



What Am I Forgetting? Experiences with Alzheimer's and Memory Loss Thursday, May 26, 2022



<https://youtu.be/inqlx5Ve--k>

Chat Notes

Presenters:

- **Lisa Albrecht**, 1951 – Contact: lisaalbrechtsocialjustice.com or lalbrech@umn.edu
- **Elda Dawber**, 1944, and **Mariellen Langworthy**, 1943

For those who asked about the books written by Elda and Mariellen
Elda Dawber:

- *Wait Until I'm Dead, A Novel of Family Secrets*
- *The Weirdest Saturday Ever*
- *Nana and the Hungry Whistle-Pig*

Mariellen Langworthy:

- *All the Way Home*
- *Soul Sister*

All available on Amazon. Hint: Use the Amazon Smile account for OLOC!
[<https://smile.amazon.com/ch/76-0393649>]

These are general comments placed in the Chat during the Zoom presentation.

What is the difference between Alzheimer's and other forms of dementia?

There are over 90 kinds of dementia; all are different. There's no treatment (for Alzheimer's) that's found to be effective (so far)—lots of studies but nothing definitive. At this point, the available drugs don't cure; they just slow the progression (and there really isn't a good way to know if a drug is slowing down the progression).

Supports from other Lesbians:

- Check in with each other. Ask how she (and partner) are doing.
- Know how and where people are; be present where they are
- Find your helpers, people you trust
- (Comment by Lisa about her community): We're in it together ... support each other ... great Lesbian community, support from Lesbian friends. I have a sense of security to know someone is looking out for me.
- Talk to the person with Alzheimer's; don't talk to partner or person with her [instead]. She (woman with Alzheimer's) is still here.
- When giving instructions or asking us to do something, give one thing at a time, not too much information at once (can't process it).
- Connections with each other are very helpful.

Concerns:

- Will my kids/relatives, etc. take care of me? An unknown.
- Who will take care of me? I have some plans but don't always know and I want to have control of my life.
- Death with dignity: it's a struggle, especially for people with Alzheimer's. Generally, you need to have terminal diagnosis and [be] expected to die within six months.

Tips (general):

- Asking for help is a good thing, not really a weakness. As we get older need to learn we can't do it all. Do what we can.
- You have to have humor. Maintain a sense of humor. Humor saves our lives.
- The more engaged you are in learning new things and doing things, the better chance you have of "staying" longer.
- Ask us questions. We're not silent about this.
- And never be silent in the face of injustice.
- Questions are more important than answers. Don't be afraid to ask.
- If you have a diagnosis, see if you qualify for a research study in your area.
- Alzheimer's Association: find the one in your state. They may have helpful resources and supports, though experiences differ state to state.
- Find a caregivers support group if you are caring for someone. Important for you to have support as well.

Reflections:

- It's dreadful to watch someone you know and love not remember and not be the person they want to be and were.
- (Comment by Lisa): My pandemic humor about my partner, Pat: She has no pandemic stress because she doesn't know what's going on around her. Sometimes I wish I didn't know what.
- There is no template for Alzheimer's.
- People freak when you say you have memory loss.
- Sad and afraid of the future. Doesn't mean we can't do it.
- We're still being activists in [our] current situation.
- Lisa: I'm connected to an elder LGBTQ community in Minneapolis/St. Paul, Minnesota
- The longer we live, the more likely we are to have some memory loss.
- There's no shame in not remembering.
- Has *Lesbian Connection* ever done a whole issue on elders? And talking about dementia? That would be cool.
- You don't die from Alzheimer's or Dementia; you die from other health complications.
- We need more geriatric doctors.
- Issues of racism, sexism, homophobia still exist among providers.

Resources

These were suggested by participants and are therefore not necessarily endorsed by OLOC or the presenters.

Aging with Pride (<https://ageidea.org/>) All panelists are currently participating in this program. Aging with Pride: IDEA is the first federally-funded project testing a program designed to improve quality of life for LGBTQ people who experience memory loss or who help those experiencing memory loss. Participants are compensated for their time and can live anywhere in the US.

Caring Across Generations (CAG - <https://caringacross.org/>) is a national program and I (Lisa) was in a Zoom cohort with some fabulous people. It's not queer but it was wonderful. You'd want to email Aisha Adkins.

Death with Dignity Resources

Final Exit (<https://finalexitnetwork.org/>) provides information and methods to make your own choices, including if you're diagnosed with dementia, if you make your decision and act while you're competent to make a decision.

Compassion and Choices (<https://www.compassionandchoices.org/>) is the organization that is getting this done and they do have help for dementia and consultants. Their website is phenomenal.