Pomai and Her Papa

Growing Up Around Memory Loss and Holding on to What Matters Most

Created by Hā Kūpuna National Research Center for Native Hawaiian Elders

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Resource Center for Native Hawaiian Elders

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This moʻolelo (story) of Pomai and her Papa is dedicated to kūpuna (elders, grandparents), moʻopuna (grandchildren), and ʻohana (families) everywhere. In your journey through the challenges of dementia, may you know that you are not alone.

Hali‘a

HALI‘A means fond or cherished memories. These can be of our favorite foods or of songs and stories that remind us of happy times with people we love.

Dementia is a disease that affects the brain. When someone has dementia, their personality may change, and they may not be able to remember many of their hali‘a (fond memories). **Dementia is not a part of normal aging.** Though there are many types of dementia, the most common type is Alzheimer’s disease.

We can use the letters in the word **HALI‘A** as a *mnemonic* (memory tool) to help us remember some ways to tell if a kupuna’s behavior is a normal part of getting older, or if they should visit a doctor to ask if they are being affected by dementia.

H: Hard to remember names, events, basic information. May lose track of days, dates, time of year. Hard time finding things.

A: At risk of wandering and other unsafe behaviors.

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

I: Increasing difficulty in remembering words when speaking or writing.

‘A: ‘Ano (a person’s basic nature, personality) changes. With these changes can come confusion, frustration, anger, and impatience that can be seen in facial expressions, voice, gestures, and behaviors.

We hope the story of Pomai and Papa's journey with dementia will help you know that you are not alone in navigating this challenge.

Aloha kākou,
I'm Pomai. I live with my mom, my dad, my cousin Ikaika and my Papa. Papa has lived with us my whole life and always looks out for me. He makes me feel special by doing small things like having my favorite fruits cut up and waiting for me when I get home from school.

HALIʻA - Fun Times Together

Papa and I have lots of happy memories together playing at the park, making poi, and swimming at the kahakai (beach)!

But lately, I've been worried because Papa hasn't been his usual fun self.

Papa, are you okay?

Papa has a **hard time remembering important things** like paying bills. He loses things more often. Papa used to love having fun. But now it seems his 'ano is changing — he loses his temper quickly. Even when we're in the same room, he doesn't seem to notice me. Papa seems like he's in his own world.

I miss the way Papa used to be and am worried about him.

What did I do to make him so unhappy? What's happening to my kind, fun Papa?

The word HALI‘A can help us understand what might be happening to Papa.

Hard to remember names, events, basic information

At risk of wandering and other unsafe behaviors

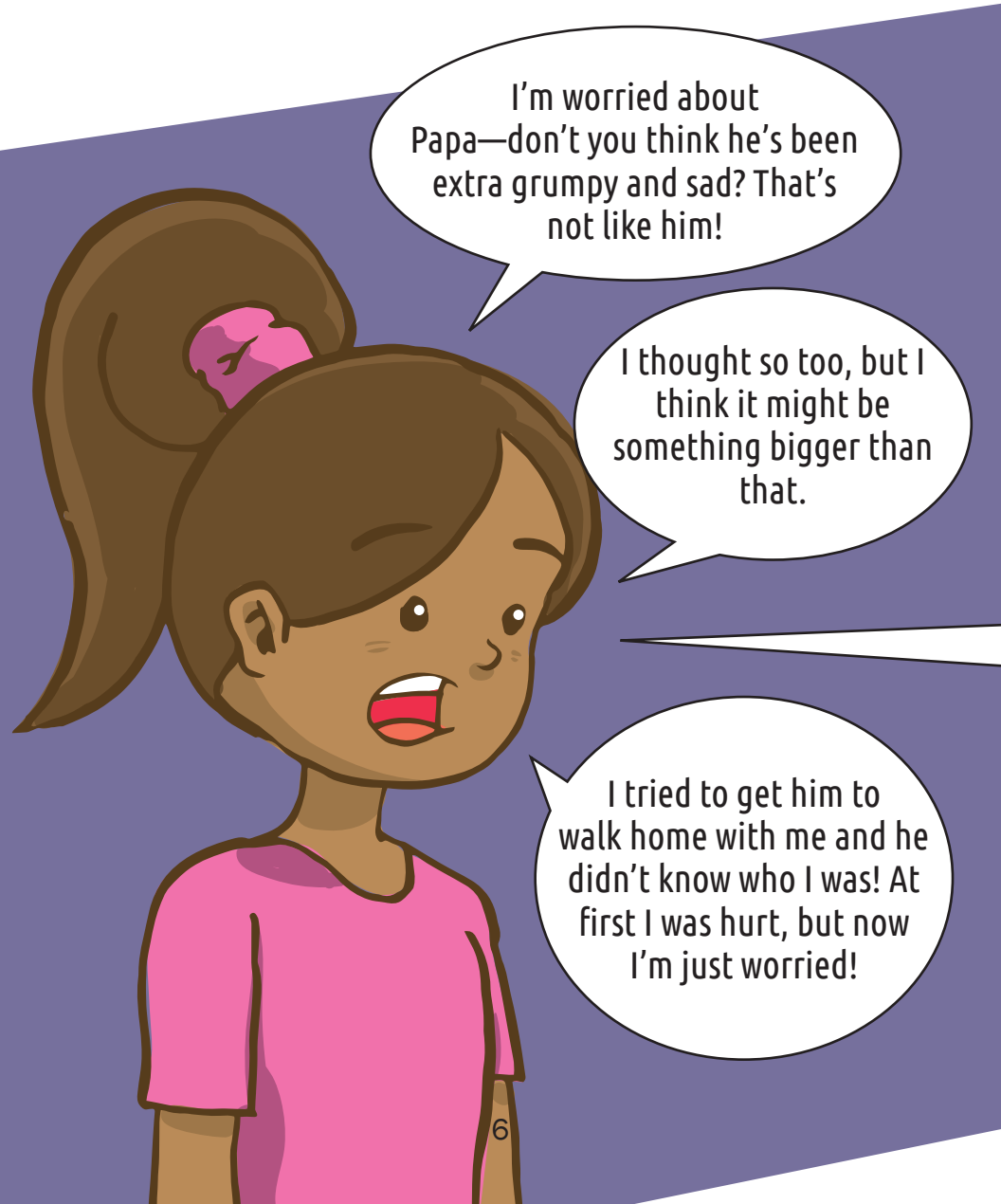
Loses judgment, has harder time problem-solving

Increasing difficulty in remembering words

‘Ano (a person’s personality) changes

Pomai Talks to Cousin Ikaika

Ikaika is my cousin and my best friend. He knows and loves Papa too.



Yeah, but he's probably just getting old.
The other day I saw him at the park, just sitting there alone, looking confused.
Whoa, that is kind of scary. I think we better tell your mom and dad.

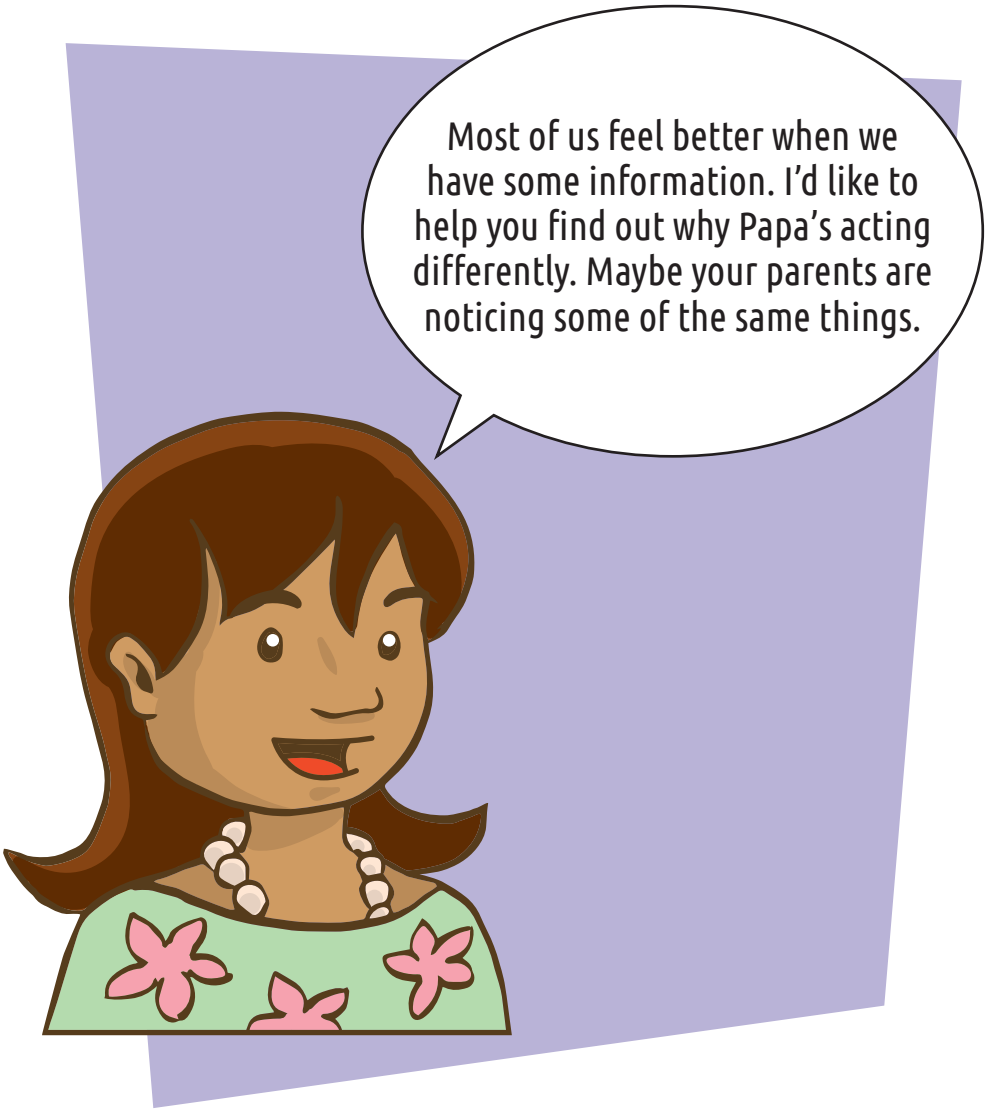
Pomai is Worried and Gets Support

Lately I can't stop thinking about Papa, even when I'm in class. Something seems wrong with him, but I can't figure out what it is. It feels like a dark cloud is hanging over me. One day, my teacher notices and asks me to stay after class. Uh-oh!

After class, my teacher asks me what's wrong. I have a hard time telling her what it is. At first I think I'm in trouble, but she is so kind and patient. She recommends I talk to the social worker at school for extra help.

Hi Pomai! I'm Ms. Parker, but you can call me Aunty Pua. I'm the social worker here at school. Tell me a little bit about what's going on with your Papa.
Papa doesn't talk much anymore, he just sits in his chair and stares at the wall. Sometimes he doesn't even recognize me.
I don't understand what's happening. I want to help him, but I don't know how.

Aunty Pua tells me that I shouldn't have to worry about Papa alone. She suggests we share my concerns with my parents to see if they've noticed the same changes in Papa. I'm so relieved!



Pomai's Family Gets Involved

Aunty Pua, the school social worker, meets with my parents. They've also been wondering if Papa's memory loss and odd behaviors are just normal changes that happen when people get older.

They've noticed he often asks the same question over and over again. They're concerned that Papa may get lost and are worried he may have Alzheimer's disease. They want to take him to the doctor but think that Papa may get angry at this suggestion. He's changed and doesn't seem like himself.

Aunty Pua uses HALI'A to teach our 'ohana (family) about behaviors that are not part of normal aging. She recommends that the family take Papa to his kauka (doctor) to find out what could be causing these changes. The doctor may refer him to a specialist, like a geriatrician or neurologist.

It's best to express caring with concern. HALI'A is a way we can identify possible symptoms of dementia that differ from normal aging.

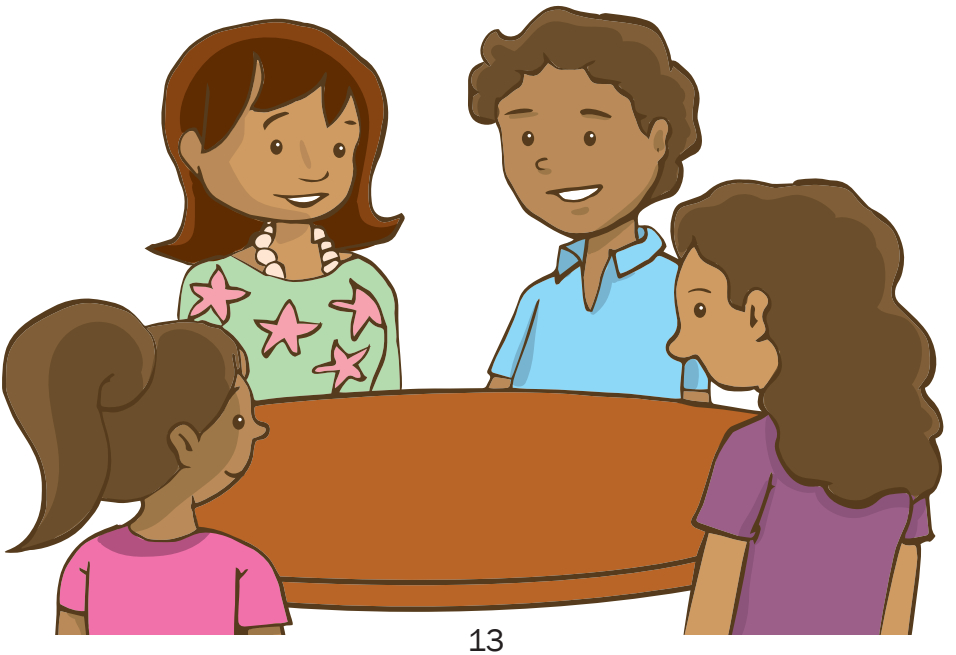
Hard to remember names, events, basic information

At risk of wandering and other unsafe behaviors

Loses judgment, has harder time problem-solving

Increasing difficulty in remembering words

'Ano (a person's personality) changes



Family Meeting

It feels better to talk openly and get our worries out on the table. For the sake of the family, Papa finally agrees to go to the doctor.

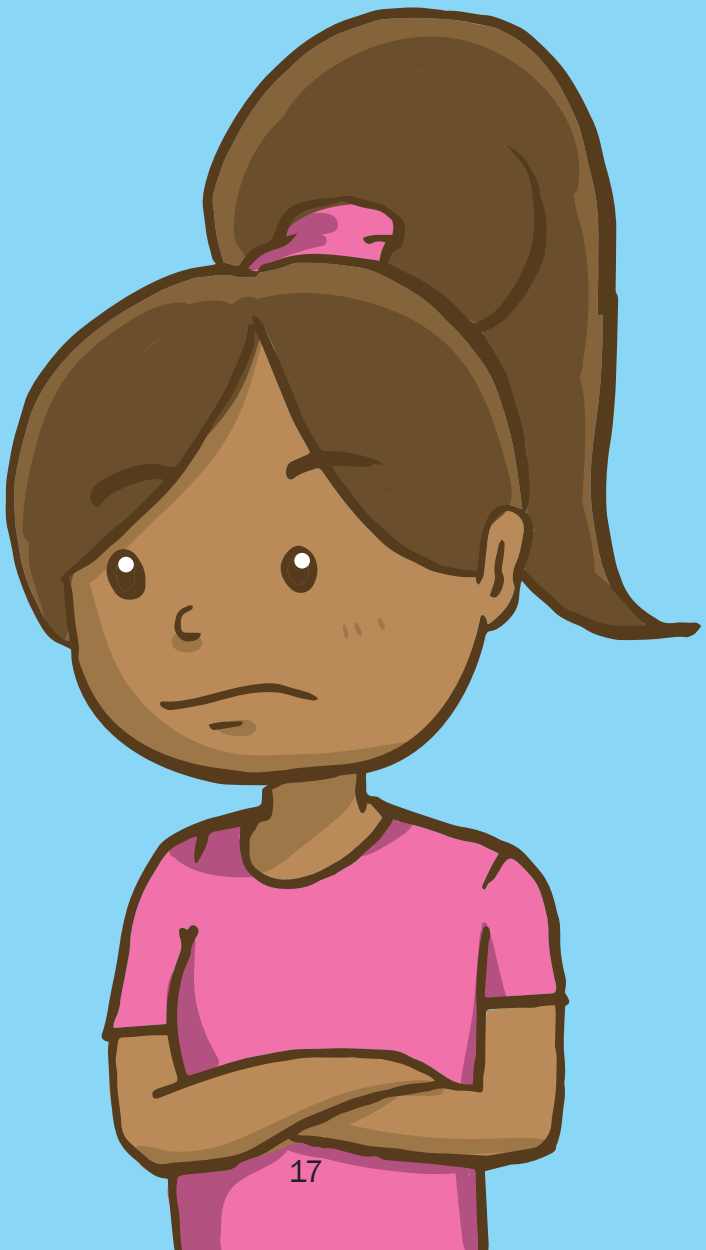
At the Doctor's Office

We take Papa to his kauka. We then see a geriatrician who specializes in care of elders and a neurologist who focuses on care for our brains. After about a month of tests and appointments, we learn that **Papa has Alzheimer's disease.**

The doctor recommends that we create a health plan with help from a social worker at a community organization that works with people living with Alzheimer's or other forms of dementia and their ʻohana.

We learn how Alzheimer's disease affects everyone in the family. We get helpful information and learn about other community services, including resources for kids like me. Together, we create a plan to help Papa with important things like taking his medicine and keeping him safe. I get to ask as many questions as I want and get a better understanding of what I can do to help Papa.

Seeking Answers to Common Questions



Pomai Learns More

The Alzheimer's Association has found that young people often have questions like these. You might too! You can read more at **alz.org/help-support/resources/kids-teens**

Will my mom and dad get Alzheimer's disease?

Will I?

Most people who get Alzheimer's are older—like Papa. Many scientists believe that there's a greater chance of getting the disease if someone in your family has it, but not everyone who is related will get it. You can't catch Alzheimer's like you can catch a cold or flu.

What is Alzheimer's disease?

Alzheimer's is a disease that affects how the brain works and how a person thinks and acts.

Can Alzheimer's disease be prevented?

Scientists continue to study how to prevent Alzheimer's. Taking care of our hearts, exercising, eating healthy, taking care of our teeth and gums, getting together with friends, and doing brain games may help. Preventing head injuries by wearing helmets and seatbelts is important too. It's never too late or too early to start!

Why does Papa call me by someone else's name?

Why does he ask me the same questions?

Papa's brain may be changing in ways that make it hard for him to remember names or even what you just told him.

Be patient and know that this is not your fault or his. Even if Papa is sometimes confused, he can still feel your kindness.

Can Papa get better or will he get worse?

Will Papa die from Alzheimer's?

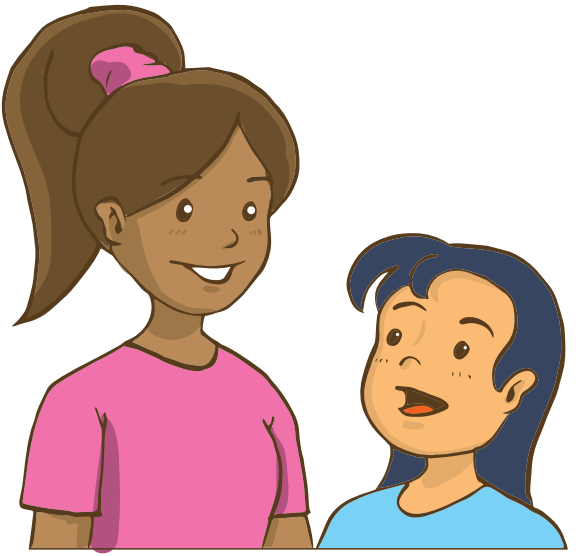
Alzheimer's is progressive, which means it gets worse over time. Sadly, there's no cure yet and Papa's symptoms will get worse. Right now we don't know for sure what will cause his death — it could be Alzheimer's disease or another serious health condition.

Is there anything I can do?

Yes! You can do many of the things you've done with Papa in the past. You told me that you and Papa like to watch football, play music, and walk at the beach. You can still do all these things together.

Pomai in High School

As I've gotten older, so has Papa. His memory continues to fade, but now I feel less scared about what is happening and more prepared to help. Papa has good days and bad days. Sometimes he gets mad over small things, but now I know that it's not his fault or mine either! I've learned that there's no shame in asking for help when I need a break or just someone to talk to.



Today I'm a peer educator. I teach other kids and teens how to help someone with dementia. Here are some lessons and resources that have helped me with Papa. I hope they'll help you too!

Normal changes that may happen as you grow older

Makes a bad decision once in awhile
Gets busy and forgets to pay a bill
Forgets the date or day of the week, but later remembers
Sometimes forgets what word to use
Loses things from time to time, but is able to retrace steps to find them
Becomes frustrated when a regular routine is changed

Signs of possible Alzheimer's disease-related changes

Has a harder time making good decisions—may cross busy streets without looking, wants to give money to strangers and may be cheated
Cannot remember how to pay bills or even what bills are
Loses track of the season or year
Cannot seem to find the right words, and has a hard time talking, reading, or writing
Misplaces things and is unable to retrace steps to find them
Major changes in 'ano that cannot be easily explained; feelings may seem over the top, out of proportion

Resources

Mahalo for taking time to learn more about my life with Papa. On the next few pages, check out some activities to help you remember what we talked about and resources to learn more!

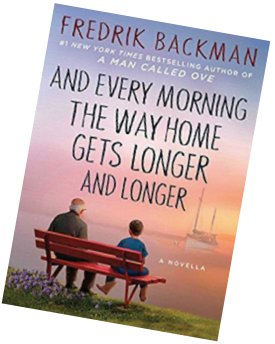
Dementia is tough for any ‘ohana to face. But by supporting each other through taking turns and sharing the new responsibilities, we can keep Papa safe and keep our aloha for each other strong.

There are many things I can still do with Papa. Having fun lifts everyone's spirits! Some days, he'd rather watch than join in, and that's ok too!

- Take a walk together
- Garden or do yardwork
- Kanikapila! Sing, play, or listen to music
- Watch TV or a movie
- Read to each other
- Look at old photos
- Play with a favorite pet
- Cook or bake a simple recipe
- Play a board game or cards

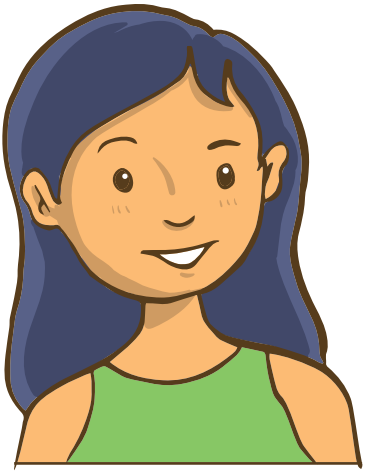
What are some of the fun things your family likes to do?

There are many people who are caring for a grandparent with dementia, like me, and maybe like you. Here are a few of their stories. I hope they help you like they helped me!

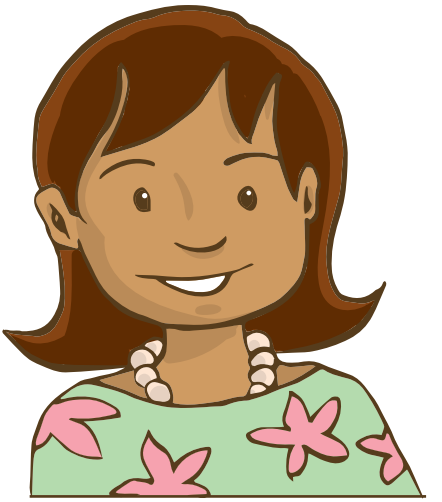


People Who Can Help

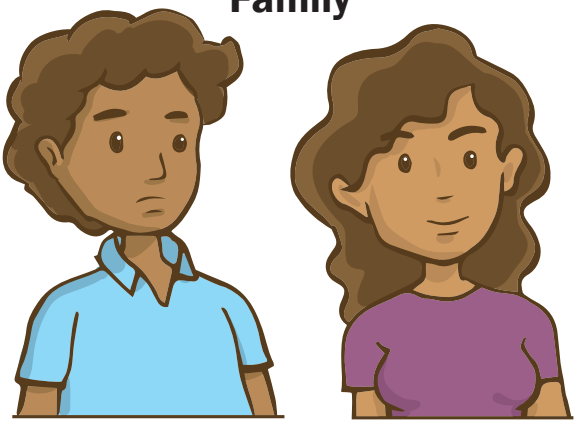
Teachers



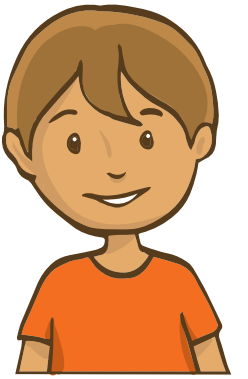
Social Workers or Counselors



Family



Friends



Check out
alz.org/help-support/resources/kids-teens
for good information.

More Information and Ways to Connect

Check out these stories on YouTube

YouTube

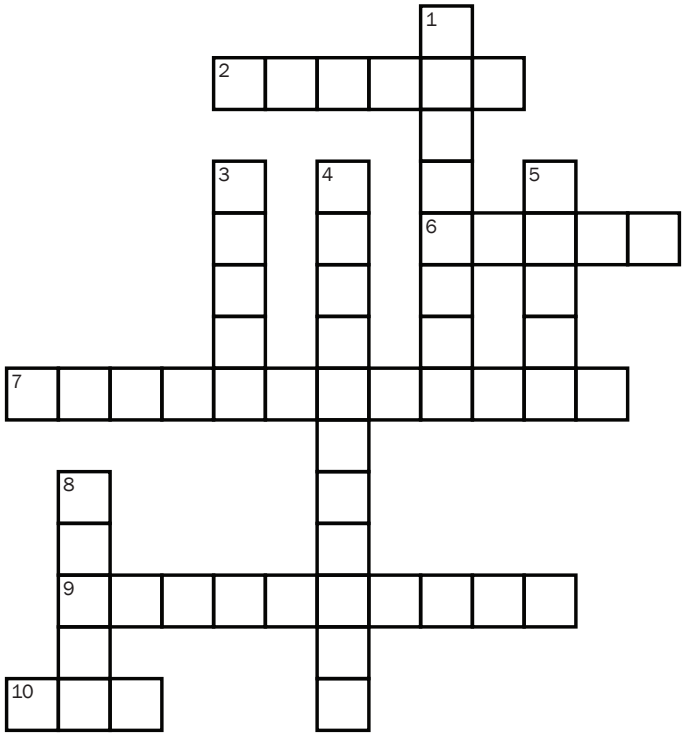
My Name is Lisa
Lisa tells us about her journey with her mom as she loses her memory.

Dan's Story
Dan talks about his grandma who has Alzheimer's disease.
bit.ly/DanStoryALZ

Get connected!

Alzheimer's Association Hawai'i	@alzhawaii	facebook.com/alzhawaii
The Youth Movement Against Alzheimer's	@theyouthmvmt	facebook.com/theyouthmovementagainstalzheimers

Lessons from Pomai and Papa



ACROSS

2 Hawaiian word for elder

6 Hawaiian word for family

7 Doctor that specializes in care of older people

9 The most common form of dementia

10 Hawaiian word for personality, character or nature; this may change when someone has dementia

DOWN

1 A tool to help us remember something

3 Hawaiian word for doctor

4 This word describes a disease that gets worse over time

5 Hawaiian word for cherished memory

8 The part of the body that is affected by dementia

Hā Kūpuna National Resource Center for Native Hawaiian Elders

Hā Kūpuna National Resource Center for Native Hawaiian Elders is one of three National Resource Centers for Native Elders funded by the U.S. Administration on Community Living/Administration on Aging (ACL/AoA), Department of Health and Human Services. Additional support is received from the Barbara Cox Anthony Endowment and the Thompson School of Social Work & Public Health at the University of Hawai‘i at Mānoa (UHM).

Established in 2006, Hā Kūpuna seeks to expand knowledge on Native Hawaiian elders to improve services, increase provider sensitivity, and inform effective programs and policies.

Hā Kūpuna has contributed new knowledge on Native Hawaiian elders to the literature and classroom on a wide range of topics, including life expectancy, disease risk, preferences for health and long-term care services, issues facing keiki (children) caring for kūpuna with dementia, issues facing kūpuna caring for grandchildren, the lives of kūpuna who live outside of Hawai‘i, historical wisdom from Hawaiian-language sources, and contemporary wisdom from kūpuna served by the Ke Ola Pono No Nā Kūpuna Program of ALU LIKE, Inc.

Our advisory council includes representatives of ALU LIKE, Inc, Lunalilo Home, Lili‘uokalani Trust, Papa Ola Lōkahi, the Office of Hawaiian Affairs, Partners in Development, the Executive Office on Aging, and the four county agencies on aging. Members from UHM include representatives from the Department of Geriatric Medicine, the Department of Native Hawaiian Health, and the UH Center on Aging, as well as the university’s Native Hawaiian Affairs Program Officer.

For more information, visit our website at **manoa.hawaii.edu/hakupuna/** or our Facebook page **facebook.com/HaKupuna**

A free download of this publication is available at our website at **manoa.hawaii.edu/hakupuna/pomai-and-her-papa/**

Let us know what you think about this book at **bit.ly/PomaiSurvey**

He mau makana nāu kēia mai kō mākou kūpuna.
These are gifts for you from our elders.

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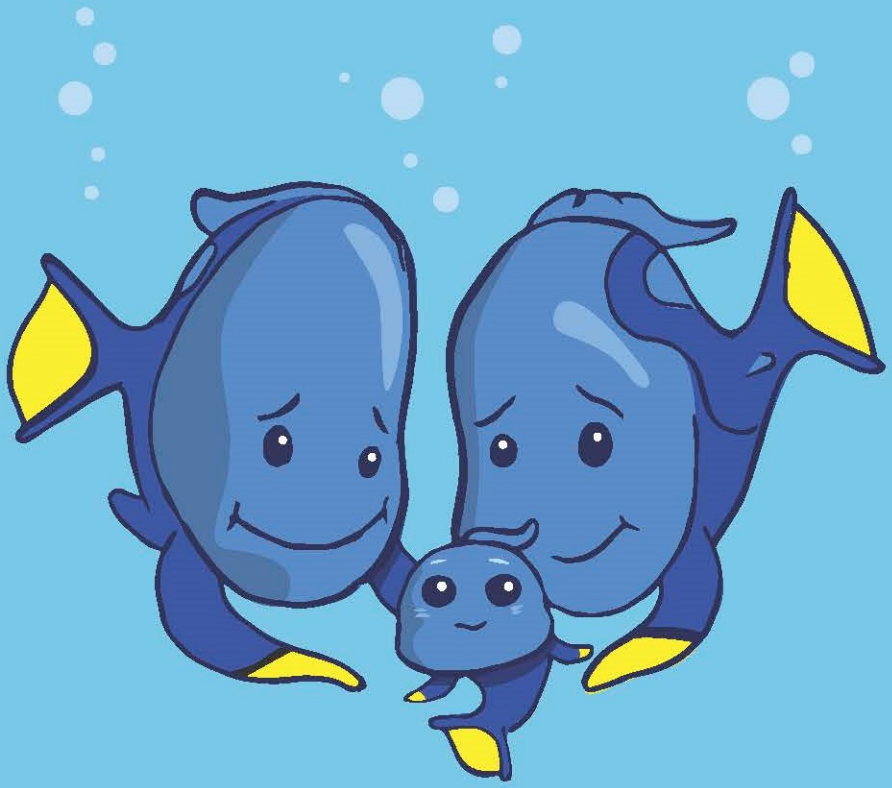

Do you remember the story of the little blue fish who has problems remembering and loses her way home? This can happen to people in real life too.

In this story, Pomai's Papa (grandpa) begins to lose his memory. He gets lost. The way he acts changes. This doesn't happen to all older people, but when it does, your kupuna (elder) may have dementia. It is important that they see a doctor to know for sure. Pomai's family is worried and is having a hard time talking about what to do. Read about Pomai as she sets off on a journey to learn how to help Papa.

No one remembers everything all the time, but when someone begins to forget important things, we can all help.

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