

At the 11/21/24 meeting, the workgroup gathered to discuss and finalize these edits to the caregiver toolkit. Jacob and Madelyn will work on creating a document with these edits and share with OSDH communications so they can begin work on creating the final product.

OHBI Caregiver Toolkit Edits

Please use this document to record your suggestions for edits and additions to the OHBI Caregiver Toolkit adapted from the Alzheimer's Association Greater Missouri Chapter's Basic Dementia Care guide shared with you via email on 7/18/24.

We will use this document to work collaboratively on improving this document and tailoring it to Oklahoma. For clarity, when suggesting edits/additions, **please list your name, the section heading and page number where you would like to make the edit/add content, and the information you would like to change or add.** For example, if I wanted to add a section about driving safety, my note on this document would look something like this:

EXAMPLE

Jacob Guinan

After "Wandering and Pacing"

Page 18

What would you all think about adding a section on retiring from driving? We could provide resources for making a plan around driving cessation and tips for families to help their loved one maintain their independence and ensure safety while preserving the dignity of the person living with dementia.

Thank you all for your help with this project! Please add your notes on edits and additional information for the toolkit below:

Jacob Guinan

Overall recommendations

1. Change all images. These stock images belong to the Alzheimer's Association. Use images that reflect our state's diverse population.
2. The document generally uses "him or her", "he or she", and "himself or herself" and in a few places just uses either masculine or feminine pronouns. For inclusivity and clarity, I think it would be good to use gender-neutral language such as "they, them, themselves" or "the person/the person living with dementia (PLWD)".
3. Change the text font, that one is specific to the association

Jacob Guinan

"What is dementia"

Page 5

Technically no such thing as "reversible dementia". Reword for accuracy,"Just because a person has dementia-like symptoms..." "many things can cause dementia-like symptoms..."

Jacob Guinan

"What is dementia"

Page 5

Need to update statistics

Jacob Guinan

“What is dementia”

Page 6

Might want to remove section that says Alzheimer’s can only be confirmed with an autopsy. This may not be true much longer

Jacob Guinan

“Other types of dementia”

Page 6

Change explanations for vascular and Dementia with Lewy Bodies. Don’t need to MID next to vascular, and don’t need the extra explanation on Lewy Body dementia, since the rest don’t have one. We could provide stats on each type, like Alzheimer’s 60-80%, Vascular 20% and so on. Could also provide a brief explanation of each type. It should be consistent.

JG

“Stages of Alz”

Page 7

Let’s swap the brain image here with the one our coms department made for the UAD factsheet

Jacob Guinan

“Early Stage”

Page 8

Instead of “contact the Alzheimer’s association early and often” make it “reach out for support” or something more general.

Jacob Guinan

“Ideas for Everyday Routines: Afternoon Activities”

Page 16

Does the coffee or tea really need to be caffeine free? Probably only really important if the person is experiencing incontinence or sleep issues.

Jacob Guinan

“Common Behaviors: Wandering and Pacing”

Page 18

Remove bullet point talking about the AA Medic Alert + Safe Return program, this has been discontinued. Make general recommendations for GPS tracking tech/ Medic Alert accessories Also add disguising door, black place mats. Add info about modern small GPS tracking devices.

Jacob Guinan

“Common Behaviors: Social Inappropriateness”

Page 19

The last bullet point mentions companion cards to explain to people in public that the person with you has dementia. What if the next page is cardstock and is a page full of business card sized companion cards printed that the caregiver can cut out?

Jacob Guinan

Should we also add a section with information for the PLWD? Things like national council of dementia minds, early stage social engagement and support groups

Jacob Guinan

Should we add a section about risk reduction? Or is that not relevant for this audience?

Jacob Guinan

Should we add the "notes to take to the doctor" handout to the care notes section?

Linda Thompson

On the cover page, replace the Alzheimer's logo with the OBHI logo.

On the back cover, put the phone numbers for the Oklahoma Alzheimer' Association offices.

Page 3 - should we add information about OBHI in the section with acknowledgements?

Page 6 - could we include a section about prevention? The toolkit states that Alzheimer's cannot be prevented. This is true to a degree, but there are a lot of strategies that can decrease risk or delay onset - like exercising, maintaining a healthy weight, having good social interactions, etc.