helpful, especially if marketed in a way that hospitals were automatically referring families to such a resource. She noted that if one doesn’t speak English as a first language, or is not of a certain socioeconomic status, or if one “can’t drop everything” in their lives to focus on handling care, they may be in “the gap.” She suggested that these gaps may be addressed by centralizing relevant information in this way. Ms. Johanson added that having dementia-trained advocates across the state would also help.

Dr. Budson noted that within the VA health care system, social workers work with individuals and families, and there are day programs and respite care available. He acknowledged that such a system is the exception to the norm, and that many people experience barriers to resources like these. He agreed that a clearinghouse would be a good solution, along with assigning a case manager/social worker to those who don’t have family nearby. Mr. Wessler agreed, and mentioned that there are referral programs within Dementia Care Coordination, and individuals are proactively called by a social worker. He also noted that in Scotland, every person with dementia is assigned a home visit and a call within the first year after diagnosis with a caseworker.

Mr. Wessler thanked all of the panelists for their participation. He then asked them whether their work places had been supportive of their need for flexible schedules while caregiving. Ms. Callahan replied that she was lucky in how supported she felt, but also that she happened to have six months of sick time. She noted that there is a lot of financial risk involved for caregivers to make such decisions. Mr. Davis echoed this, stating that he was fortunate to have a flexible employer, but that he realizes that others may not have that luxury or the ability to communicate openly with their employers, and that maybe some public education could help alleviate that.

Ms. Pellegrini asked the panelists if any of them had received NaviCare training around being caregivers. Ms. Johanson replied that she did early on via the Alzheimer’s Association, but observed that “by the time you need more training, you can’t leave the house.” Ms. Levin also received this training via the Association. Mr. Davis did not receive training, but noted that he accompanied his mother to all of her appointments, and learned a lot from asking her providers questions. Ms. Callahan also did not receive trainings, and recognized how helpful they would have been in her situation.

Dr. Kohl spoke about her difficulties using the Springwell program via MassHealth, due to staff training, turnover, and ineligibility due to her husband’s age. She noted that “the nature of this disease is that they’re resistant, confused, fearful, and easily agitated. You can’t just drop them off somewhere, it’s unrealistic.” She advocated for an improved volunteer program for families to connect with early on. She noted that the BU Medical School has a program to pair patients with medical students, which she considers a “win-win.” She added that the disease is “very isolating and lonely and unique” for caregivers, and that it’s important to consider the burdens on caregivers that aren’t directly related to their loved one.

Ms. Osborne-Pollar noted that the ASAPs miss an opportunity when individuals are diagnosed and seeking help, and that when they are referred to an ASAP, the options counselor may be experienced and understand dementia deeply, but sometimes they don’t. She noted that there should be an individual at each ASAP who is a dementia specialist. She added that in her own family, her and her sister became very isolated with one another in caring for their mother at home, and that to have someone else in the home once in a while would be very helpful.

Ms. Meehan added that as you move farther away from the greater Boston area, the amount of resources lessens. She noted the importance of support groups, especially in more removed geographies, such as the Cape.

Ms. Antkowiak thanked the panelists for their participation. She asked them for their thoughts on technology, and whether there is an opportunity in that space to close a gap, perhaps via webinars. Ms. Johanson replied that technology was very helpful for her education, particularly the ability to look things up in the middle of the night. She noted that to have a chat function online where caregivers could ask questions and get instant answers would be helpful. Ms. Levin and Mr. Davis agreed that this would be helpful. Mr. Davis also noted that having a hotline for information, help filling out forms, or just to talk to somebody would be helpful, as his parents aren't well-versed in internet use. He noted that "this would be a gap that is easily closed." Ms. Johanson added that it would be helpful to be able to refer her children to such resources. Ms. Levin added that she would like to hear more podcasts for caregivers for Alzheimer's/dementia. Ms. Callahan agreed that she could see how that would be helpful, how the experience of caregiving is so "unbelievable and otherworldly," that "being able to tune into someone else who's going through it, I can imagine how that would be really helpful."

The Secretary thanked the panelists for their willingness to share with the Council. She noted that some of the recommendations put forth are very "user-friendly," such as chat rooms, podcasts, and ASAP expertise. She noted that "it's about how to create opportunities so people don't get isolated."

The Secretary reminded the Council that an annual report is due in March, and then welcomed Mr. Wessler and Ms. Antkowiak to present on the 2012 plan. Mr. Wessler provided a brief history: a group was convened by Executive Order of former Governor Patrick, which was organized closely with the former Secretary of Elder Affairs. Over a ten month period, the group compiled a set of recommendations, and incorporated those recommendations into a plan, which Ms. Antkowiak would present. She would also provide a status update on these items.

Ms. Antkowiak proceeded to present updates to the 2012 plan (see posted presentation).

The Secretary asked members to review the 2012 plan, along with the 2018 State Plan on Aging, and to consider the public health framework. She asked that in the next few weeks, members send Amy Kaplan (Program Manager, EOHHS) their priorities for the Council's report. She noted that Secretary Chen's presentation would take place at the next meeting.

There was a discussion about adding a person who is living with Alzheimer's/ dementia to participate on the council.

Vote: Ms. Callahan introduced a motion for the meeting to adjourn, which was seconded by Dr. Jackson and unanimously approved, by roll call.

The meeting was adjourned at 5:01 pm.