Meeting title: Dementia Action Collaborative Date: September 27, 2017

Location: Tukwila Community Center Time: 9:30 AM – 3:30 PM

ATTENDEES

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **√** | **Attendee** | **Role** | **√** | **Attendee** | **Role** |
| **√** | Aziz Aladin | Developmental Disabilities Council |   | Christine Kubiak | Resdential Care Services DSHS |
| **√** | Amanda Avalos | Health Care Authority | **√** | Todd Larson | Family Caregiver |
| **√** | Cindy Balbuena | Alz WA Volunteer | **√** | Bob LeRoy | Alzheimers of WA / LTSS Chair |
| **√** | Marigrace Becker | UW Medicine Memory & Brain Wellness Center | **√** | Maureen Linehan | Aging & Disability Svcs |
| **√** | Bazia Belza | UW Healthy Brian Research |  | Kathy Lofy | WA State Dept of Health |
| **√** | Alison Boll | Aging & Disability Services | **√** | Joel Loiacono | Alzheimer’s Assoc |
| **√** | Kim Boon | NW Regional Council | **√** | Yolanda Lovato | ALTSA |
| **√** | Dave Budd | Full Life Care | **√** | Mary Lynn | Sound Options |
|  | Carla Calogero | Elderlaw – WA State Bar | **√** | Cathleen Macaul | AARP |
| **√** | Leslie Emerick | WA State Hospice & Palliative Care | **√** | Myriam Marquez | Consumer |
| **√** | Susan Engels | State Unit on Aging ALTSA | **** | Jason McGill |   |
| **√** | Erik Erickson | WA Home Care Coalition | **√** | LeighBeth Merrick | Leading Age Washington |
| **√** | Porshe Everson | Facilitator | **** | Emma Medicine White Crow | Governor’s Council on Health Disparaties |
|   | John Ficker | Adult Family Home Council | **√** | Bill Moss | Chair |
|   | Aimee Fink |   | **√** | Peter Newbould | Alz WA |
| **√** | Karen Fitzharris | ALTSA | **** | Diane Oakes |   |
|  | Aimee Ford | Qualis Health | **√** | Mimi Pattison | Franciscan Hospice & Palliative Care |
|  | Charissa Fotinos |   | **√** | Cheri Perazzoli | Hearing Loss Assoc |
| **√** | Marci Getz | WA State Dept of Health | **** | Jerry Reilly |   |
|  | Julie Gray | Aging Wisdom | **√** | Kristoffer Rhoads | UW Medicine Memory & Brain Wellness Center |
| **√** | Caroline Ham | WA Dept of Health | **√** | Marty Richards | Caregiver/Social Worker  |
| **√** | Hillarie Hauptman | ALTSA | **√** | Tatiana Sadak | UW School of Nursing |
| **√** | Jan Higman | Alzheimer’s Assoc | **** | Bruce Smith |   |
| **√** | Patricia Hunter | WA Longterm Care Ombuds | **** | Lauri St. Ours | WA Health Care Association |
| **√** | Debbie Hunter | Caregiver | **√** | Rep. Steve Tharinger | 24th Legislative Dist Rep |
| **√** | Sumi Jayadev | UW Medical Ctr – ADRC | **√** | Robert Thompson | Hearing Loss Assoc |
| **√** | Arlene Johnson | Family Caregiver | **√** | Cheryl Townsend-Winter | State Council on Aging |
| **** | Senator Karen Keiser | 33rd Legislative Dist Rep | **√** | Robert Wellington | Consumer |
| **√** | Lynne Korte | Project Coordinator | √ | Jeff West | Qualis Health |
|  |  |  | √ | Karen Winston | Aging & Disability Svcs |

AGENDA

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| --- | --- |
| **Topic** | **Key Points and/or Decisions Made**  |
| 1. Welcome and introductions
 | * Welcome by Bill Moss
* Goals – Review accomplishments and upcoming work
 |
| 1. Evidence-based Recommendations - Bree Collaborative
 | Ginny Weir presented recommendations from Bree Collaborative for Alzheimer’s and other dementias* The report focused on 6 areas: 1) diagnosis, 2) ongoing care and support, 3) advance care planning, 4) higher levels of care, 5) preparing for potential hospitalization, and 6) screening for delirium risk prior to surgery.

1) Diagnosis – recommend training to prepare primary care providers to discuss concerns about memory and be comfortable using screening tools that would be included in Medicare Annual Wellness Visit or other visits.* **For Action** – Bree to add conversations about hearing loss into the document – Kris

2) Ongoing care and support management – Identify goals of care, provide education and appropriate assessments 3) Advance care planning – promote putting advance directives in place early, and have meaningful conversations with care teams * Recommendations are directed to patients, family, and providers
* Recommends [Death Over Dinner](http://deathoverdinner.org/) website

4) Higher levels of care – goal is that families have a plan if/when decline is more than what can be handled by family5) Preparing for potential hospitalizations – having conversations early and re-visiting conversations if/when there are changes. Keep communication open with physician. Provide enough information to comfortably make a decision. Ensure accurate charting about diagnosis, allergies, other needs6) Screening for delirium prior to surgery - Ensure team asks questions to understand if patient could be at risk for delirium after surgeryNext steps: * + DAC members are asked to review the Bree Recommendations for Alzheimers and Other Dementia Care and provide feedback. Encourage others to also provide public comment

**GO TO** - <http://www.breecollaborative.org/topic-areas/alzheimers/> * + 4-week public comment period ends Oct 27, 2017.
	+ Presentation for final adoption to Bree in mid-November.
	+ Bree workgroup re-convenes in early November – public welcome.
	+ Recommendations would then go to Health Care Authority for adoption.
* **For Action**  – Kris

Include racial disparities, references to nurse practitioners in addition to physicians, and some reference of younger onset |
| 1. What’s New in the Fight Against Alzheimer’s?
 | Sumi Jayadev, MD provided an update on the state of affairs in Alzheimer’s research* There are at least 5 million people currently with Alzheimer’s. That number will double and triple in coming decades
* Funding for research, according to NIH, while the actual amounts have increased, the inflation-adjusted dollars have decreased so we are behind where we were 5 years ago
* Changes in funding - more funding is coming now more from biomedical and device firms and pharmaceutical firms while NIH funding percentage has gone down
* Removing amyloid protein (plaques) from the brain was unsuccessful in first phase. New phase provides more hope. Using biomarkers from spinal fluid, we can detect changes before symptoms occur. Now we are looking at how we get to people early and enroll them into the right clinical trial.
* Individuals may have different paths to the disease – one drug may not work for all
* Research has relied on animal models, but need to go beyond mice. New technology allows research on human cells
* Beyond drugs, there are additional options. The Lancet published an amalgamation of research to see what factors could be modifiable. They suggested we need to be ambitious about prevention – active treatment of hypertension in middle age, more childhood education, exercise and social engagement, less smoking, diabetes, and depression, manage hearing loss. Treat cognitive symptoms, individualize treatment, protect people with dementia, and manage neuropsychiatric symptoms – first with behavioral interventions, then drug treatment. Consider end-of-life issues.
* Studies showed that dealing with smoking, hearing loss, and education had a significant impact on risk for Alzheimer’s. Potentially modifiable factors account for 35% of risk
* Risk factors 3 areas – brain cognition, brain inflammation, direct damage to brain neurons. Within each area there are modifiable factors. Some factors require more research.
* Ways for people to get involved: follow people yearly, get involved in biomarker studies, cerebral spinal fluid donation, skin and blood donations for cell research, DNA donation, clinical trials
* MRI studies can identify degree of decline and the type of decline earlier
* Inflammation – gene changes happen in Alzheimer’s that do not in the general population. This has helped identify cell research opportunities. Inflammation can be studied in immune cells in the brain. Immune cells help get rid of debris. If we can rev immune system, it may be a way to prevent build up
* “Disease in a dish” studies can study brain cells and help to predict who could benefit from different types of intervention
 |
| 1. DAC Subcommittee Reports | Accomplishments & New Work
 | Subcommittee Chairs reported out Public Awareness – Community Readiness - Cheryl* Ongoing recommendations from 2016
	+ 1a1 – single access web-based portal. Adding enhancements to CLC website dementia page. Identified 4 enhancements and 11 goals for the site. Review process was just completed. A final report should be out in the next week, then enhancements would be initiated.
	+ Our team is making use of search-word analytics data to look at frequently-searched words.
	+ The idea is to identify a unique url for the page to improve the search ”find” of the site.
* **For Action – all DAC members**

Use CLC page link – this helps elevate the url in future searches. Here’s the link - <http://www.waclc.org/connect> * + 1f1 – healthy aging brain health – Team completed Action Brief. Partnered with UW and Dept of Health on Asian Communities using $25,000 grant from the national Alzheimer’s Association/CDC. Working to get Action Brief in the hands of physicians working with Asian/Pacific Islander population. Group recently received $10, 000 award from Seattle Innovations (Age-Friendly) grant to disseminate. Next targeting African American women.
	+ 2c1 – developed critical elements and began dissemination of fact sheets (posted on DAC webpage). They have been working on incorporating the DF principles into the AARP Livable Communities Iniative. Also: have been selected to be part of a state-wide library conference and have a poster presentation at the Elder Friendly Futures conference this fall. Have started work on a webinar that will provide information on things including how to start an Alzheimer’s café – to be January 24, 2018. Also presented a poster presentation at the UW Elder Futures Conference a couple weeks ago.
	+ 3b1 – safety info kit was completed and is being disseminated. Posted on DAC webpage.
* New recommendations for 2017
	+ 3c1 – make legal forms available at no cost. Will also incorporate 1d1 and 1d2 – informing care givers about end of life planning. Carla Colegero is leading the team.
	+ 2b1 – integrating dementia into state agency plans. They have a first draft Implementation Plan & a rough draft Project Action Brief (to help clarify what is being done).Lynne is working to integrate with next ALSTA strategic plan.
* **For Action – all DAC members**

If you know of state or local agency strategic plans that would benefit from having dementia included, please share these with Lynne/Cheryl* + 3a1– Dementia Capable Systems grant is funding the development of an introductory module on memory loss/dementia for Community Health Workers (training program managed by DOH)
* Recommendations to consider with funding
1. 1e2 – promoting & publicizing website
2. 3c1, 1d1, and 1d2 (see above)
3. 2b1 – scope and effect of integrating into plans could be very broad. Could collaborate with AARP, for example
4. 1A3 – getting info to underserved populations. Can we develop a project team in eastern WA? If so, some funding would be needed for travel.
5. State-wide public awareness program. This would require big dollars, but 8 recommendations could be part of this. Could look for a private partner first, then go to legislature to match.

Long term Services and Supports – Bob * Please let Bob know if you’re interested in helping with any of this work, or individuals who could be introduced to this work
* Accomplishments from this year:
	+ Caregiver Roadmap was completed. Initial print run has been distributed, another will be available tomorrow. Let Bob/Lynne know if you would like a supply. Next step will be taking the roadmap online. Need technical resource for web development. Also looking at someone with creative web design experience. The team is developing a business plan and case for support. Will then look at a public/private partnership. Need to find an owner to continue to house Roadmap and keep it updated.
* **For Action – all DAC members**

Please add the link to the roadmap to your websites. Email Lynne if you don’t have the link already.* + Care Coordination team – put together valuable information around the definition of care coordination and an inventory/assessment of resources across the state. Team is looking to partner with others to disseminate information.
	+ Early-stage Programming – The project team will be recreated focusing on early-stage programs. Lynne will chair initially. Two new members of Alzheimer’s Assoc will be on the committee as has Bob Wellington. Look at successful programs and how they can be replicated/implemented in more communities - e.g. walking group and Alzheimer’s Café models.
	+ Diverse Communities – originally focused on Native American communities. Now need to pull all of the threads together. Interest in beginning outreach to African American community in 2018.

Health – Medical – Kris * Accomplishments from this year:
	+ 5a1 – establish expert panel by partnering with the Bree Collaborative (a Governor appointed panel/program developed to improve health care quality. Anticipate recommendations being approved for public comment. This work addressed 4 recommendations in goal 5 and sets the table for 11 more.
	+ Position Paper on Cognitive Screening tools for primary care practitioners is completed in final draft form. Will add more graphics, then get feedback from various primary care providers. We will keep this open for any additional comment through October 27.  Posted on DAC webpage. Should be finalized in November.
* For the coming year:
	+ Medicare Annual Wellness Visit awareness and guidance – now that Bree has completed, they will pick it up along with
	+ 5e2 – billing codes such as Medicare G0505 that offer good reimbursement rate for practitioners to to care planning for people with dementia.
	+ Also this year, 7b1 – identify institutions that provide dementia-related services and link them to research opportunities
* **For Action – all DAC members**

Review Position Paper on Cognitive Screening tools for primary care practitioners, provide input (including ideas for graphics). Provide comment and share with others to provide comment by Oct 27th. Responses to krhoads@uw.edu * **What would benefit from funding**
	+ Products and toolkits will need to be disseminated so outcomes can be evaluated
	+ Tele-medicine/Tele-Health – interested in dementia care be part of UW’s ETeleEcho program (tele-health)
 |
| 1. DAC Partner Program Announcements
 | * Peter Newbould – 15 upcoming town halls start next Thursday in Spokane and will go through mid-November. The goal is to educate the public about Alzheimer’s and the DAC. If available, please come to town halls. There is an opportunity to contribute to open discussion.
* Marigrace Becker – Alzheimer’s Café webinar in January – open to everyone. Fliers are available for distribution. Ride for Alzheimer’s article about the road show this past summer is also available on the resource table.
* Jean Smart will be interviewed by Kris Rhoads at Benaroya tonight
* Susan Engles – the CDC has a healthy brain initiative 5-year plan and are working on the next iteration. WA State was ranked as #1 in the nation in LTSS, and invited to participate on this national workgroup. There is a support of caregiver and early diagnosis domain for the 2018 – 2023 version
* Cathy MacCaul – AARP has a mailing that goes to care providers across the state. Nov is family caregiver month and AARP will be sending a mailing to members across the state with information about the CLC and Dementia Road Map
* Mayoral forum on October 10 sponsored by AARP and KOMO – focus on aging and creating an age-friendly Seattle
* Supporting Veterans, Seniors and Human Services levy
* Aging and Disability Services w/w Alzheimer’s Oct 21 African American Caregiver forum at Doubletree
 |
| 1. Subcommittee Meet Up Time
 | * The three subcommittees met together for some planning time
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| 1. Brain Health Messaging Team Projects and Request for Input
 | * DOH partnering with National Asian Pacific Islander Association and UW HPRC develop Action Briefs on messaging to/working with AAPI population.
* Also, working with Center of Multi-Cultural Health in Seattle regarding outreach with African American community regarding healthy/active living/brain health
* DOH is requesting help with general messaging for the public – pick prevention messages for the webpage and other campaigns
* Attendees voted on messaging around healthy living on diabetes, obesity, exercise, head injury, midlife hypertension, and smoking
 |
| 1. Increased Supports for Family Caregivers
 | Cathy Maccaul * The CARE Act helped push WA State to #1 in caregiver support. CARE is a state-based legislative act that AARP has helped advance caregiver support using the existing doctor/hospital infrastructure.
* We have 800,000 caregivers in Washington which amounts to billions of dollars in unpaid care. The population is aging and more care will be needed.
* AARP Caregiving Priorities
	+ CARE Act Implementation – consumers now have a legal right to designate a caregiver who can receive training on needs related to the care of that individual
	+ Workplace Flexibility
	+ Respite Care and Telehealth are also AARP Caregiving priorities
* Interventions and priorities AARP has been working on. There is a national conference in Chicago in November to learn more about this work. If attending, would ask your help in implementing
* Family Medical Leave – Washington State passed legislation this last session that provides up to 12 weeks at a time for sick leave to parents, caregivers, grandchildren, grandparents. Leave pay varies from $100 to $1,000

Susan Engels* Implemented new Medicaid waiver expansion supports for family caregivers this month. There has been quick uptake in this program.
* Family caregiver support program is being expanded. We had only been able to serve 1% of caregivers. The new program, part of a federal waiver (Medicaid) m is now available to individuals 55 and older across Washington. Individuals without a caregiver are now also eligible as well as those who didn’t qualify financially previously. New brochures are available – let Susan know if you would like some. Additional communication about the program is scheduled as part of Family Caregiver Month in November. Referals for this program should go to AAAs.
 |
| 1. Advocacy Planning
 | Bill Moss, Bob LeRoy, Maureen Linehan, Cathy Macaul* DSHS – this is a supplemental year to fix things that were a problem in the budget, not new policy-level requests. So would be hard for DAC to put anything forward now. But, we should participate in the process and could ask for requests for outreach dollars. Need to be clear on amounts needed and begin talking to legislators.

Bob LeRoy - Alzheimer’s Assoc * Plan to go forward with a request for modest amount of funding for agency staff to support the work of the DAC. Will add more specificity this year regarding what the staff might do and tie to specific programs/projects.
* Begin conversations with legislative champions on requests we might offer in the next budget-writing session
* Articulate our support of the JLEC

Maureen Linehan - Area Association on Aging* In October, advisory councils meet and discuss legislative agenda. The next day there is a lobbying meeting. Throughout the session, representatives will be lobbying in Olympia.

Cathy MacCaul - AARP* Started having conversations with legislators in September focused on proposing $20 increase in personal needs allowance in Social Security. WA is very low currently.
* Hearing aids – got included in senate budget last year, not House, but are including in a memo to the governor in a few weeks.
* Also working on senior property tax exemption. They received support from Washington State Association of Counties and Assessor’s office. Needs a constitutional amendment to do. Would like to raise maximum to $50,000.
* Create a long-term care trust act to help families who cannot afford long-term care. This likely will not pass, but it’s helpful to start the conversation and get information out there.

Representative Steve Tharinger* Our work is important and we need to keep up the momentum. Rep Tharinger will help to get our work in front of the House Health & Wellness committee and JLEC.
* Anticipates a fairer, less regressive tax plan that relies more on a gradated excise tax.
* JLEC will be looking at making guardianship easier, and at long term care services. Support is strong for the JLEC. Business plans with private partnerships are appealing to the legislature.
* Message for legislators best includes: the problem, we have solutions, what’s needed to support them
 |
| 1. Moving Forward – Priority actions 2017-2018
 | Tables discussed how the DAC is doingWorking well* Energy, passion and knowledge of members
* Lynne and ALTSA staff
* Dissemination of information
* Everyone is in synch and have a shared vision
* We have completed products – these will help us get funding, keeps us going internally too
* Structure of DAC
* Strong leadership and organization

Opportunities to improve* Get people from eastern WA involved
* More cross-subcommittee sharing
* More members – come up with a recruitment piece
* More champions
* More consistent participation
* Advocacy – create a new subcommittee?
* Overall marketing and comms plan for DAC
* Recognizing participation
 |
| 1. Public Comment
 | * Caroline Ham – Falls Prevention Specialist. Dementia is a significant fall-risk factor. Would like to get more involved with the DAC
 |
| 1. Wrap Up/Next Steps
 | * The meeting wrapped up with thank yous and the action items below
* Let Lynne know of any other suggestions
* A fact sheet will be available prior to this fall’s legislative session – will be sent to the group for input prior to distribution
 |
| **ACTION ITEMS** |
| **ACTION STEPS**  | **ASSIGNEE** | **DUE DATE** |
| Go to [Bree Collaborative/Alzheimers](http://www.breecollaborative.org/topic-areas/alzheimers/) and send feedback to Ginni Weir **GO TO** - <http://www.breecollaborative.org/topic-areas/alzheimers/>  | All DAC members | October 27, 2017 |
| Review Cognitive Screening Toolkit and provide suggestions to Kris Rhoads krhoads@uw.edu  | All DAC members | October 27, 2017 |
| Bree to add conversations about * Hearing loss into the document
* Include racial disparities,
* Include references to nurse practitioners in addition to physicians, and
* Some reference of younger onset
 | Kris Rhoads | October 27, 2017 |
| If you have not yet put a link to the Dementia Road Map on your organizational webpage, please do so. If you don’t have the link you can email Lynne.  | October 27, 2017 | October 27, 2017 |
| Please link to the Community Living Connections (CLC/AAA) website – this helps elevate the URL in future searches. Here’s the link – if you want the logo to place on your website for this, contact Lynne. <http://www.waclc.org/connect> | All DAC members | Nov 1, 2017 |
| If you know of state or local agency strategic plans that would benefit from having dementia included, please share these with Lynne/Cheryl | All DAC members | Nov 1, 2017 |
| Please let Lynne if there’s any information needed  | Advocacy Committee – * Bob LeRoy
* Cathy MacCaul
* Cathy Knight
 | October 15, 2017 |