

**Texas Council for Alzheimer’s Disease and Related Disorders
Workgroup Meeting – January 14, 2021
1:00pm**

Meeting Notes

Attendees	
Eddie Patton, Jr.	Sudha Seshadri
Byron Cordes	Michael Gayle
Marc Diamond	Lynda Taylor

The purpose of the workgroup meeting was to discuss and create a list of possible actions for the Texas Council on Alzheimer’s Disease and Related Disorders (Council) to consider regarding Alzheimer’s disease and other dementias. There was no quorum, and the workgroup did not vote on any matter. The workgroup engaged in an informal discussion about various topics of interest. Notes were captured during the call and then shared with the Council to solicit additional feedback.

Workgroup-Generated Questions

- The leading question: What resources are available to the Council?
- What can the Council do with the resources available?
- What resources can the Council ask for in biennial reports?
- When suggesting various Council activities, what obstacles or concerns might arise with certain topics (e.g. brain donation)?
- The Council cannot lobby the Texas legislature, but what are ways the Council can highlight specific needs?
- What are the best ways to use the Council’s biennial report to craft robust recommendations and describe activities to pursue?
- How can the Council and DSHS work with partners or stakeholders that may have different goals?

Themes for Action

The following themes were captured during the discussion:

- **Research Translation**
 - Enhance scientific goals and advance understanding of scientific ideas.
 - Work more closely with the Texas Alzheimer’s Research and Care Consortium (TARCC) on issues of care.
- **Education**
 - Develop educational materials on many topics. Examples: clinical trial registration, brain donation, explaining the science of Alzheimer’s,

aging at home, getting a diagnosis, what resources are available to the public and professionals, hypertension best practices, aging at home.

- **Policy**

- There has been movement on Alzheimer's funding on the federal level, but state funding has not increased.
- Medical leave. State enhancement of what happens federally.
- Navigating uninsured and underinsured populations.

- **Caregiving**

- Addressing the concerns of caregivers at all stages.
- Helping people with a diagnosis and their family caregivers know what to do at all stages. Examples: difficulty getting the care they need; diagnosis; then the attention they need over time – both patient and caregiver; family medical leave; things they haven't thought about or don't know to ask. Highlight any related state-sponsored programs.

- **Partnership and Collaboration**

- Additional ways to use the influence of the Council Texas-wide to address the things we think need to be done. Expand the Texas footprint.
- Partnering with other organizations: Goals of various organizations may differ.

Proposed Initial Activities

- **Online resource center**

- Because providing education and information about resources is a great need, and an activity that can begin now, the idea of an online resource center was proposed for people diagnosed with Alzheimer's, their caregivers and professionals.
- The online resource center could be guided by these questions:
 - What do people diagnosed with Alzheimer's and their family caregivers need the most? And at what stages?
 - What is the big picture – how do I handle this? What is the easiest way to provide this information to them, especially when first diagnosed?
 - What is the spectrum of care for Alzheimer's and other dementias?
 - What do healthcare professionals need to know to help their patients?
- The resource center would not be a duplication of materials provided by existing community associations and programs. Rather, the information would address topics seldomly found in other resources (or are not easy to find) and would address specific aspects of finding

information in Texas. Referrals to other organizations would be offered as appropriate.

- The DSHS Alzheimer's Disease Program website (<https://www.dshs.texas.gov/alzheimers/default.aspx>) can be enhanced to serve as a more robust online resource or starting place for people with dementia, their caregivers and professionals.
- The Council must use the existing DSHS webpage design and layout, but the current layout does support the creation of 'portals' for various audiences to contain information and resources specific to them.
- This activity would allow Council members to research and write about topics of interest in collaboration with DSHS staff to include in the online resource.
- All materials must go through DSHS review and editing, and also must adhere to DSHS best practices. This includes writing in plain language and fully citing information.
- Note that the DSHS Alzheimer's Disease Program does not currently have the staff capacity to serve as a helpline for Alzheimer's or create a comprehensive warehouse of all resources throughout Texas.
- **Collaboration with TARCC**
 - Working with TARCC may be a possibility as they may have more flexibility with their web pages to house resource information for caregivers and physicians as part of an online resource center connected to the DSHS Alzheimer's Disease Program website.
 - Work with TARCC to research certain topics and provide suggestions. There is a need to implement research. Qualitative.
 - Understand the reasons for poor outcomes.
- **Additional areas to explore:**
 - Working with Area Agencies and Agency (AAA) and Aging and Disability Resource Centers (ADRCs). Because these entities already provide information directly to the aging populations in Texas by phone and online, the Council with DSHS can explore ways to work with them.
 - Work with companies focused on aging services and healthcare professionals to learn what people are asking for the most.
 - For the future, look at ways to address other topics that may require resources not currently available. Ideas can be turned into written topics on the website or small group efforts of some kind. Or turn the ideas into powerful recommendations for the biennial report.

Additional Considerations

- The Council has the authority to make recommendations in its biennial report, including recommendations regarding the Council's needs.
- The Council's biennial report is the Council's opportunity to let decision makers know what they think is needed regarding Alzheimer's and other dementias in Texas and for what outcomes. In the biennial report, the Council can name specific agencies and programs they think can be involved in suggested activities and recommendations, however, DSHS and other state agencies and programs are not required to follow the recommendations. But the recommendations can plant the seed for further exploration. The Council can work with DSHS staff to reach out to the Health and Human Services Commission on collaborative activities.
- Current DSHS staff capacity can assist the Council administratively but cannot oversee major projects.
- Even with a lack of funding and staff, there is an expectation that the Council will address in some way the duties listed in statute. The Council can address some of these duties in statute through recommendations in the biennial report and by activities such as the proposed resource center activity mentioned below.

Post-Meeting Feedback

Meeting notes were shared with Council members to solicit additional feedback:

- The Council can and should request funding for additional DSHS staff in the biennial reports; however, the Council can work on certain activities now and should not wait for funding for additional staff. (Dr. Mary Quiceno)
- The Council needs adequate time to work on the recommendations for the next biennial report. Work should start now and a subcommittee may be needed. (Dr. Mary Quiceno)
- Dr. Diamond followed up with TARCC about adding care resources to the website. As a first pass, TARCC suggested the following resources for consideration for different ways to provide information (posted for informational purposes only, and does not reflect any endorsement by TARCC):
 - DSHS Alzheimer's Disease Program:
dshs.texas.gov/Alzheimers
 - Alzheimer's Association:
https://www.alz.org/local_resources/find_your_local_chapter
 - Alzheimer's Texas:
https://www.txalz.org/research/#alz_advocacy
 - UsAgainstAlzheimer's Facebook Support Group:

- <https://www.facebook.com/groups/usagainstalz>
- UsAgainstAlzheimer's A-LIST
<https://www.usagainstalzheimers.org/networks/A-LIST>
- Aging Life Care Association
https://www.aginglifecare.org/ALCA/Regional_Chapters/South_Central_Chapter/ALCA/Regional_Chapters/South_Central_Chapter/South_Central_Chapter_Home_Page.aspx
- Caregiver Action Network
<https://caregiveraction.org/family-caregiver-toolbox>
- AARP Family Caregiving
<https://www.aarp.org/caregiving/>
- National Alliance for Caregiving
<https://www.caregiving.org/resources/general-caregiving/>
- PsychArmor
<https://psycharmor.org/caregiver-binder/>
- Help for Alzheimer's Families
<https://www.helpforalzheimersfamilies.com/get-help/dementia-care-services/>
- Being Patient
<https://www.beingpatient.com>
- healthline
<https://www.healthline.com/health/state-of-alzheimers#cost-of-alzheimer's---caregiver-health>