## Stakeholder Advisory Council Meeting Agenda August 13, 2019 Academic Learning and Teaching Center, room 2.206

1. **Mike Foster, Co-Chair - Stakeholder Advisory Council**
2. **Updates and Announcements**
   1. Alzheimer’s Association Walk (Janet & Bill)
      1. Caring for the Caregiver Team <http://act.alz.org/site/TR?fr_id=12431&pg=personal&px=10982768>
      2. Dementia Friendly at airport (Bill)
      3. Other updates?
3. **Online Community:** [**utcaregivers.org**](file:///C:\Users\valenzuelaba\AppData\Local\Microsoft\Windows\INetCache\Content.Outlook\FWALA3TW\utcaregivers.org) 
   1. Create your accounts and profiles
   2. Pass out flyers to get others to join
4. **Review & Discuss** ***Core principles for involving people with dementia in research***
5. **Share contact info and birthdays with the group**
6. **Next meeting September 10, 2019**

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**Attendance:**

Sheran Rivette James Buttler

Ginny Funk Bryon Cordes

Mike Foster Sara Masoud

Kiki Foster Carole White

Carol White Claudia Valenzuela-Baird

Debbie James

Sara welcome Mike as chair of the board, and Sheran express her gratitude for his acceptance of the position.

Dr. White talked about conference in Austin, specially on the topic on how to bring compassion to the work that we do and how we treat each other.

Giny Funk mentioned some new dementia practices and recommendations for any professionals, clinical and administrative which are being review by an audience.

Dr. White mentioned how important is palliative care, how this type of care is supporting living well for the patience and how we must involve them in the process.

Giny funk: Update on Walk. The fist Walk will be in September in Corpus TX and everyone is invited to participate. Not necessary to register but encourage to do the fundraising in order to meet the goals.

Kiki mentioned the visit of Major Nirenberg to the Meadows and how she was trying to get in contact with his people to have it participate in the choir right after the event. She was awaiting for confirmation.

Sara demonstrated how easy is to create an account on the community online page. She walked thru it step by step using Debbie James as example. It was discuss adding options such as: Type of person

on a drop list.

Giny Funk. Shared there was not going to be support groups this week. Only Tuesday -Family support group.

It was proposed to have the Alzheimer’s support groups participate on the discussion of the online community by bringing the questions to them and post them in the community site. This way can be test it in a small group and work from them the items that need to be improve.

Discussion on the paper “Core principles for involving people with dementia in research”

Moderated by Sara and Mike

1. I never heard what happened.

Person living with dementia wants to be heard. Keep him/her involved and more active participant of the care process.

Have more researchers come and share their findings once they complete their research., provide them with findings no matter what the outcome is, since they want to be part of the whole process. PLWD wants their family members and caregivers involved in the findings as well as their own communities.

Giny Funk mentioned “We want to be a factor not as an object” James mentioned.

Conveying respect to individuals and the value to research as well the importance for the PLWD to be involved in process from start to finish.

Sara share about how people in research do not always share the findings and does not necessary share all the information when they do share it. James agreed.

Kiki mentions when a family caregiver is involved in the process, they feel validated and important part of the research, which Dr. White thinks is a must in all research to include the caregivers.

1. Knowledge comes from all sorts of places.

Information comes from many places. People living with dementia is something they can not turn off is there all time. The researchers usually have all these questions for them, and they expect the answer but never consider discussing the importance of their research goals as they align with the everyday of the PLWD. Their goals might not be what it’s important to the them and their caregivers. They want more meaningful research and therefore the answers and findings will be more relevant to all. It’s about creating partnerships. Researcher --PLWD

Mike mentions that the first goal should be to find the cure.

Dr. White would like to have the 10 questions on web and submit them to the online community to help prioritize them and create a discussion.

1. We need to be in a safe and secure environment

When participating in research the space always should be safe and secure. Participants need to be emotional and physically safe. Times and places are most important with a PLWD due to the changes they go thru during the day. Finding the appropriate time frames will assure a better and more focus response form them. Researchers also must take in consideration the different learning abilities and experiences of the participants and be respectful of the them, by designing more meaningful care questions. Researchers need to create empathy and safe environment for the PLWD when conducting their investigation, Giny said.

1. Keep it simple…. Less is best

PLWD needs to be able to understand the information giving to them. It must be simple and when talking not them they need to remember to talk slow, Mike said.

Sara .The use of acronyms and other abbreviations should be discourage , because not every one understand or know their meaning. Documents should be easy to ready and in a language that PLWD can understand. Keep it simple.

Supporting and sharing in a common language the information will be more applicable to all, Dr. White said.

1. Why should anyone be let loose, who hasn’t had the training…

People involve in research must be compassionate and be dementia aware. All the word mentioned on the article are very important and resonate with members of the board. Giny . Basic human respect must be offer not only to the PLWD but all people in the medical field.

1. Keep to “dementia time”

Be aware of the limitations of PLWD and take breaks and accept when the participant is tired and recognized it’s time to end or pause the conversation so the PLWD can renovate and get their minds a break. Time is value for both parties and should be respected.

Debbie James invite everyone in the board to exercise these principals.

Announcements:

Dr. White invited everyone to assist her on the paper she is presenting for the new grant and will share her paper for everyone to review and make suggestions.

Kiki share the Oasis catalog has more dementia offerings now.

Giny. Aug 20,2019 3-7 pm VDT at Arden Courts by the Alzheimer’s Association

Sheran. Santikos is offering special sensitivity-cinema movies at some of their theaters.