



# DEVELOPING A CULTURALLY RESPONSIVE DEMENTIA STORYBOOK FOR NATIVE HAWAIIAN YOUTH

## TAILORING STRATEGIES

### For Native Hawaiians

- Used Hawaiian names: Pomai, Papa, Auntie Pua
- Used Hawaiian words: hali'a (fond memory), kupuna (grandparent), mo'opuna (grandchildren)
- Demonstrated Hawaiian values: Respect for elders, multigenerational family focus

### For 'ōpio (young people)

- Used comic book format; pictures with dialogue and narrative text
- Added links to web-based resources e.g., YouTube, Instagram

### Best Practices

- Reviewed literature
- Checked with dementia experts
- Reviewed content with key informants
- Held focus groups with youth
- Revisited revisions with community

To download your free copy go to [manoa.hawaii.edu/Pomai-and-Her-Papa](http://manoa.hawaii.edu/Pomai-and-Her-Papa)

Native Hawaiian 'ohana (families) provide the bulk of care to their aged parents, including those with dementia. Native Hawaiian youth are more likely to live with grandparents, including those with dementia, because they are more likely to live in multi-generational families than youth of other ethnic groups in Hawai'i. Limited research has focused on the needs of youth caregivers who are largely invisible to the eldercare service network. This knowledge gap is especially critical for Native Hawaiians due to their heightened risk for chronic diseases associated with dementia.

To address this gap, we developed a culturally responsive storybook for Native Hawaiian 'ōpio (youth) using plain language and scenarios relatable to a Hawai'i audience. The book includes frequently asked questions, links to web-based resources, and a crossword puzzle to guide readers to key lessons.

The story introduces Pomai as she navigates troubling changes she is noticing in her Papa (grandfather). Pomai is not sure how to help and is struggling at school. With the help of supportive adults, Papa is diagnosed with Alzheimers disease and Pomai learns age-appropriate ways for her to contribute to Papa's care.

The story opens with hali'a, fond memories of good times together. It was important to show Papa before the onset of dementia. HALI'A is used as a mnemonic throughout the book to help readers recognize dementia-related memory loss and how it differs from normal aging.

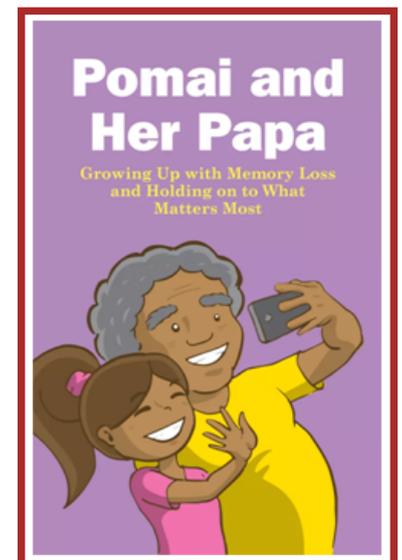


Figure 1: Cover page of Pomai and Her Papa storybook

# Community-engaged Methods

## Literature Review

With students from the Thompson School of Social Work and Public Health, we conducted a literature review on evidence-based, dementia-education models for youth.

## Subject Area Expert Interviews

Experts knowledgeable of dementia and community services were interviewed about educational needs of youth on dementia.

## Native Hawaiian Youth Discussions

Four groups of young people residing in the Papakōlea community participated in discussion meetings on developing this resource.

## User Survey

We continue to gather feedback from readers on how they've used the resource to help us in refining the storybook further.

## Findings

- Youth were familiar with dementia, but knew little about the disease, its progression, or ways to help.
- Youth voiced interest in an educational comic book featuring local people, places, and words.
- Youth wanted links to web-based and social media resources
- Experts recommended distinguishing dementia from normal aging and stressed the importance of being realistic about disease progression
- Experts also felt the storybook should identify things youth and kūpuna can do together, despite a dementia diagnosis

**H Hard to remember** names, events, basic information, and finding things

**A At- risk** of wandering and other unsafe behaviors.

**L Loses judgment**, has harder time problem-solving.

**I Increasing difficulty** remembering words, writing, and speaking.

**'A 'Ano (a person's basic nature, personality) changes.** With these changes can come confusion, frustration, anger, impatience, and other feelings.

Figure 2: HALI'A mnemonic to help remember signs of dementia-related changes

## Implications

Using community-engaged methods, Hā Kūpuna reflected the needs and strengths of Native Hawaiians in ways that they could feel good about. We compiled reliable research on dementia prevalence and risk factors, evidence-based care models, and paid specific attention to the resilience of family caregivers. People of all ages benefitted from the storybook, which readers described as "easy to understand". Youth learned new ways to interact and help with an elder with dementia, and families sought out new education and supports for young carers. Findings to-date highlight the potential for culturally responsive services and indigenous-centered approaches in dementia care.