

A Summary of Commentaries Submitted by Those Living with Dementia and Care Partners

**Prepared by the NASEM Alzheimer's Decadal
Advisory Panel for the NASEM Alzheimer's Decadal
Committee**



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Panel members: Cynthia Huling Hummel, DMin, MDiv, & BS (co-chair and lead author); John Richard Pagan (co-chair); Marie Israelite, MSW; Ed Patterson; Brian Van Buren; Geraldine Woolcock MPA, Multi-Level Teaching Credentials, BA

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Introduction

This paper, **“A Summary of Commentaries Submitted by Those Living with Dementia and Care Partners,”** was prepared by a group of six individuals who were brought together to serve as an Advisory Panel for the National Academy of Sciences, Engineering and Medicine (NASEM) Decadal Survey of Behavioral and Social Science Research on Alzheimer's Disease and Alzheimer's Disease-Related Dementias. The Advisory Panel, which includes four individuals who are living with dementia and two individuals who have served as care partners for a family member with dementia, was assembled to ensure that the Decadal Survey would receive direct input and advice from those living with dementia or directly impacted by it.

The paper is a compendium of the responses to the “Call for Commentaries from Individuals with Alzheimer's Disease or Other Dementias and Care Partners” that was issued by NASEM on the recommendation of the Advisory Panel. The paper was also informed by responses to a survey conducted by the Alzheimer's Association.

The paper highlights four reoccurring themes that were identified in the submissions and provides questions for reflection that we hope will be considered by the Committee as they prepare their research recommendations. This paper also details how and why this project was initiated. It describes how the members of the Advisory Panel worked together to seek input from others living with dementia and from care partners so that we could better inform the Decadal Committee. It describes the challenges that we faced, especially in light of COVID19. The paper also includes all the responses that were received. They can be found in the appendices. Finally, we include biographies of those on the Advisory Panel. We on the Advisory Panel are grateful for all those who took the time to answer our request to share their experiences via the NASEM'S “Call for Commentaries” portal. We want them to know that we have read and reviewed all the submissions that detailed the experiences of those living with dementia and of those who are supporting them (or who have cared for) someone with dementia. It is our hope that this paper will inform the NASEM's Decadal Study Committee members by providing first-person accounts of the impact of a dementia diagnosis on the lives of all those who are affected, thereby guiding the committee as it identifies, considers and prioritizes proposals for dementia research for the next decade¹. We hope that the Decadal Committee members find this document useful. We thank them for their work on our behalf! Their work is vitally important as their conclusions and recommendations will have a direct impact on us and on our families. We thank them for their taking the time to review our findings and again, thank them for their service.

¹ For additional information on the project, please visit <https://nationalacademies.org/alzheimersdecadal>.

SUMMARY OF OUR FINDINGS AND EMERGING THEMES

As described in greater detail below, at the recommendation of the Advisory Panel, NASEM issued a “Call for Commentaries from Individuals with Alzheimer's Disease or Other Dementias and Care Partners.” The call for commentaries invited respondents to provide submissions that touched on the following topics as they relate to Alzheimer's disease or other dementias:

- experiences and challenges related to the diagnostic process,
- support services for both individuals with dementia and care partners,
- communication with medical providers,
- how living with dementia or caregiving responsibilities has affected your employment and engagement in social activities and hobbies, and
- how communities might better support those affected by Alzheimer's disease and other dementias.

As of June 1st, 2020, we had a total of 16 submissions in response to the “Call for Commentaries” – six direct submissions from individuals living with a dementia diagnosis (**APPENDIX 1**) and ten direct submissions from care partners (**APPENDIX 2**).

Additionally, we received two reports from the Alzheimer's Association summarizing responses to a survey they conducted that was designed to collect input related to the topics outlined in NASEM's call for commentaries. The questions are included in the two reports Alzheimer's Association provided. The first report shared the reflections of 16 individuals living with dementia (**APPENDIX 3**) and the second report summarized the reflections of 9 care partners (**APPENDIX 4**). This increased our total to 22 commentaries from people living with dementia and 19 commentaries from Care Partners for a total of **41 commentaries**.

We include excerpts from all of these submissions in our discussion below. The excerpts are coded so that readers can easily navigate to the source of the excerpt in the appendices. For commentaries that were submitted directly to the National Academies, the codes correspond to the commentary category and number (i.e., CP1 = Care Partner 1; PD3 = Person with Dementia 3). For excerpts from the summary reports provided by the Alzheimer's Association, coding is structured to distinguish between responses from individuals with dementia and care partners, with numbering to help readers locate the full comment in Appendix 3 or 4 (i.e., AACP8 = the 8th response in Appendix 3; AAPD22 = the 22nd response in Appendix 4).

There were four reoccurring themes that emerged from the submissions to our “Call for Commentaries.” These reoccurring themes were:

Theme (1) Difficulty in obtaining an accurate and timely dementia diagnosis

Theme (2) Problems in obtaining supports and services

Theme (3) Communications challenges with doctors and other health care professionals

Theme (4) Fear and loss

A sampling of the supporting comments follows, and the reader is also encouraged to visit the submissions (in their entirety) in the Appendices.

Comments Relating to Theme 1: Difficulty in obtaining an accurate and timely dementia diagnosis.

Each of the six individuals living with dementia and three care partners reported some difficulty in getting an accurate dementia diagnosis.

PD 1 reported frustration that her type of dementia could not be determined and a “diagnosis of dementia of an unknown type” was a barrier to enrolling in clinical trials. When PWD1 pressed her doctor for more definitive diagnosis (after two years) she was told by her doctor *“Why bother, it won’t change your treatment approach.”*

PD2 Reported that one of the specialists had ordered a PET SCAN, but her request was denied with the explanation that “It was a waste of money because even if the scan confirmed AD, there was no cure or treatments.”

PD3 Reported that his initial diagnosis was for anxiety and essential tremor. An adverse reaction to medication that he was prescribed for this put him in an inpatient mental health facility. He sought out another neurologist and after 5 months was diagnosed with probable Lewy body dementia with Parkinsonism.

PD4 Reported a very poor diagnostic experience. He reported feeling like an inconvenience to the doctor. PD4 reported that he was handed a long report and left to figure it out.

PD5 It is important to receive a diagnosis as early as possible so you can leave work before you are fired due to the performance issues that dementia inevitably causes. I was fired from my job, but I did not get diagnosed until 5 years later.”

PD5 noted that “procedures need to be written and doctors need to be required to take CEU credits so that they are better prepared to diagnosis and serve individuals with dementia.”

AAPD3: It was difficult at first because with each new doctor I had a different diagnosis.

AAPD8: My doctor did not believe me. My primary physician thought my problems were all due to the high stress of my position.

AAPD11: My internist wouldn’t refer me to a memory center in 2016 when I asked because he said that there was no effective treatment.

CP1 Reported that even though she reported symptoms to the family doctor, that it took four years for the PCP to conclude that her husband had some form of dementia and finally referred them to a neurologist who confirmed an Alzheimer's diagnosis.

CP2: Reported that when his wife was diagnosed with dementia of the Alzheimer's type that they were given a prescription to slow down the symptoms and was told that the doctor would see her again in six months.

CP6 Reported that her dad was confined to a psychiatric ward for a week after frightening family members with a gun because of terrifying hallucinations. They visited psychiatrist and later a neurologist—a neuropsychologist finally diagnosed Dad with Lewy body dementia.

CP7 Reported the difficulties in getting a dementia diagnosis and surmised that doctors "seem to pass us around because they don't want to deliver a diagnosis for a condition that has no medical treatment."

AACP2 Well the diagnosis kept changing. It started with MCI, then Lewy body due to Alzheimer's then back to Lewy body.

PD6: I sought medical help for my symptoms for 10 years prior to my diagnosis 2 years ago.

CP10 Here I was working in the aging field, and I didn't recognize that what was going on in my own family was dementia.

Comments Relating to Theme 2: Problems in obtaining supports and services

PD1 Said that getting support services "has been the next biggest battle." She is not allowed to participate in support groups or classes through the Alzheimer's Association without being "accompanied by someone." She lives alone and does not need a caregiver yet. She noted that the OFAs [Office for the Aging] have free classes but they are not dementia-specific. Her insurance will not cover the costs for her to attend Day Care and other activities

PD2 Reported that she was given no resources, supports or counseling after her diagnosis but was told to "get her house in order." She was able to figure it out and said it was hard and is hard but so far she is managing. She reported that she loves the arts programs in her city for those living with dementia and loves to sing. PD2 wishes there were more music programs for those with dementia. They help with loneliness and isolation. She lives alone. Looking ahead at supports and services, she is worried about entering a care facility and the lack of staff training in dementia care, and the possibility of abuse and poor care.

PD3 Noted that support services are geared more toward care partners and not for those with the actual disease and recommended that the focus be on developing

comprehensive support services to help people live the best they can with a diagnosis of dementia regardless of their zip code. Also creating dementia friendly environments.

PD4 Stated “Doctors in a position to provide a dementia diagnosis should be in a position to offer resources and support options.” He reports great family support and care right now, but fears that in the future that he will not be able to afford the care he needs. “this is something that many of us fear.”

PD5 shared “There are not many supportive services. Examples of services I am aware of are the Alzheimer’s 800 line and some local services, but quality is mixed and more support is needed. It would be helpful for there to be alternatives to hospitals for individuals with dementia. I would like to see the establishment of a help line for people with dementia...”

CP1: “I needed to continue working and believed he was both unsafe and frustrated at home alone. I reached out to the OFA to see if they could provide names of caregivers, their policies prevent them from doing so. I live in a rural area. CP1 also said that she attended an Alzheimer’s Association support group once, but the facilitator was new, ineffective and unable to control the group. CP1 never returned to the support group.

CP2 stated that neither the medical nor the social services community do a good job in providing information, education and support. This care partner noted that many services and supports are noted on websites- but many care partners do not search out services on the web. “This population that grew up with radio, broadcast tv, direct mail information is NOT getting to the Greatest Generation and to aging Boomers.”

CP3: discussed the challenges of finding an Adult Day Service to meet the cultural and language needs of her mother who was living with dementia. CP3 did the research on her own, found a center that would meet her mother’s needs and offered to obtain dementia training materials, translate materials on dementia and to educate the staff.

CP4 reported that “The community that we have lived in for 44 years does little to support my husband who has AD, nor does it do anything to support me as the caregiver who is still working fulltime”

CP6 wished that “someone would help us figure out how to care for “Dad” before he endangers himself or the people around him.”

CP7 Shared that “we desperately need support services such as respite, day clubs that don’t infantize individuals living with dementia and volunteers who could come into our home to offer support. CP7 also shared: “I love my husband and want the best for him, but his condition is draining every fiber in my body.

CP8 states that “Some days caring for my Dad is completely overwhelming. On better days, I am more willing to embrace the good things that come with ADRD”

Comments Relating to Theme 3: Communications challenges with doctors and other health care professionals

PD1 reported that her doctors don't communicate with each other and that her dementia diagnosis is not flagged in her records. She has to ask her health care professionals to "slow down" when giving instructions or explaining things. No one seems to (understand) that she needs help with verbal instructions and that this leads to extremely stressful visits. She is stressed just getting to and from appointments. She wished that we had a specialized or doctor or team to work with.

PD2 reported that because of her relatively young age that some people INCLUDING medical professionals routinely doubt and question her AD diagnosis. She gets tired of having to prove herself to them and wonders what gives them the right to question her diagnosis.

AAPD12: Just getting a physician to give me an appointment is hard. He states that insurance only pays for one visit a year. He also has been hard to get him to help me getting referral to other doctors for additional help with problems I am having as my condition progresses.

AAPD22: "My biggest frustration is communicating with my Geriatric Specialist ..."

CP2 "I have been told that some doctors have refused to hand out to their patients, information about Alzheimer's disease or other dementias and material about available resources and support. "

CP2: "Neither the medical nor the social community does a good job in providing information, education and support

CP6: Reported "we took Dad to a neurologist. The doctor did all kinds of tests that showed there was nothing wrong with his brain. She basically shrugged and sent us on our way."

CP7 reported that communication is "non-existent. They are not helpful or frankly knowledgeable."

Comments Relating to Theme 4: Fear and loss

PD1 Reported "I live in fear of getting worse with no financial options for assisted living or memory care.

PD2 shared that "I was told to get my house in order. I was given NO resources, counseling, supports, NOTHING."

PD3: "I felt I had lost my purpose, and my vision of a retirement that would be free of worry and full of adventure had to be rewritten."

PD4: “I was forced to take a medical leave because of my symptoms and lost my employee health insure three days before I turned 65, so I would not be entitled to a pension.”

PD4: “People are suffering financially and emotionally in the early stages and this should not be necessary as there are therapeutic and other support options that could and should be employed to maintain personhood for as long as possible.

PD5: reported “I am unable to pursue my hobbies. I would love to still have the right to work in my old job and not get paid for it.”

CP1: “I wish that there had been someone whom I could have called, someone who had traveled this path before, but there was no one to connect me with anyone.”

CP4 reflected on how she has reached out to a animal shelter inquiring about her husband living with dementia) would like to volunteer and how no one has returned their calls

CP6 reported that her Dad “lives in constant fear which is wearing down my mother. We really don’t have any resources to turn to for help.”

CP7 shared that “I have had to essentially give up any interests and hobbies and focus o working and just getting through each day. I’ve lost weight, I am now anxious, don’t sleep and am fearful about our financial situation.”

CP8 shared that “our accountant estimated that my Dad wrote checks worth tens of thousands of dollars to charities, bogus care warranty companies, scam lotteries and gold coin merchants” and nearly lost his home due to non-payment of taxes.”

AACP19 “I don’t socialize any more. I don’t take vacation without her”

AACP17: “We used to go to movies once a week, now it had been at least six months since we have gone to see a movie”

CP10: Too often our culture tends to think of dementia as a death sentence, or maybe as something to be ashamed of, rather than as what it is: a chronic disease that a person is likely to live with for many years.

Reflecting on the Responses to the Call for Commentaries

- 1) Many respondents reported difficulties in getting an accurate and timely dementia diagnosis. What steps can be taken to ensure that medical personnel have the needed training, tools, and the most up-to-date information so that they can diagnose dementia in an accurate and timely manner?
- 2) Several respondents reported that doctors are not comfortable communicating a dementia diagnosis to individuals and families. How can institutions better prepare practitioners to be more effective and supportive when sharing a dementia diagnosis?
- 3) Multiple respondents reported that the health professionals they met with did not refer them to, or provide information about, available support services. Is this due to a lack of knowledge about what local or virtual supports are available? Does this reflect a lack of support services in the community or both? If medical personnel are not familiar with the supports and services that are available in their areas for those living with dementia and for care partners, they cannot make appropriate referrals. How can this be overcome?
- 4) Several respondents described their feelings of fear and loss – such as loss of abilities income, identity, and/or connections (isolation); fear of not being able to pay for needed services, fear of being preyed upon (by scammers, sexual abuse in nursing homes, etc.) What can communities and organizations do to support those who are experiencing feelings of loss and fear? How might dementia navigators and/or dementia-friendly communities provide support. What research is there? What further research is needed to increase the knowledge base about how best to provide support in this area?
- 5) A few respondents² wrote about the stigma and shame of a dementia diagnosis. Stigma around dementia can be a barrier for some to seek a diagnosis. What steps can be taken to reduce this stigma? What's effective? What's not? To what extent does stigma create a barrier to participation in research?
- 6) A number of responses came from those diagnosed with non-Alzheimer's dementias, such as Lewy body dementia and vascular dementia. We also heard from care partners caring for those with "other dementias." The respondents underscore that needs for support and services vary and that jurisdictions and organizations offering such services need to avoid a one-size-fits-all approach for individuals with dementia and their families. We need to learn more about what works well, and for whom? What doesn't?
- 7) A few respondents mentioned therapy and/or counseling services. Some described it being beneficial to their well-being, while others wished that options for therapy had been made available to them. How might this inform future research?³

² Noted by PD3, CP3, CP10 AAPD23, and AAPD35

³ Noted by PD2, PD3, CP1, CP9, AAPD3, AAPD23, and AAPD24

APPENDIX 1: SUBMISSIONS FROM PERSONS LIVING WITH DEMENTIA

PD1 SUBMISSION

I live alone. This makes all aspects of trying to live with dementia very different from those that live with family/friends. In some ways, I think it's better to live alone. Other times, I wish I had someone here (nightmares/night hallucinations). I think it's better because I do not have the added stress of having noise, activity, and people making suggestions or telling me what to do. Worse, is living with someone who denies the disease even exists, so in that way I am blessed. But....I don't have someone to help me with ADL's. - I pay to have groceries delivered, I pay to have my apartment cleaned, and eventually I will have to pay for a caregiver, for which I DO NOT HAVE the money to do. I live in fear of getting worse with no financial options for assisted living or memory care. Where will I go? What will I do?

The type of dementia I have has not been determined due to overlapping symptoms and imaging results. My Dr. refers to my symptoms as "can be seen in neurodegenerative diseases". That is the best that she can offer. It is not her fault. When I ask for more testing after two years, she said, "why bother, it won't change my treatment approach. You have a neurodegenerative disease"

Testing/Diagnosis: I understand that dementia is not a "one size fits all" disease but because she cannot, with complete accuracy, give me a probable or possible diagnosis, I am unable to qualify for clinical trials that might give me a better quality of life, I am unable to know which medications to avoid; those that might exacerbate my symptoms, or even worse, expedite my death (antipsychotics /LBD). And I don't know if a new symptom is something related to the disease or a function of "getting older".

There should be a diagnostic criterion for "dementia of unknow type" or some other category that would enable people like myself to participate in clinical trials.

Support Services: This has been the next biggest battle. My local ALZ Association will not allow me to participate in support groups, or classes "without being accompanied by someone". I am being denied support because I live alone and do not yet need a care giver. I am excluded at the very times I need the support the most; right after diagnosis. Although telephone support and on line support can be valuable, there is nothing like having people who live in your area as support systems. It's how it should be.

I am not allowed to drive. Paratransit services are a nightmare. Not enough buses/drivers to accommodate the disabled population so they drop me off up to 1-1/2 hrs BEFORE my doctors appt and are sometimes up to 45 min later than the 30 min pick up window. This means a 30 min drs appt can end up being a 4 hour day and is extremely stressful. I end up paying Uber/Lyft to drive me, some of the rides round trip over \$50. There are stipulations for paratransit that I can lose my privileges if I am a "no

show" more than 2 x a month but none if they are late or do not show up. That's not right.

Day Care for Dementia: Kaiser does not cover the cost which is \$150 per week at this time. There needs to be a way to get insurance companies to fund Day Care and other activities for people with dementia.

Office of Aging: The activities they "offer" are the free classes that nearby cities offer through their Dept of Recreation and are not dementia specific, and you have to drive yourself or use paratransit.

Medi-Cal in California: They could provide me with a caregiver but I make more than the minimum income and do not qualify for assistance. The Share of Cost program would leave me with no money for food/rent/medical insurance etc.

Communication with Drs. For some reason, Drs do not speak with one another. My psych doesn't talk to my neuro, my neuro doesn't talk to my primary, and Kaiser does not have Geriatricians. My biggest complaint is that my Dementia dx is not flagged to health professionals, so I have to ask the medical assistant to give me instructions slowly, or inform my urologist to slow down when explaining something. No one seems to that I need help with verbal instructions etc. This makes any kind of appt extremely stressful; from the late/early paratransit ride, to check in, to review purpose of visit with Med Asst, to speaking with dr. Whew! I'm exhausted by the time I get home. My brain is fried. We need 1 specialized dr/team to work with us.

Socialization:

(note: The PD1 submission ended here. Information was **not** redacted.)

PD2 SUBMISSION

I was in my late forties when I started having memory problems. One of the specialists I was seeing, wanted me to have a PET scan, but my insurance denied the coverage- because (I was told) it was a waste of money because even if they confirmed AD, there were no cure or treatments. That was pretty discouraging.

When I was diagnosed in my 50's, with amnesic MCI, I was only given a follow-up appointment for 6 months and told to get my house in order. I was given no resources, offered no supports, no counseling, NOTHING. I live alone and I had to figure it out on my own and it was hard and is hard- but so far, I'm managing.

Because of my relatively young age- some people- including medical professionals doubt and question my AD diagnosis. I get tired of having to "prove" myself to them. Would they do that to someone with prostate cancer? NO. What gives them the right to question my diagnosis?

Living alone with dementia has it's challenges and it's blessings—it forces you to deal with things and keeps you on your toes, so to speak.

I worry that my end of life wishes will be ignored by the care facility that I will most likely end up in. I read something in the newspaper recently about a woman who went to a lawyer to have her “affairs put in order”- and learned that the place that she was in would **not** withhold feeding as end of life neared. That's worrisome.

I worry about being sexually or physically abused in a care facility and not being able to report it- or not having someone believe me- or even noticing the reason behind my distress..

I wish that my state would recognize and offer compassionate end of life options for people like myself living with dementia. I do NOT want to be kept alive in a vegetative state.

I love the arts programs in my city for people with dementia. They help with loneliness and isolation. It can be hard to live alone with dementia.

I try and focus on the things that I still can do. Too many people (especially in health care) focus on the things I/we can no longer do. I can still cook my meals, clean my house, pay my bills, and much more. I get angry when people focus on the things I can no longer do- and the challenges I face. Everyone has things that they can't do and everyone faces challenges. I say- focus on the positives. Don't discourage me. Build me up.

I hate to be in loud environments. I HATE noisy restaurants – especially those places with 10 TV sets and a radio to boot. Places where you have to scream to be heard across the table. I would rather have a pb & j sandwich in the comfort of my own home- that to be in such a noisy place. Where you can't even hear yourself think.

I hate it when people treat me with sympathy when they hear I am living alone. “That's SOOO sad! Isn't there anyone who would take care of you?” (talk about making someone feel worse). In case you're wondering - it's not a helpful thing to say to someone living alone with dementia. Please don't play the “blaming the victim game.” I sometimes have to bite my tongue not to tell that &^#@! off.

Please don't make jokes about my disease. Trust me. It's NOT funny. If you are tempted to make a joke- DON'T GO THERE. Don't be an insensitive idiot. Remember what your mama taught you. “If you can't say anything nice- don't say anything at all.” Don't make jokes about AD or about my owing you money or I might have to make jokes about your being a &&*## . Zip it. It's really not funny.

I worry about care facilities. The aides are overworked and underpaid and there is a terrible turnover. Most are not trained in dementia care and don't know what to do to de-

escalate a situation. I worry that I will be left to sit in a dirty diaper for hours. I'd rather be dead. Seriously.

Singing makes me happy. I can remember the words. I wish more organizations would hold free music programs for those like me- with dementia. I miss reading books- I can't do it anymore- but I can remember the words to so many songs. It makes me smile from the inside out. Thank you.

PD3 SUBMISSION

My experiences related to the diagnostic process were mixed. When I started experiencing cognitive decline, tremor, and balance issues, I discussed with my PCP at a world recognized hospital network. I was referred to a neurologist and movement specialist within this hospital network and they determined I had anxiety issues and essential tremor. After coming up to the therapeutic level of the prescribed anti-anxiety medication, I had an extreme adverse reaction that landed me in an in-patient mental health facility. This was a frightening time for my entire family and my spouse, sought out one of the top-rated Neurologists at another world-recognized Neurological Institute for another look at my situation. After extensive testing and evaluation over a period of 5 months, at age 51, I received a diagnosis of probable Lewy body dementia (LBD) w/ Parkinsonism. My experience at this second center of excellence was very good. It was very thorough, with competent and caring professionals handling a very delicate and disturbing situation.

I was forced into early retirement after my diagnosis, after a long and successful career in business and technology consulting. I felt that I had lost my purpose, and my vision of a retirement that would be free of worry and full of adventure had to be re-written. Having teenage children still at home, my wife and I agreed that the entire family would enter into life-event and trauma counseling. This counseling lasted almost a year, and was very beneficial to getting everyone on the same page as to what to expect, and more importantly showed us there was a lot more living to do, versus the dementia death sentence that so many fall into after diagnosis.

I have found there to be a BIG gap in knowledge of LBD outside highly trained Neurologists, Neuropsychologists, and those of living with this disease. Particularly with Emergency Room situations, and other medical specialists. Support services are geared more toward care partners, and not for those with the actual disease. For those with young-onset dementia, there is very little that focuses on this part of the effected population. We are NOT all drooling, incoherent, slumped over with vacant stares, as the dementia stigma would suggest. Online support groups are helpful, but are challenging as members are all facing very unique problems and are at different parts of their journey living with the disease.

My disease is one that fluctuates greatly and encompasses cognitive, physical, autonomic, and sleep related challenges. I can feel almost normal at times, only to have the rug pulled out and any one or more of symptoms takes over. This isn't about a good day or a bad day, it's about good moments that get completely hijacked with a multitude of challenges without warning. This creates added challenges with travel, socializing, and activities. I have still held onto my hobbies, and they help tremendously and bring joy, just as they did before LBD.

I think we all want a cure, but the most impactful areas that I believe should be focused on are developing comprehensive support services to help people live the best they can with a diagnosis of dementia regardless of their zip code. I also think that education in the medical field and creating dementia friendly environments will help tremendously.

PD4 SUBMISSION

I am a person living with a Vascular Dementia diagnosis for 8 years. I am eager to contribute to your efforts to understand and address the issues facing those of us living with dementia of any form.

My experience with diagnosis was very poor from the very start. After a grueling testing I finally arrived for my results a couple of days later with eager anticipation. I felt like it was almost an inconvenience to the doctor! The doctor (psychiatrist) handed me the long report with graphs and left me to figure out the result and how I was going to respond. I was in shock!

When I first saw a neurologist he gave me a short test and a prescription, and that was that. He gave me no information about Vascular Dementia or any other resources at all. This is unacceptable for a terminal illness! Doctors in a position to provide a dementia diagnosis should be in a position to offer resources and support options!

I was diagnosed officially at age 57, but I lost my career a few years before that when I was forced to take a medical leave of absence because of my symptoms. I lost my employee health insurance three days before I turned 65 so that I would not be entitled to pension.

I am fortunate that I have a great family to support and care for me right now. I do not have long term care insurance and am fearful for the possibility that I will need care outside of the home in the future and will be unable to receive it because of finances. This is something that many of us fear.

If a cure can be found that would be fantastic, but in the meanwhile people are suffering financially and emotionally in the early stages when this should not be necessary as there are therapeutic and other support options that could and should be employed to maintain personhood as long as possible. Social engagement and education is key!

Online support and advocacy organizations have provided me with a voice, support from people who know and care, and a new purpose in my life. Please support them both intellectually and financially.

PD5 SUBMISSION

I hear many stories from people who experience difficulty during the process of obtaining a diagnosis after the onset of symptoms of Alzheimer's or other dementias, especially if the onset of symptoms is at a younger age. I believe part of the reason for this is that the medical field is reluctant to give a diagnosis for a condition that practitioners cannot intervene on. However, it is important to receive a diagnosis as early as possible so that you can leave work before you are fired due to the performance issues that dementia inevitably causes. I was fired from my job, but I did not get diagnosed until five years later.

Procedures need to be written and doctors need to be required to take CEU credits so that they are better prepared to diagnosis and serve individuals with dementia.

There are many areas where improvements could be made to make things more dementia friendly. For example, at the hospital, instead of providing menus with many choices to individuals with dementia, they should be given just one or two choices at a time, as capacity for decision-making is negatively affected by dementia. Dementia patients will give bad answers and need a different approach from other patients.

One way that Alzheimer's affects me is that it is much easier for me to function in the morning; by the afternoon, I am burnt out. This is known as "sundowning" – it's being mind-drained, and many people with dementia experience this.

It is important for people with dementia to be part of efforts like the NIA dementia summit and other activities where policy avenues and research directions related to dementia are discussed and developed. One advance in this area is the NAPA class action lawsuit that led to the requirement that meetings have a phone line open so people with dementia can participate.

Being engaged slows advancement. When people get a message that they can no longer participate and then they spiral downward.

Doctors are supposed to notify DMV when they give a dementia diagnosis. There are disadvantages for the patient when the diagnosis is made. As another example, right-to-die directives can't apply to individuals with dementia.

There are not many supportive services. Examples of services I am aware of are the Alzheimer's 800 line and some local services, but quality is mixed and more support is needed. It would be helpful for there to be alternatives to hospitals for individuals with dementia. I would also like to see the establishment of a help line for people with dementia, where they could follow logic path prompts to get directed to information

related to specific questions they have. According to the Alzheimer's Association, it would cost approximately \$1 million to set up such a line.

In terms of how Alzheimer's has affected my ability to engage in work and hobbies, I am unable to pursue my hobbies anymore. I would love to still have the right to work in my old job and not get paid for it. I wish there were mechanisms in place to help individuals with dementia participate in work and hobbies. It would also be wonderful if individuals with dementia could sit in on college classes and listen to lectures. It would be great if this could be offered for free; it would help individuals with dementia stay engaged and mentally active.

In terms of resources to educate caregivers, much more is needed. It seems that people are afraid to write procedures because they might get sued. Caregivers need help figuring out how to take over household responsibilities.

Dementia-Friendly America is making progress, but more is needed.

Technology can play a key role to our ongoing survival but they need to include us in the creation of these products. It can help us stay social and to live at home safely. "Nothing About Us Without Us". This term should apply to everything related to dementia.

PD 6

My take on the diagnosis of dementia with Lewy bodies. I am a neurologist who retired early because of symptoms of dementia with Lewy bodies (DLB). I sought medical help for my symptoms for 10 years prior to my diagnosis 2 years ago. This delay in diagnosis occurred primarily because the neurologists involved did not believe that my serial neuropsychological exams, motor, EEG, autonomic and imaging abnormalities, although consistent with DLB, were sufficient to make the diagnosis. Also, I believe, my subjective symptoms did not conform to their narrow concepts of what constituted significant cognitive fluctuations and recurrent visual hallucinations. For example, one leading dementia clinic required cognitive fluctuations to last from 1 to 24 hours in order to be considered valid. Similarly, my visual hallucinations did not consist of formed people or animals, and consequently, were dismissed. I have had a clinical course similar to other affected members of my family, namely my paternal grandmother and her mother, my father (who had pathologically confirmed diffuse Lewy body disease), and two of my siblings.

Although my personal experience may be unique, there are many other patients with dementing illnesses who seek medical help for years before obtaining a diagnosis. This delay in diagnosis means patients often do not receive appropriate medical management or social or financial support in a timely fashion. I confess that I am highly motivated to remedy this problem because I have two sons, who I fear are at high risk

for the condition. To add to my concern, I diagnosed REM behavior disorder in my husband's grandfather, who subsequently developed dementia with Lewy bodies.

In the United States, research scientists have been excessively focused on finding a static marker that will serve as the Holy Grail of biomarkers in DLB. Both scientists and clinical neurologists have placed much more value on objective data than on the subjective patient experience. As a result of these inclinations, both research efforts and patient care have suffered. In contrast, in the United Kingdom, Europe and Australia, where "old age" psychiatrists and neurologists have collaborated more, there has been more progress in understanding the essential feature of DLB that distinguishes it from other dementias, namely rapid fluctuations in multiple domains of neurological function over time. From the details they have gleaned from their patients, UK and European researchers have synthesized superior theoretical frameworks and devised more sensitive diagnostic tests for detecting early DLB.

While I understand the need to identify groups of patients using rigid inclusion/exclusion diagnostic criteria for research purposes, it is not always appropriate to apply those same criteria for the diagnosis of clinic patients with complex or poorly understood neurological disease. The currently published DLB Consortium consensus designations for possible and probable "prodromal DLB" and (overt) DLB do not contain sufficient detail or sufficiently sensitive tests for clinical use in all cases. The reluctance of physicians to render a neurological diagnosis in the face of diagnostic uncertainty until all the signs are aligned and diagnostic criteria are fulfilled is understandable given current circumstances. The ICD-10 prohibits use of possible and probable diagnoses. Yet insurers and government agencies simply won't act to provide a patient with appropriate benefits without a sufficiently specific diagnosis. My sister, who has both dwarfism and DLB, could not make any progress in obtaining benefits after the pre-eminent cognitive disorders specialist at one of the DLB Centers of Excellence gave her a diagnosis "dysexecutive syndrome," despite characteristic cognitive decline in multiple domains and Parkinsonian motor features for which he advised her to pursue Social Security Disability Income. Two years and 3 neurologists later, she was finally diagnosed with DLB. Only then did her physicians begin to treat her appropriately, including advising her not to have a lengthy surgery because of the risk of accelerating cognitive decline. Physicians may encounter more uncertainty in diagnosing DLB as we learn more about the commonalities shared by various dementias and the frequent co-existence of multiple pathologies in the same patient.

I propose that physicians adopt the designations "provisional Lewy body type mild cognitive impairment" or "provisional Lewy body type dementia" when clinical and laboratory data point to the diagnosis, but do not fulfill all the criteria. It would be imperative that health care and governmental agencies and insurers accept these terms. The concept of a "working diagnosis" would be understandable to most people and would be useful in addressing the types of problems these patients may encounter.

APPENDIX 2: CARE PARTNER SUBMISSIONS

CP1 SUBMISSION

I was the care partner of my husband for 8-10 years that he likely had Alzheimer's

Diagnosis – Having worked briefly in a retirement community with an Alzheimer's residence, taken some training, and interacted with residents with Alzheimer's,

I was familiar with the signs and about 7 years before my husband passed away asked his doctor to offer him cognitive tests (as a benchmark). He performed those tests every year, and after four years concluded that he did have some form of dementia, and referred him to a neurologist who confirmed his diagnosis. For three years he offered the same tests, but did little else, and did not even mention the Alzheimer's Association

- A. Support and Services – In 2010 I began looking for support for both my husband and me, with limited success
 - 1. Caregivers – Because I needed to continue working and believed he was both unsafe and frustrated at home alone, I reached out to Office for Aging to see if they could provide names of caregivers; their policies prevent them from doing. I live in a rural area. In the nearest larger city, there are multiple agencies who provide care, but they are unwilling to service areas as far away as I am
 - 2. Support – I knew very little about the disease, how to provide the best care, and what might lie ahead. I wished there had been someone whom I could have called, someone who had traveled this path before, but there was no one to connect me with anyone. I did call Office for Aging to ask about support groups; they connected me with one provided by the Alzheimer's Association which I attended once. There was a large group of people there, most of them with parents in nursing homes, and much more talkative than I. The facilitator was new and was unable to control the group. I felt like it was a waste of my time, that I got nothing out of it, and never went back. It would have been nice if there had been some follow-up from the Alzheimer's Association to ask how I was faring.
 - 3. Services – The only thing I ever asked the Alzheimer's Association for was recommendations on memory care assisted living options; they were unable to help (which I needed). It never occurred to me to ask them for things I am now aware of (social events, education events, individual counseling)

CP2 SUBMISSION: A caregiver for my wife with YOAD for 13 years so far, I am also a dementia awareness activist presenting a full schedule of classes and talks about these diseases and caregiving in a several county area.

Diagnostic Process

“ ‘She has dementia of the Alzheimer’s type’ said the doctor out loud; ‘here’s a prescription for a pill that might slow down some symptoms for a little while. I’ll see her again in six months. The nurse will show you the way out’. What the doctor didn’t say out loud was, ‘Now get out of my office so I can see someone I can actually do something for.’” I have heard this story many times from people who have attended my lectures. And I experienced it myself years ago.

I don’t know that this represents doctors’ real sentiments, but I do know that this is the message that persons living with dementia and their caregivers are receiving. This is a problem that needs to be fixed.

Further, I have been told that some doctors have refused to hand out to their patients information about Alzheimer’s disease or other dementias, and material about available resources and support.

“We don’t want to do that” the story goes “because then we’d own the diagnosis, and because Alzheimer’s is 100% fatal and we can’t do anything about it, and we can’t be quite sure about it, and people don’t want to hear it, and....and...and.... well, (in a fading voice) we don’t want to get blamed.” The medical profession beyond the big centers, i.e. out in the real country, needs to come out of the 19th and get into the 21st century.

Support Services

At least as frightening as the swelling number of persons living with dementia (one every minute) is the enormous amount of ignorance about it. Persons receiving the diagnosis, their caregivers and families are almost always nearly totally ignorant about the basics that are true of almost all of the dementias (i.e. it’s a degenerative, slowly progressive, untreatable, 100% fatal brain disease). And most have no place to turn, no way to overcome their ignorance. They feel alone (but of course they are far from that). Neither the medical nor the social service community do a good job in providing information, education, support.

The husband of a resident of my wife’s memory center asked me why my wife was now in a wheelchair. “Did she fall?” he asked. I blithely told him no, but that her disease had simply progressed to the stage where she has now forgotten how to walk. He looked at me wide-eyed. His wife is in the memory center with Alzheimer’s too, but no one had ever told him, and he had never learned, that that is how the disease progresses. The poor man went pale with the realization.

“Everyone knows that.” is one of the great fallacies of the English language. And the fact that XYZ agency mentions its dementia support services somewhere in 8 point type on its website is irrelevant. If information and support exist, but few people who need it know about it, it doesn’t really exist.

I gave various dementia awareness talks to over 1000 people last year and never found a single person who’d ever heard of Alzheimers.gov, nor of NIH’s free Alzheimer’s publications—including the care directors of several residential facilities. These are valuable resources but they aren’t doing much good. The information about dementia exists; some support exists, but it is not effectively getting to the huge population (Greatest Generation, and increasingly, Aging Boomers), who need it.

To reach the dementia target population who did not grow up with “websites”, “facebook” or anything more technological than radio, broadcast tv, and direct mail, agencies cannot rely on the “passive” communication of putting up websites or using social media (“whatever that is”) designed by millennials. Millennials design information outreach for themselves. (“It looked fine on my computer screen” is not adequate quality assurance for information products for 70 or 80 year old eyeballs.)

To achieve better awareness about dementia and dementia support throughout the aging population it will be necessary to develop communication strategies and techniques that reach them where they are, not where millennials are. This may require educating younger professionals in the realities that even healthy, sharp, older folks might not see and hear as well as 30-somethings and might not take in rapid fire sentences quite as well, and don’t enjoy learning “new apps” just by putzing around.

Sometimes it seems our growing divide is not red vs blue, its black/blond/brown vs gray.

CP3 SUBMISSION Alzheimer’s Disease - Family Caregiver Perspective

My mother has Alzheimer’s disease and I along with my other four siblings are her primary caregivers.

We are fortunate to be able to still care for her but there have been challenges along the way as the disease progressed to where she could not be home alone. In the beginning, we knew she either needed someone to come and visit with her or she needed to be able to go somewhere to socialize and stimulate her as her interest in reading, watching TV, attending church and other social activity or any other activity dwindled. On top of that, she could no longer remember how to cook which was one thing she loved to do – cook for her family and friends.

When her friends and social group did not visit often, I knew finding a place for her to socialize would have to be a priority, otherwise, sitting in dark room on a sofa looking out the window all day was becoming the norm. It was a challenge finding a place that was not only culturally the right fit, since communicating in her native language was

important along with having familiar cultural activities and food, but also because Alzheimer's disease limits her ability to fully participate in activities and other concerns relating to the disease must be considered.

Finding an Adult Day Service to meet the cultural aspects that was in her neighborhood was a first step, but it took more researching than one would expect. The doctor's offices' social services at the time was not responsive and did not provide any assistance in locating a place, and I, not being familiar with local community services in her neighborhood made it more challenging. I had to google and research on my own but was able to find a wonderful place that met her cultural needs but did not have an official program for those with Alzheimer's disease. I was very fortunate in that the person I met with at the ADS center to learn about their program and to get her enrolled was also very receptive to some form of partnership with one of the Alzheimer's organizations in which I was a volunteer for. I was able to bring the two organizations together to start a partnership and begin the process of getting training material translated and educating the staff on Alzheimer's disease and hopefully to be the community resource. The challenge now is to continue this community aspect of raising awareness, reducing the stigma, and having these community organizations build strong programs and services for those with the disease as well as their caregivers. Having programs and activities specifically geared for those with cognitive impairment or any form of dementia is greatly needed for those that can still go to a program such as an ADS center and hopefully help to slow the progression with activities to stimulate their brains and provide social engagement prolonging the time they may need further assistance, such as a skilled nursing facility.

The need for more organizations that meet cultural needs in a community for those suffering from all forms of dementia along with their caregivers is important not only in the early stages of the disease but there is also a great need now for more places that addresses these cultural and language needs in the community when the disease progresses and a more skilled nursing facility is needed.

When a community is informed, educated, aware and given easy access to program and services for those with any form of dementia it helps ease the stress of a caregiver. More community programs that allows for a safe place for those with dementia and have disease appropriate activities along with educated staff, that also incorporate respite care and caregiver and community education is greatly needed.

CP4 SUBMISSION

The community that we have lived in for 44 years does little to support my husband who has Alzheimer's disease, nor does it do anything to support me as the caregiver who still is working fulltime. One example of frustration for me is that I have reached out to the local animal shelter to inquire about my husband becoming a volunteer at the shelter. I have filled out an application on line and called numerous times explaining his

diagnosis and what he is capable of, but gotten no response. He is perfectly capable of cleaning out cages, walking the dogs and playing with the cats. He does not wander off, and would need minimal supervision from the people in charge. My guess is that they do not want to be responsible or liable for him. But I know it would be great for him as well as the animals. People with Alzheimer's disease can still contribute to the community at large, with cooperation from local resources. We live outside a large metropolitan city, and I find that resources are much more available to people living inside the city, but less so to us in the outlying suburbs. But I will continue to advocate for him, and look for ways for him to support and be supported.

CP5 SUBMISSION

How living with dementia or caregiving responsibilities has affected your employment and engagement in social activities and hobbies ,

My experience as a caregiver has been empowering, especially in terms of my employment! I'm an African-American female and work in a demanding job. But, I'm able to take time off to be with my Mom, take her to appointments and outings, AND speak at various memory care communities about our 14 year journey with the disease. I give the attendees information, apps and websites that will help them to realize that they are not alone on their journey with Alzheimer's.

Why are my employers so supportive? Because almost everyone in the office I work in has a direct connection to Alzheimer's. Two have had close family members die of the disease during the 7 years I've worked there. They cheer for me every time I head to the airport to catch a flight to a speaking engagement, or if Mom is sick or has had a fall, they want me to text from the hospital to give updates on her condition. It's almost as if my Mom has been adopted by my co-workers and bosses. People follow us on Social media and their comments and support really keep me going, especially on the bad days! I have a good support system outside of work as well if I ever need anything. Even after my husband who did so much for my Mom died suddenly almost four years ago, a support group was formed at my church and they helped me to do some of the things that my husband had done for Mom over the first 10 years after her diagnosis.

I ensure that I remain connected with Mom to our hobby of building things with LEGO bricks. Even though she no longer knows who I am, somehow she must remember the hundreds of hours we spent building with the bricks was a kid with a lot of allergies who couldn't always go outside to play. One of the most difficult things about this disease is the blank stare our loved ones have. Even though she's not always alert, she seems to come alive when we get the LEGO bricks out and she's able to put a few pieces together. That makes me incredibly happy.

Though Mom is slowly losing her strong balance and likely heading into the later stages of the disease, we still get to go out and enjoy the weather, and trips in the car to visit an old friend or to drive through holiday lights so she doesn't have to walk a long way but can still enjoy the bright lights. I try to encourage families to include children to engage with their loved ones with dementia, because they really can give them a big boost emotionally and make those with dementia smile. We've done activities with my now 8 year old granddaughter and my Mom since my granddaughter was two. We've done Easter egg hunts and coloring, coloring in a coloring book I created, throwing a ball, and reading together. Mom and I also do other activities like assembling 30 piece puzzles, playing with fidget toys, celebrating the holidays in some small way even if she's lost the meaning and understanding of each holiday. She understands love and joy and that works for me and keeps me going. She just turned 91, but instead of having Happy Birthday written on her cake which she no longer understands, I just purchase a brightly colored cake and we are just two women enjoying cake—we just happen to be eating it on the day she was born many years ago!

CP6 SUBMISSION

Three years ago, I received a frantic phone call from my mom. She said my dad, age 80, had suddenly become extremely fearful that someone was going to break into their house, and he was sitting at the window with a gun. We were successfully able to remove the gun from their house, but we had no idea we were entering a whole new stage of my Dad's life.

A few nights later, my dad called 911. The voices in his head told him that someone was coming up the driveway and they were going to break in and rape my mom. When the police arrived, he was sitting at the window with a knife.

Dad was taken by ambulance to the hospital. They put him in a psychiatric room with blank walls, no windows, no remote for the television, no silverware for his meal, and no access to a bathroom. It was the most inhumane room I have ever seen. It took hours for the on-staff psychiatrist to visit. Because Dad's memory was very sharp, dementia was not even considered. The psychiatrist recommended he go to a psychiatric ward at another hospital.

Dad stayed in the psychiatric ward for a week. The people in the ward were more than half his age and they all had severe mental issues. Dad did not feel safe there. They diagnosed him with schizophrenia. He was put on anti-psychotic medications. He pretended the medications were working just so he could go home.

We tried to get an appointment with a local psychiatrist, but no one had appointments available. The only person available was a physician's assistant in a mental health clinic. Over the course of months, she tried every anti-psychotic medication out there. None of them worked. All they did was turn Dad into a zombie.

We took Dad to a neurologist. The doctor did all kinds of tests that showed there was nothing wrong with his brain. She basically shrugged and sent us on our way.

As I watched Dad turn into a zombie, caused by the anti-psychotic medications, I couldn't help but question how an 80-year-old man could suddenly become schizophrenic. All of my research showed that schizophrenia typically shows up in a person's twenties. I stumbled upon a specialist in Neuropsychology. She did testing on Dad and diagnosed him with Lewy body dementia. We were so excited to finally have a diagnosis that made sense!

From there we tried to find a doctor who specialized in Lewy body. We tried his general doctor and two neurologists. None of them had answers.

Dad's hallucinations continue to get worse. It's frustrating that no amount of rationalizing with him can ease his fears. He lives in constant fear, which is wearing down my mother. We really don't have any resources to turn to for help.

Dad is too physically healthy for a nursing home or assisted living, his memory is too good for a memory care facility, but he's too mentally unstable to continue living at home. We wish someone would help us figure out how to care for him before he endangers himself or the people around him.

CP7 SUBMISSION

Experiences and challenges related to the diagnostic process -

Like many others I've spoken with who have a family member living with dementia, getting an accurate diagnosis of dementia is extremely difficult. Doctors seem to pass us around I suspect because they don't want to deliver a diagnosis for a condition that has no medical treatment. This behavior only compounds our fear and lack of information about how to live with a condition that likely will last many years.

Support services for both individuals with dementia and care partners –

I live in a major U.S. city and realistically there are no support services for either my husband or myself besides support groups. We have a young son and I have to work to support the family. We don't have any family where we live. To move closer to family would not be possible for many reasons. Life is so difficult without supports that I have begun taking anxiety medication and I see the toll it is taking on our young son.

Communication with medical providers –

Non-existent – they are not helpful or frankly knowledgeable.

How living with dementia or caregiving responsibilities has affected your employment and engagement in social activities and hobbies –

Our situation may be a bit different from most as I married an older man. We have a young son to raise that is very difficult with my husband's dementia. I have had to essentially give up any interests and hobbies and focus on working and just getting through each day. I've lost weight, am now anxious, don't sleep well and am fearful about our financial situation. I love my husband and want the best for him, but his condition is draining every fiber in my body.

How communities might better support those affected by Alzheimer's disease and other dementias -

We desperately need support services such as respite, day clubs that don't infantilize individuals living with dementia, and volunteers who could come into our home to offer support.

CP8 SUBMISSION

It Might Get Better For the last several years Alzheimer's and Alzheimer's Disease Related Dementia (ADRD) conditions have been getting the red carpet treatment from both the media and entertainment industries. Arguably, ADRD has become a genre in its own right. Still Alice, The Notebook, The Meyerowitz Stories and Away From Her are just a few of the current and noteworthy films to tackle the disease. Now, NBC's popular drama, 'This is Us', has added a storyline about ADRD, that highlights not only the challenges facing those with ADRD, but also the impact on families. Of this I am well aware as over the last several years, I have provided much of the care required by my parents. I am not paid. And though I have a team of home health aides and my parents have good medical coverage, the cost to me,

has been considerable. Current predictions by the Alzheimer's Association estimate the number of people with ADRD, to be 5.8 million and are expected to grow to 88 million by 2050. This means that a significant portion of the American population over 65 will need full time custodial care in their homes and/or additional provision for long-term care facilities. At the time of this writing, most insurance companies do not cover custodial care. Those without private medical insurance and who do qualify for Medicaid are eligible to receive 45 minutes of home aide help for washing and dressing. In some instances they may also receive financing for a place in a day center or state run nursing home. My private conversations with insurance companies have not been promising, as they will explain that the amount of money and resources required for elder care would cost them too much. I believe that response is just not good enough. Ms Muldoon agrees, 'The Alzheimer's Association is mostly known for its funding of research to find a cure, but we place just as much emphasis on advocacy for improving care of those with Dementia and public policies to ensure that resources are allocated as dementia prevalence rates are astronomical.

The Alzheimer's Association strongly recommends early diagnosis. They argue, correctly that individuals in the early stages of the disease have a better chance of benefitting from currently prescribed medications and drug trials. While, I agree this suggestion in principle, my own experience is that those with ADRD are not only less likely to seek help, but they may actively avoid any suggestion that something is wrong. My Dad certainly showed many of the '10 signs of Alzheimer's long before he agreed to see a neurologist. Even then, he dismissed the memory tests and refused to see that doctor again. This response is not atypical of those with ADRD, as fear and confusion are common indicators and effects of the disease. Several months after the initial diagnosis, I was able to persuade my Dad to visit another neurologist, 'as we were on the way to lunch anyway.'

In my view, Alzheimer's screening could and should take place as part of a comprehensive yearly physical. Most physicians and/or insurance providers recommend yearly visits to a primary care doctor and screenings for breast, prostate and colon cancer. These measures would provide the same benefits to those living with ADRD, in terms of treatment. As importantly, early screenings provides an opportunity for communicating important information about ADRD to members of the public. Ms Muldoon explains, 'People who are informed about dementia are more likely to engage in financial planning, in doing things like naming health care proxies or powers of attorney to represent them, and to make their preferences known about what kinds of medical interventions they want and don't want.'

Caring for those with ADRD must be a whole nation effort. As it stands, those with ADRD are all too often targets of cyber and phone crimes by scammers preying on those whose judgement is compromised by the disease. According to Ms Muldoon, ADRD often leads to poor decision-making, especially when dealing with money. America needs to do more to protect the rights of its citizens, especially those with a chronic and terminal illness that could potentially wipe out their hard earned savings and lead to the loss of their home.

Our accountant has estimated that my Dad wrote checks worth tens of thousands of dollars to charities, bogus car warranty companies, scam-lotteries and gold coin merchants. As my Dad was yet undiagnosed with Alzheimer's he nearly lost his home due to non-payment of property taxes, not because he did not have the money, but because he did not remember how to do so. When I asked the administrator at the town tax office, why they did not make provisions for ADRD seniors, I was sent from office to office. My point here is this; it is too easy for ADRD's need to be recognized by local townships and governments.

To prevent my Dad from spending every cent he had, I went through the process of calling each charity and organization to request they stop their solicitations. Some did, but most, even the more reputable organisations did not comply. I went so far as to call our telephone provider, who advised me to stop using the landline or buy a new phone. My trip to the central post office was even more unhelpful as I was told that the United States Post Office 'cannot legally prevent mail from being delivered so long it is paid in full, and that includes any mailer, even those the receiver suspects of scams. In the end I reported the lottery mailers and phone calls to the Federal Trade Commission, who investigated, prosecuted and gained a conviction against two 'lottery scammers'. Though, I do take some solace in the knowledge that two guys in Utah have lost their luxury homes and Rolls Royce(s), I still find it difficult to believe that the only means I had to protect my Dad was creeping down the hedgerows to pull the mailers and dump them in the recycling before he saw them, yet it is true.

Some days caring for my Dad is completely overwhelming. On better days, I am more willing to embrace the good things that come with ADRD. Recently, I gave my Dad a glass of water. After taking a long sip, he paused, before asking, 'what is this liquid?' When I replied, 'Water', he said, 'Well, I have never tasted anything so delicious in my life'. I did laugh, but I was also made happy by the idea that what Alzheimer's takes away, it also gives back, as a re-experiencing of that which is lost or forgotten. What a gift for him and me too. Sometimes that is as good as it gets, but then again it might get better.

CP9 My father was diagnosed with dementia in September 2017. We had seen signs of the disease before we were sure what to call it. For his entire life, my dad had been able to tally large sums in his head in seconds, he worked as an accountant and lived in numbers. The first time I remember having the panicky feeling that something was wrong was when he handed a waitress his credit card at a restaurant and said "Just put a 20% tip on the card". The waitress told him that he would have to do it and he was unable to do the arithmetic. I spoke to my mother about the situation and she said she had also seen behaviors that scared her. A week later she took him to be tested. They had my dad draw a clock and he drew the numbers on the outside. They did brain scans and determined he should be put on Aricept. All of our lives have changed in the past two and a half years, my father can no longer be in the house by himself. He becomes nervous when one of us is not in his eye line every couple minutes. In a lot of ways, we've been lucky, he surrendered his license with little protest after an accident, he's never cussed at us or become violent. The disease has taken a toll on our family especially my mother. For the past two and a half years, she has acted as his full time caretaker. She stepped up and took over all of the household finances, scheduling both of their doctor's appointments and making sure that my father is comfortable and looked after. My mother and I did a lot of research after initial diagnosis. We became aware that dementia is unpredictable and there is no baseline for memory or behavior. There are moments of joy when I see my father's former behavior. He loved to joke around and tease and sometimes the playful side of him will still be there. More and more often lately, he's been drifting in and out of naps or sitting silently. He loves television (and always has) so we keep a rotation of his favorite movies on. Old classic westerns and mob movies stay in rotation and recently A History of Violence has become one of the new favorites. Last year I read the Godfather series so I can talk to my dad about it. He's been a fan of the movies as long as I can remember and can recall all the characters and their traits as if they are family. He's also allowed more vulnerability emotionally. In the first year, he started saying "I love you" more than I remember ever when we were growing up. When I confided in a professor friend that I was surprised at this shift in behavior, she told me that medically they refer

to a change like this as “pleasantly altered”. I’ve found that one of the harder parts of dealing with this illness has been relating to other people outside of my family. When we started to lose my father, I felt like I was in mourning permanently. Dementia behaved like a thief that stole my father and parsed him back to us in bits and pieces in an unpredictable pattern. I’m lucky enough to have a job that understands the challenges of caregiving and allots ten caregiving days a year. Being able to help my mother with neurologist appointments, provide respite care, and take her to some of her doctors appointment has been a blessing. She is doing the lion’s share of the caregiving and any opportunity I have to provide relief, I’ve tried to utilize. Currently, he attends an adult daycare center two days a week in order to give my mom a break. With the outbreak of COVID-19, respite care is going to become more complicated. My mother and I discussed it and I am no longer going to go down to the house for fear of bringing new germs and my father won’t attend the center. Social and dating problems that had seemed paramount the previous year, felt inconsequential after my dad got sick. I’m in my mid-thirties and when I was still casual dating, I would give each guy a quick elevator speech along the lines of: “My dad has dementia. Sometimes my family will need me. I will probably go dark on you and I need you to be ok with that otherwise this is not going to work.” The worst is when a man I had been on a couple dates would say: “It’ll get better.” Or “don’t worry.” Whenever I heard sentiments like that I grew furious with resentment because they had no idea what a disease like dementia does. There is not “get better”, only worse and there are no easy decisions as my family and I quickly learned. I’ve settled down with a boyfriend who understands. When we first started dating, I gave him the usual speech and he didn’t spout any platitudes. He just held me and said “That is so hard I can’t imagine.” and that was all I needed. My mom and I joke about how our “bullshit tolerance” has reach an all-time low. Experiencing a constant loss like this really shifts things into perspective. I’ve become more confident in making boundaries and cutting out problematic people from life, out of necessity. My mother began going to therapy and I’ve moved my therapy sessions up to twice a week. We are big believers in process and are trying to use all of the resources available to soften the process.

CP 10 Submission

By the time my dad reached his 60s, he had become someone who other people did not want to be around. He seemed to grow increasingly self-centered, and increasingly obsessed with sex, and he didn’t seem to care or notice that he made other people uncomfortable. One by one, other members of my family banned him from coming to their homes, based on inappropriate things he said, or inappropriate advances he made toward their guests. I limited my interactions with him, too, because I didn’t want to be around that kind of behavior either. Then in his 70s, he began to have problems with balance and walking, and incontinence. And swallowing. Still, it was not until the last year and a half of his life that I came to understand that he had developed – and at that point was in the end stages of – a type of dementia that is characterized NOT by memory loss, but by socially inappropriate behaviors including hypersexual behaviors. My dad didn’t lose his memory, but his behaviors and physical abilities deteriorated very dramatically. And that’s when I learned that Alzheimer’s disease, which is characterized by memory loss, is just one type of dementia. Here I was, working in the aging field, and I didn’t recognize that what was going on in my own family was dementia. My experience with my dad made me realize how unprepared my family was for the unhealthy changes in his brain that occurred as he aged. And how unprepared other families are, and our communities, and our nation really. Because my family was unprepared, our family

relationships were damaged. Opportunities for joy and togetherness were lost, and estrangement was the result. People sometimes ask, why get a diagnosis when there's no cure? You might think, I'd rather not know. Or maybe, I don't want to lose my freedom, or my dignity, if other people find out I have this going on in my brain. Well for one thing, new treatments are being developed as we speak, and there may be treatments or clinical research trials that you or your family members might want to be involved with

But whether a cure is on the horizon or not, knowledge is power. Early diagnosis allows patients and their families time to adjust and make plans for how their lives will become different... to help preserve or repair family relationships.... to make informed decisions related to things like housing, transportation and finances... to recalibrate and reimagine their lives moving forward. Too often our culture tends to think of dementia as a death sentence, or maybe as something to be ashamed of, rather than as what it is: a chronic disease that a person is likely to live with for many years. It shouldn't be like that. When we do that -- when we just think about how we're going to die, and not how we're going to live -- we miss out on opportunities for people to continue to live well, with joy and purpose... or at least to live *better* than so many people with dementia do now.

APPENDIX 3: ADDITIONAL RESPONSES FROM THE ALZHEIMER'S ASSOCIATION FROM PERSONS LIVING WITH DEMENTIA

(PLEASE NOTE THESE COMMENTS ARE NUMBERED FOR CITATION PURPOSES ONLY)

When thinking back to when you presented early warning signs to a medical professional and when you first received your diagnosis, what were some of the challenges or service gaps that you encountered within the diagnostic process?

AAPD1 Once I starting receiving symptoms, it took almost 2 1/2 years before I was diagnosed. My medical professional originally tested me several times for Thyroid imbalance, diagnosed me with menopausal issues and finally depression before finally asking for a brain scan and MRI to help refer me to a neurologist

AAPD2 Doctor dismissed my problem for several years without any testing...said I was "too young". Finally referred to neurologist and took long time before PET scan approved by insurance.

AAPD3 It was difficult at first because with each new doctor I had a different diagnosis. First I was diagnosed with mild cognitive impairment. Then I was diagnosed with Lewy body with Parkinsonism and then Alzheimer's and finally Lewy body with Parkinsonism. Also, at first I received no kind of counseling that took into consideration my dementia. It was only recently have I received both psychiatry and social worker benefits along with my diagnosis.

AAPD4 Doctors initially indicated it was cholesterol medication. The med was changed with no changes to symptoms. Taking months to see a neurologist. Getting the insurance company to pay for scans ordered by my Neurologist. After 2 attempts, the insurance company turned both down.

AAPD5 I presented my problems to my neurologist several years before my diagnosis. I had a prior mini stroke and heart issues that he thought were the causes of my memory issues. They became worse over time and, after telling him my father had Alzheimer's, he began the testing.

AAPD6 was very fortunate having good health insurance, a great medical center and a friend who is a Neurologist who referred me to the appropriate doctors.

AAPD7 I knew I had dementia before anyone else did. I have it in my family. My neurologist and general m.d. would not accept that I had it, even though my psychologist said I did. I am thinking it was 2 years before my neurologist finally agreed I had Alzheimer's.

AAPD8 The doctors did not believe me. My primary physician thought my problems were all due to the high stress of my position. When I went back, I was seen by a cardiologist and a pulmonary specialist. It wasn't until I was referred to the Mayo Clinic that any doctor gave me even a short neuro-psychological exam.

AAPD9 I receive my diagnosis at (redacted). The entire process took about 3 1/2 or four months. The early part was cognitive testing. ie, memory recall, object identification, drawing etc. I found this frustrating because I never got any feedback from the administers of the testing. The second part of the testing was medical. I had a MRI, then a PET scan and finally a lumbar tap. The entire time I had no idea how I did on the cognitive testing nor did I receive any information on how I did on the pet scans etc.

This format left me and my wife worrying and anxious about the upcoming outcome. I feel strongly that updated information along this path would have for me been very helpful.

AAPD10 For several years I made medical appointments pertaining severe fatigue, memory loss and stress, all was blamed on my age (50's) and menopause. Finally, after a stroke, I was diagnosed with white matter disease. My diagnosis was not explained in medical or social detail. I was told to "go live my life" by the neurologist. I was diagnosed with MCI and a year later I was diagnosed with vascular dementia.

AAPD11 My internist wouldn't refer me to a memory center in 2016 when I asked, because he said there was no effective treatment. After hearing the weird and scary memory lapses I was having in March, 2017, he referred me to a Doctor of Geriatrics who was in charge of a Geriatrics & Nutritional Sciences Clinic as well as a researcher in the field of dementia. This appt took 3 months to get in. This was at a teaching hospital/medical school so all of my appt have been with a group of resident doctors and the main doctor. At my first appointment, I received the full batch of cognitive screenings and they reviewed the MRI that my Internist had already ordered as well as the blood tests. My MRI showed small vessel disease. I passed the cognitive testing. The preliminary diagnosis was minor neurocognitive disorder due to small vessel disease and anxiety. I was referred to a neuropsychologist, which took 3 months to get an appt. I was told not to cook when (Redacted) wasn't home, not to drive on highways, and to schedule a driving assessment with a rehabilitation professional and come back in 2 months (the end of August, 2017). In August, I had many more strange memory lapses to report and I was given the cognitive test at the beginning of the appt and at the end. The reason they gave the test twice was that I kept passing and she wanted to get me into the IDEAS Study which involved a PET Scan with radioactive tracers. I passed both times, but she talked to the doctor running the study and got me in anyway. In Sept., I had an EEG (to rule out small seizures) and the PET Scan with radioactive tracers. At the end of Sept., I had a 3 hour assessment with the neuropsychologist and a followup appt a week later with the results. This doctor told me I did not have Alzheimer's because I scored so high, even though the PET scan showed a moderate amount of Amyloid Plaque. She explained that many people have the amyloid plaques and never get Alzheimer's. In October, I saw the Geriatric Specialist for the third appt and passed the cognitive test again. Her conclusion was that I had vascular dementia due to the small vessel disease but that I would probably end up with Alzheimer's. She said that she would write a prescription for Aricept, if I wanted to try it, but it had extreme side effects and wasn't effective. I asked if I could be referred to a Neurologist and she said there was nothing else to be tested but she would talk to the researchers at the local Alzheimer's Association. She called me back and said that the neurologist she talked to agreed with her that there was no reason for further testing and that "I was a strong woman and would get through this." She also told me to work with the Psychiatric Nurse Practitioner that I had seen for anxiety and depression to get my anxiety under control and come back in a year.

Following being diagnosed with dementia, what are some of the challenges you have experienced communicating with your medical providers?

AAPD12 Just getting my physician to give me an appointment is hard. He states that insurance only pay for one visit a year. He also has been hard to get him to help me getting referral to other doctors for additional help with problems I am having as my condition progresses

AAPD13 Once diagnosed, my neurologist provided very good information and guidance regarding my condition. My primary care physician does not deal with any dementia related issues.

AAPD14 I haven't really had challenges communicating with medical providers although I have had difficulty finding primary care physicians and some other specialty doctors who no little about the symptoms of Lewy body.

AAPD15 After diagnosis by a research/study company after PET scans, I wanted to find a neurologist. \$ months after getting an appointment, seeing the neurologist, he no longer subscribed to my insurance company. Then, locating another neurologist. Even with a positive Amyloid accumulation and a spinal tape, as told I didn't have Alzheimer's. Seeing a third neurologist, I as told I am Early Stage Alzheimer's. Getting the right meds for anxiety, depression, focus, mood swings.

AAPD16 My primary care physician has been great but has had issues with my neurologist. I live in a small community and he is the only one we have (with a good reputation). He has become so overwhelmed that he doesn't have sufficient time to give to me during my appointment. I found out this week he has decided to retire and close his practice. I will now be looking for another neurologist about 60 miles from where I live or will need to go to (redacted) which is about 240 miles away.

AAPD17 Initially it was the need for a support group for individuals with younger onset. Once several became vocal about the need, (redacted medical center) identified the resources and created a support group. While I did not have any communication challenges with my doctors, did experience a great deal of frustration with the SSDI process.

AAPD18 I had to tell them what I was doing to control/slow down my Alzheimer's. I really don't have any challenges because I only see them occasionally. They are actually learning from me what I do to slow down the process, or at least make the best of it.

AAPD19 It was hard to get a firm diagnosis beyond mild cognitive impairment or cognitive impairment. My neurologist believes that the disease is progressive, but at this time, he is unsure exactly what I have, whether it is Alzheimer's or Lewy body dementia or something else.

AAPD20 When I see any sort of medical care provider for any medical issue whatsoever I always inform them that I have Alzheimer's disease. An example would be the spine surgery that I had last May. I see my internist at Northwestern on a regular basis. He's the same doctor that sent me to the neurology department for my diagnosis. He never asks me anything about my Alzheimer's disease.

AAPD21 Since my stroke, my internal medicine doctor does an excellent job of managing my overall health. I see her every three months due to my diagnosis.

AAPD22 My biggest frustration with communicating with my Geriatric Specialist is that at the beginning of each appt, (Redacted) is taken into a room with the Geriatrician and the other resident doctors and nurse and I am taken to have cognitive tests. (Redacted) is with them quite awhile. I see the doctor after my tests and there are usually two or three other medical professionals in the room as well. She brings up issues that Jim has mentioned but obviously has already made up her mind about my current memory problems, because she has gotten (Redacted)'s opinions first. This frustrates me because I am quite capable of describing my memory lapses and (Redacted) underplays them.

Describe your experiences with support services for people living with dementia, either online or in your community. What has helped you live well with your diagnosis? What do you feel is missing?

AAPD23 Locally, the area that I live in only has the director of the local office for support counseling. There are no group support systems. I have a peer to peer support with my ESAG group members. I live well with my Dementia by trying to stay positive. Also getting out and telling my story keeps me motivated and upbeat. I wish that there were more support systems or ways that I could reach out to individuals to make them overcome the shame of the stigma of the Alzheimer's diagnosis.

AAPD24 The local chapter of the Alzheimer's Assoc provided one on one counseling and education/support groups for both me and my caregiver. However, continuing support groups are only available for caregivers and not for patients diagnosed and living with early stage dementia. Therefore, no support group assistance is available for early stage patients until their condition advances to needing respite care.

AAPD25 The Alzheimer's Association support groups for people living with early stage Alzheimer's or other forms of dementia have been extremely helpful for me and my care partner. Also, (redacted medical center) has provided needed support services including support groups, the buddy program, social work, and psychiatric assistance.

AAPD26 The major support services and a positive experience has been with the Alzheimer's Association as a public policy advisor, community service advocate, and speaking to others and groups about my "journey" and having the best Care Partner. Being accepted and the support by family and friends. I'd like to find a local support group. Governments support is definitely missing, including the VA.

AAPD27 There are no support groups for me in my community. Everything is geared toward the care givers. I met a couple of ladies who are also early stage through a friend who lost her husband to Alzheimer's last year. We are trying to meet for lunch at least one time a month. The Alzheimer's website has been a great source of information.

AAPD28 I am very thankful for the (redacted) Alzheimer's chapter who were instrumental with getting the first early stage support group in collaboration with (redacted medical center) in our area. They have also provided guidance concerning existing resources in the community. There definitely could be a greater focus placed on developing additional social programs for early onset individuals. What I feel is missing is identifying transportation options for individuals once they are unable to drive.

AAPD29 I really enjoy Facebook's "Alzheimer's and Dementia Patients Helping Patients" group. Patients <https://www.facebook.com/groups/2133567863536884/?ref=search> I also follow a caregiver's group and they really have been appreciative of my contribution to the group. There are local support services, and I've considered going, but honestly, I'm not ready to do that. I know I would be helpful, but I'm already getting more nervous about the future. I have been going to see my mother, who moved recently to an Assisted Living/Care facility and I enjoyed visiting with her and her friends. For some reason, I enjoyed that and want to go more often and for a longer time.

AAPD30 The Alzheimer's Association has been a godsend. Without the association, I would have never known of the local groups. I currently attend a signing group for Alzheimer's patients and related dementias. We get together each week not only to sign, but more importantly share information and friendship. The disease is lonely and it is great to know that there are others with whom you can share information.

AAPD31 (Redacted hospital) has a lot of supportive programs for families and individuals living with dementia. Most all of them design to get you over the immediate hump of having been diagnosed. Secondly, and for me most importantly is the Alzheimer's Association itself. Their support of programs has been pivotal in my progress in learning to live with Alzheimer's. Specifically, the MCI support groups that are available several times a year for persons and families living with dementia. For me the support groups were pivotal in my getting comfortable with this diagnosis. I like being in the support groups to being among a group of mentors. I've been around long enough where I'd like to think of myself as one of those mentors.

AAPD32 I fell into a long depression after diagnosis. I finally found several on line support sites which offer peer to peer online support groups. Dementia Alliance International and Dementia Mentors are the two I currently use. My local community is lacking an in person peer to peer support group for early stage dementia folks. I feel that in person would be so much more meaningful than on line. We could help each other and build in person friendships that are so important when one is diagnosed with any life altering medical condition. Support groups work.

AAPD33 The (Redacted) Chapter provides a moderated monthly conference call which is composed of men and women with early stage dementia. We each share what is going on in our personal life, get feedback from others, and share information about treatments, drugs and trials, also. We have become close over the past year, even though we have not met in person.

Have you experienced any changes to your social activities, participation in hobbies, or employment status as a result of your diagnosis of dementia? If so, please elaborate.

AAPD34 Once diagnosed with MCI, I immediately left my job. It was the first time since adulthood that I wasn't employed so now I have nothing to do except hobbies. Currently, most of my time is spent at the local Alzheimer's office. I also spend quite a lot of time in the community speaking to groups of people about the disease and how I deal with mine. Other than that I usually spend some time crafting. I don't have many other hobbies, because reading which was my biggest hobby is actually very hard for me to do because of the dementia. I now have a hard time concentrating so I can only use my Alexas to both read and listen to music daily.

AAPD35 Memory and personality changes forced leaving my career. The stigma surrounding "dementia" created distance with friends and family. Inability to make decisions or control emotions makes every task difficult.

AAPD36 Yes, my recent bowel and bladder incontinence have limited my ability to get out of the apartment. I use to take public transportation all over after I lost my license, now my care partner has to drive me everywhere.

AAPD37 Social activities continue to be good, have lost interest in hobbies, difficulty retaining reading materials and understanding what I've just read. I hate my depression, anxiety and mood swings.

AAPD38 Big change in employment! I was a mortgage loan officer and department manager. I left that position thinking my issues were just stress related, took a marketing job and started struggling there as well. I was terminated a few weeks after confiding to my HR lady that I was having issues. The reason for the termination was "It's just not working" and she could not elaborate on that. I am now a receptionist in a church office doing clerical duties had struggle some days with this.

AAPD39 I am very fortunate to have a large circle of friends who make an effort to reach out and socialize. I have lost interest in hobbies and exercise over the past 12 months but continue to push myself. I had to retire once I received my diagnosis.

AAPD40 I have, but not my choice. I noticed I am not being invited to lunch, activities, etc. with my friends who used to invite me. Even when I invite, I have had no response (sometimes). I finally wrote a post on Facebook re that, not to get more invites, but to let people know that I'm not a zombie. I still want to do things. There was a good response.

AAPD41 My employment terminated immediately after my diagnosis of mild cognitive impairment. I was an attorney which poses severe ethical problems. I have also become more isolated and don't go out very much. My business acquaintances have shied away from me. It is a really lonely disease.

AAPD42 I was retired when I got my diagnosis so I don't have any employment issues. As to a social activities, I certainly still enjoy them but if there are too many people and too many conversations going on at the same time I find it frustrating. Another issue that comes immediately to mind is my ability to do certain kinds of projects around the house. Electrical work or plumbing, stuff I was able to do for years is now more challenging. Some projects I just decide not to tackle myself.

AAPD43 Yes to all above. My physician removed me from work due to high stress; I medically retired a year after the diagnosis of my brain disease. I find that social events, large crowds are confusing and stressful. I have difficulty following conversations often and my loss of memory hinders my life immensely. My hobbies were forgotten for the first 2 years, but I am finding my way back to designing jewelry and listening to audio books, as I find lengthy reading difficult.

AAPD44 Because of my memory problems, I can no longer drive on the highway so my many trips to St. Louis (2 1/2 hr away), where I have relatives and lifelong friends, as well as my only daughter and only grand daughter, have become very infrequent because (Redacted) is taking me. I can't organize fun things to do with girl friends without pointing out that someone else has to drive. I am no longer comfortable in noisy, crowded places and find that I don't participate in conversations like I used to.

APPENDIX 4: ADDITIONAL RESPONSES FROM THE ALZHEIMER'S ASSOCIATION FROM CARE PARTNERS

(PLEASE NOTE THESE COMMENTS ARE NUMBERED FOR CITATION PURPOSES ONLY)

What were some of the challenges or service gaps that you encountered while accompanying your friend/family member in obtaining their diagnosis?

AACP1 (Redacted) symptoms started with a couple of falls, resulting in concussions. We spent the first 2-3 years focusing on concussion protocols. In retrospect the falls may have been the earliest signs of Lewy Body Dementia (of which he is now diagnosed).

AACP2 Well the diagnosis kept changing it started with MCI then Lewy body dementia to Alzheimer's then back to Lewy body.

AACP3 The general practitioner community still seems lacking in the skills to identify a potential need for further neurological testing. Verifying what type of doctor (Neurologist, Neuropsychologist, etc.) we needed to see is also a challenge.

AACP4 No doctor would take the time to explain what is possibly expected and how the disease works.

AACP5 By starting with (redacted) hospital in (redacted), there were very little challenge/gap in getting diagnosis

Following your friend/family member being diagnosed with dementia, what are some of the challenges you have experienced communicating with their medical providers?

AACP6 The biggest challenges have to deal with the enormity of the symptoms. There is simply too much to cover. It's also hard to communicate with doctors in between appointments, and a lot happens in 6-12 months. Additionally, sometimes symptoms come and go, so it's hard for a doctor to assess something that isn't present at the exact time of the appointment.

AACP7 All of my experiences with medical staff have been great

AACP8 Our biggest frustration was with the Medicare/insurance with regard to disability. Everyone thinks of Medicare as for 65 and over and there are a lot of differences for people under 65 who are disabled.

AACP9 New physicians to her do not think anything is wrong with her so they kind of push her off. Which is frustrating because they only see her 30mins and we live with her and around her.

AACP10 very little, other than they maintain an Alzheimer's diagnosis, and I feel partner's behavior is more consistent with vascular dementia

Describe your experiences with support services for care partners/caregivers, either online or in your community. What has helped you cope with this role? What do you feel is missing?

AACP11 I use a variety of sources, professional and people impacted by the disease. The most helpful resource is our Young Onset Early Stage Support Group run through our local Alzheimer's Association chapter. Hearing from others who have also been diagnosed under the age of 65, has been instrumental in helping us navigate through the medical nuances of the disease AND the life impacts at such as early age. Having a professional social worker who understands the stages of the disease, available resources, coping strategies, etc. has also been very valuable. The medical professionals only have enough time to discuss symptoms, medications, therapies and treatments. While this is very important, it leaves a big gap in terms of how to live with the disease as a family. This is where the professional from the Association comes into play. Online I follow a LBDA Caregiver group on Facebook and an email forum. I also use the Alzheimer's Association website.

AACP12 Support groups were we both can attend then split up into separate groups has been extremely helpful. I wish there more of them

AACP13 Support groups and seminars have been a great help to not only educate us, but to let us know we're not alone in this journey.

AACP14 There is plenty of help for care givers and support. But there really isn't any support for the person with diagnosis. Which makes it difficult. I would like to have her get more relief than me at this point in the disease.

AACP15 Partner remains high functioning so my biggest challenge has been coping with personality changes which frequently, but not always materialize

Have you experienced any changes to your social activities, participation in hobbies, or employment status as a result of acting as a care partner/caregiver? If so, please elaborate.

AACP16 I am still able to work full-time although it is difficult. I have flexibility from my employer to handle (Redacted) appointments. It's mentally and physically exhausting to work full-time and care for (redacted), but I don't have a choice. I have less time for social activities and hobbies, but still do some. I read quite a bit -- I enjoy it and I can be at home with (Redacted). Dinner with friends once a month and attending church. I get the majority of my social interaction from work, volunteering for the Alzheimer's Association, or attending events with my husband.

AACP17 Yes. We use to go to movies once a week, now it had been at least six months since we have gone to see a movie. I'm working a lot less so I can be home with my husband.

AACP18 My wife has MCI and functions at a high level. She is socially active and can go places by herself. I count on that group of friends to keep her socially engaged. I did retire a few years earlier than planned fearing that she would digress more quickly than she has. Her biggest issue with social settings is when multiple conversations are gong on she can't keep up and has a tendency to withdraw. Other than that we are leading a fairly normal life so far.

AACP19 I don't socialize anymore. I don't take vacation without her.

AACP20 Yes. I seem to always be on call 24/7. I have had to take time off work, change my plans ect. But honestly all in all I just want my mom to have the best quality of life she can especially as the disease progresses.

AACP21 No longer able to host large(r) groups, i.e. more than 2-3 people or attend "noisy" or high volume functions.

APPENDIX 5: ADVISORY PANEL BIOS

Individuals Living with Alzheimer's Disease or Other Dementias

Cynthia Huling Hummel (Co-Chair)



Cynthia Huling Hummel of Elmira, NY works tirelessly to represent individuals living with Alzheimer's Disease and other dementias. She served on the National Advisory Council on Alzheimer's Research, Care, and Services and as a National Early-Stage Advisor for the Alzheimer's Association. Cynthia presented at the 2017 and 2019 NIH Alzheimer's Research Summits and has given many other talks in her role as an advocate. She serves on the Advisory Council for Dementia Action Alliance. Locally, she leads the "Faithful Friends Singers for those living with dementia, care partners and community friends. Cynthia has participated in an Alzheimer's research (ADNI) since 2010. She serves on the Alzheimer's Clinical Trials Consortium (ACTC) Participant Advisory Council and is a member of the NIA Genetics and Biomarker Committee. Cynthia received her BS from Rutgers College, her MDiv from New Brunswick Theological Seminary and her DMin from McCormick Seminary. She enrolled at Elmira College in 2011 and will be taking her 40th class this summer. A retired pastor, Cynthia speaks to faith communities about offering dementia-friendly programs and services. An artist and author, she also enjoys singing with the band, "Country Magic."

John-Richard (JR) Pagan (Co-Chair)



John-Richard Pagan is a disabled veteran with a background in Marriage and Family Therapy. In 2012, John-Richard decided to continue his education by working on a doctorate degree in clinical psychology. Unfortunately, at age 47, with one year into his program, John-Richard began to suffer cognitive challenges which impacted his studies, and even after receiving a diagnosis that included mild cognitive impairment and sudden onset adult attention deficit disorder, he was dismissed from his program and left wondering where these changes would take him. At this time, VA medical doctors have only been able to definitively diagnosis John-Richard's condition as a progressive neurodegenerative disease with moderate cognitive impairments in processing, language, and attention, thus meeting the requirements for early stage dementia with additional symptoms relating to mobility and autonomic dysfunction. However, John-Richard has not allowed this disease to be what defines him. He continues to advocate for his own health and the health of others who live with dementia and dementia with Lewy bodies. He is active in his spiritual and social community, and often describes his immediate family as the most vital part of his ongoing support team.

Ed Patterson



Ed Patterson was diagnosed with Alzheimer's disease in 2018, at the age of 71. Ed, who formerly worked in the financial sales industry, states that it was his husband David who first started noticing changes in his cognition. The first warning signs were Ed experiencing difficulty with stressful tasks like making airline reservations, and episodes of repetition. David also noticed that Ed's mood was affected – he seemed to have a short fuse and quick mood swings – and convinced Ed to bring these symptoms up with his

doctor. After performing poorly on cognitive tests, Ed was given a PET scan that was inconclusive for Alzheimer's. Ultimately, Ed entered a clinical trial for medication through Bioclinica, which allowed him to access another PET scan and a spinal tap that were positive for amyloid and tau. After receiving his diagnosis Ed states he "shut down," stayed home and didn't talk much to others about what was going on. Eventually he started looking for information and resources related to Alzheimer's and came across individuals living with the disease giving speeches and talking publicly about their experience. "Their messages woke me up, and got me going," Ed says. He "went public" with his diagnosis on Facebook and became involved with the Florida Gulf Coast chapter in advocacy, fundraising, and programming. Ed currently lives with David in Clermont, Florida, and works part-time at Disney World.

Brian Van Buren



Brian Van Buren is an Alzheimer's advocate and public speaker, a Board Member of the Western Carolina Chapter of the Alzheimer's Association, and an Advisory Council Member for the Dementia Action Alliance. He was diagnosed in 2015 with early onset Alzheimer's. He was also a caretaker for his mother, who died in January from Alzheimer's. After losing his job as an international flight attendant, Mr. Van Buren reimagined himself as an advocate, giving his voice to Alzheimer's. Being an Afro American man, he felt he needed to give a face to the disease. He was featured in a video for AARP's announcement presenting \$60 million to fund dementia research. He also feels a need to address marginalized populations such as the LGBTQ community.

Care Partners of Individuals Living with AD/ABRD

Marie Israelite



Marie Israelite serves as the Director of Victim Services at the Human Trafficking Institute. She previously served as the Chief of the Victim Assistance Program at Homeland Security Investigations, where she directed policy efforts, program development, and victim services for all federal crime victims, including survivors of human trafficking and child exploitation. Marie has held several positions within the Department of Homeland Security and the Department of Justice related to human trafficking, sexual assault, and domestic violence prevention and services. Most recently, she served as a Senior Program Manager with ICF, where she facilitated the work of the U.S. Advisory Council on Human Trafficking. Marie is a graduate of Bucknell University and the University of Pennsylvania. She lives in Washington, DC with her husband and two daughters. Her mother Lucy, a retired pediatrician, was diagnosed with Alzheimer's Disease in 2017. Marie shares caregiving responsibilities with her mother's younger sister and her brothers.

Geraldine Woolfolk



Ms. Woolfolk, retired, has had many years of experience as a care partner for her father, mother, and then her husband who was diagnosed with early onset Alzheimer's Disease (AD). Professionally, she taught on the junior high school level for a few years before she decided to teach with the Adult Education Department. For almost twenty-five years, she had – among her many other assignments – leadership roles in the development and delivery of programs that were specifically designed for people with Alzheimer's Disease or Related Dementias, and their families. She is active with AD support groups, advisory forums, and conferences. Individuals, families, and community groups frequently call upon her for information, referrals, and presentations. Ms. Woolfolk is a longtime advocate on all levels of government for educational and Public Health issues. She continues to lobby for increased funding for lifelong learning, AD research programming, and care partner support projects that enable families to keep their loved ones in the home environment for as long as possible. In 2011 Ms. Woolfolk was appointed to the first National Alzheimer's Project Act Advisory Council and served on that groundbreaking body for six years. She has a BA in Music, an MPA in Health Administration, multi-level K through Community College Teaching Credentials, a School Administration Credential, and many other certifications and recognitions that herald her leadership and service. A widow, she has three remarkable children and two awesome grandsons.