

**Texas Council for Alzheimer's Disease and Related Disorders
Activities Work Group Conference Call Meeting – September 3, 2021
9:00am**

Meeting Notes

Attendees:

Eddie Patton, Jr.
Byron Cordes
Sudha Seshadri
Michael Gayle
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 will be shared with the Council to solicit additional feedback.

Themes for Action

The following themes were captured during the discussion:

- **Help people newly diagnosed and their caregivers – Tell the story of the "patient journey"**
 - Because providing education and information about what to do after receiving a diagnosis of dementia is a great need, the idea for an educational video about what to do was proposed for people diagnosed with Alzheimer's and for their caregivers.
 - The video would also serve as education for physicians to know what families need.
 - Emphasize to the audience that there are things they can do.
- **Impact of social isolation on people with dementia and their caregivers**
 - Address the need to provide information to family caregivers who provide support to a loved one with dementia remotely during the COVID pandemic as well as families who provide care from a distance at any time.

Proposed Initial Activities

- **Educational video about the “patient journey”**
 - Propose to the Council that they explore the possibility of creating an educational video.
 - The video could be guided by questions such as the following:
 - 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 they handle the situation?
 - What is the easiest way to provide this information to them, especially when first diagnosed?
 - What do healthcare professionals need to know to help their patients?
 - Explore partnership and/or funding possibilities to create the video.
 - Explore working with the Texas Alzheimer’s Research and Care Consortium (TARCC) and its research institutions.

- **Issue brief on the impact of social isolation for people with dementia and their caregivers regarding the COVID pandemic and general caregiving at a distance**
 - Propose to the Council that they address this topic in the format of an issue brief.
 - This format would make it easier for Council members to research and write about social isolation and work with Department of State Health Services (DSHS) staff to include in the program website.
 - All materials must go through DSHS review and editing and must also adhere to DSHS communication guidelines. This includes writing in plain language and fully citing information. The process can take several months.
 - The work group will begin researching source material and provide an update at the next Council meeting.

END OF NOTES

Include any new ideas below: