

# Continuum

## End-of-Life Stories



### Participation Consent

Gathering and sharing personal stories from end-of-life (EOL) home caregivers creates space for conversations around death and dying, recognizing the difficult work of caregivers, and de-stigmatizing end-of-life issues. Being with someone when they are at the end of their life requires caring, special attention and skill. But end-of-life caregivers often go unseen and unheard. This project seeks to change that, inviting you to share your story as an EOL caregiver.

#### Your participation in this project will help us reach our goals to:

1. Encourage conversations with EOL caregivers.
2. Amplify and make more accessible EOL caregivers' stories in order to make visible and honor EOL care.
3. Highlight cultural traditions of EOL care.
4. Shed new light on EOL caregiving in the time of pandemic.
5. Offer dignity and respect to the work of EOL caregivers.

### CONSENT

I am aware that my participation in this interview is voluntary.

I received an explanation about the intent and purpose of this interview/project.

I am supportive of the values of this project in our community.

If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.

I am aware that the story/info collected through this interview will be used in a project by the Southwest Folklife Alliance to share with others on its web site and via *BorderLore*, its online journal, in an End-of-Life exhibit at the Arizona State Museum, and in other educational settings.

I grant permission for my interview/story to be used in the public ways stated above by Southwest Folklife Alliance.

I have the right to withdraw information or data collected from me at my request at any time.

I have the right to remain anonymous if I choose and my interview is selected by SFA to share for educational purposes.

If I have any questions about this study, I am free to contact SFA staff (520) 621-4046 for more information.

I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today's interview.

\_\_\_\_\_  
Caregiver's Name

\_\_\_\_\_  
Caregiver's Signature

\_\_\_\_\_  
Date