



keys
BAGS
NAMES
words

hope in aging and dementia

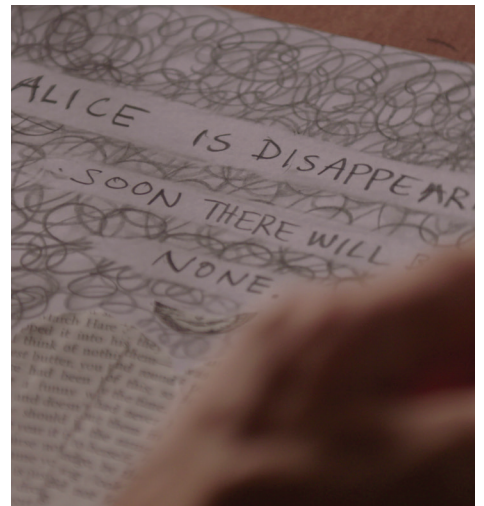


SCREENING TOOLKIT
& DISCUSSION GUIDE

A CYNTHIA STONE MEDIA PRODUCTION in association with THE GLOBAL BRAIN HEALTH INSTITUTE'S HEAR|SAY PROJECT, THE HELLMAN FOUNDATION and VOICE OF WITNESS AN 8 ABOVE RELEASE Sound by MICK CASSIDY and GREG MILLER
Sound Design by MILK DINKO Directors of Photography RONAN FOX and OWEN BISSELL
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About the Film

Dementia is one of the greatest fears of people today. This documentary aims to shift that narrative of fear and hopelessness to one of hope and action. There are things we can do as individuals to reduce our risk of developing dementia. There are ways to connect meaningfully with our loved ones, even if they no longer recognize us. We can live a high quality of life after diagnosis. *Keys Bags Names Words* shows intimate profiles of people living with dementia and their care partners. You'll meet doctors discussing what you can do in your life to support brain health and prevent cognitive decline. And you'll meet musicians and artists, scientists and policy experts from around the world engaged in a bold approach to tackle a leading global challenge for health and social care in the 21st century, dementia and brain health.

This film is not a lament to loss, but an inspiring celebration of the human spirit.



photo credit: Alex Kornhuber, Global Atlantic Fellow

Why Should We Care About Dementia?

Dementia is one of the greatest global challenges for health and social care in the 21st century.

Caring for people with dementia presents profound challenges to families and societies, and the worldwide burden is vastly underestimated. **As populations around the world age, the number of people living with dementia grows, tripling by 2050 to 152 million** — overwhelming families, communities, public health care systems and economies worldwide.

How can we prevent dementia? How can we help families cope? To connect? How can we end debilitating stigma and be more inclusive? How do we celebrate the strengths of aging? How do we find beauty and connection amidst the heartbreak of dementia?

This film is intended to create a shift. A shift in thinking among those who have dementia from hopelessness to optimism and action for a higher quality of life. A shift for carers from loss and despair to connection. A shift towards prevention and knowing how to keep our brains healthy. And a shift that comes from real people sharing their experiences — the funny, the angry, the sad, the powerful — and finding ways we can be less afraid and more inclusive.

Hosting a film screening helps to build support for creative ways for people and communities to care for their brain health. Learning directly from people with lived experience of dementia helps to break down stigma, find connection, and advocate for people with a diagnosis of dementia and their care partners.

How to Plan a Screening

A film screening can be as simple or elaborate as suits your group's needs. We welcome people to watch together in a conference room or community center, share a link to watch for an online "film club" discussion, gather for an in-home watch party, or explore renting out a theater for a large event. Here are some tips and tricks about how to ensure your screening, whatever route you take, is successful.

Setup & Promotion (4 – 6 weeks out)

Event Marketing

Use our marketing materials to put together a flier, send a newsletter to your list, and post your event to social media as early as you can.

After your initial announcement, plan for regular follow-up posts and at least 1–2 more newsletter emails prior to your event.

Send a request for promotion to any partner organizations that might want to help support your screening and encourage them to invite their membership and mailing lists. Include your flier and additional marketing materials for them to use.

Consider using the film as a tool to help raise funds and participation for dementia-related causes.

Press & Public Relations

Send a press release to local media (TV, radio, print) highlighting your event and any notable people participating.

Consider timing op-eds or letters to the editor from your members with your screening.

Ideas for Post-Film Programming

Panel Discussion: The impact of Alzheimer's disease and related dementias can touch all walks of life, and as the film explores, these conditions require creative, diverse approaches to care. In that spirit, consider bringing together voices from a variety of disciplines and perspectives on dementia for a conversation after the film. Panels could include caregivers, artists, therapists, medical providers, psychologists, social workers, and when appropriate, people living with Alzheimer's disease or a related dementia to share their stories.

Town Hall: Screening events can provide an opportunity for a town-hall-style Q&A with local experts or lawmakers about their plans for providing better support for people and families experiencing Alzheimer's disease or a related dementia.

Prepare Your People

Identify a moderator or master of ceremonies for your event — preferably, someone who can translate the film's story to your particular audience, organization, and context.

Reach out to any local officials or community leaders who you would like to include in your event. Request that they introduce the event, serve as a moderator for conversation, or sit on a panel.

Set a prep call with all panelists and speakers for the event 1–2 weeks ahead of your screening.

Prepare an agenda for the event. Include introductions, timing, and any guidelines for post-film conversation as needed.

Consider having the moderator remind the audience that this documentary shares the real experiences of some people living with dementia. There is a lot of hope, but there are moments that some living with dementia may find difficult. Please feel free to step out if you need to. It's okay. Our intention is to share the hope and beauty that can still be found under difficult circumstances, as well as approaches to supporting brain health.

Day of the Screening

- Send a final reminder email about the event to your followers and members.
- Post reminders and graphics to social media.
- Arrive early to coordinate with the venue on audio-visual needs, microphones, and any other setup needs.
- Bring handouts, literature, and printed audience survey for the audience.

Make It Memorable

Set Up a “Tell Your Story” Station: *Keys Bags Names Words* sets out to share stories of hope and promise. We encourage those with lived experience of Alzheimer’s disease and related dementias to share their stories — what has worked, what has been a challenge, and what they want the public to know about their experiences. Set up a simple video

station using an iPhone and tripod, where you can record people’s stories and reflections as they enter and exit the screening event. Consider sharing these stories on social media, a website, or a podcast as a way to empower your storytellers.

Eye-catching Takeaways: Use the film’s graphics and photo assets to create compelling postcards or other literature takeaways with clear and concise next steps for your audience.

Art Project: Invite people to use acrylic paints on small canvas panels of varying sizes to create abstract impressions of their moods, memories, and thoughts. Arrange the panels to create a community mural that shows what “brain health” means to the participants and how we can build connections to each other, even without knowing what the final result will look like. Maybe share photos of the final piece on social media.

Musical Memories: Make a playlist of music that people in the audience listened to when they were younger. Play the playlist for people to enjoy before the movie starts.



Background on the Science

Dementia is a general term for any disease that causes a change in memory and/or thinking skills that is severe enough to impair a person's daily functioning (driving, shopping, balancing a checkbook, working, communicating, etc.). There are many different types of dementia, the most common of which is Alzheimer's disease. Most types of dementia cause a gradual worsening of symptoms over the course of years due to progressive damage to nerve cells in the brain caused by the underlying disease process, which is referred to as *neurodegeneration*. The symptoms of dementia vary from person to person and may include memory problems or mood changes or difficulty walking, speaking, or finding your way. While dementia may include memory loss, memory loss by itself does not mean that you have dementia. While some mild changes in cognition are considered a part of the normal aging process, dementia is not. Age is the greatest risk factor for dementia. Dementia becomes increasingly common as people age, but dementia is not a part of normal aging.

What Happens in Dementia?

People with dementia may have different symptoms, depending on the type and stage of their particular dementia. A person's symptoms depend on which part of the brain is affected by the disease process, and the symptoms may change over time as the diseases progress to involve different areas of the brain. Different types of dementia tend to target particular parts of the brain. For example, the part of the brain that is important for the formation of new memories is usually affected early on in Alzheimer's disease, which is why short-term memory loss is often one of the first symptoms of Alzheimer's disease. Other common symptoms in dementia include difficulties with communication, planning and organization, navigation, personality changes, and psychiatric symptoms such as depression, anxiety, delusions, and hallucinations.

How Can I Improve my Brain Health?

What's good for the heart is good for the brain. Research has shown that physical exercise helps to enhance brain health and improves mood and general fitness. A balanced, heart-healthy diet, such as [MIND \(Mediterranean–DASH Intervention for Neurodegenerative Delay\)](#), and limited alcohol intake are other important ways to promote good brain health. Getting good sleep at night is another important component of brain health. This includes maintaining a normal sleep/wake cycle, practicing good sleep hygiene, and recognizing and treating sleep disorders. Staying socially active and engaged in enjoyable, mentally stimulating activities helps to promote good mental health. Keep being curious and learning new things. Other illnesses that can affect the brain, such as diabetes, depression, high blood pressure, and high cholesterol should also be treated if present.

Big Ideas to Discuss

Theme: Prevention & Brain Health

Renowned behavioral neurologist Dr. Bruce Miller says, “We began to realize that about 30 to 40% of dementia in elders could have been prevented.” Another expert, Dr. Ian Robertson, says, “Brain health is quite a new concept. We know what heart health is. We know that we have about 40% of the rate of heart attacks now than we did 50 years ago. Not largely because of advances in high-tech medicine, but because they worked out what the risk factors were, and they got people to change their behavior.” Dr. Brian Lawlor observes, “I think the problem up until now...is that we haven’t really been able to translate this evidence into policy and practice.”

“About 30 to 40% of dementia in elders could be prevented.”

—Bruce Miller, MD

- What are some ways to improve community education about brain health and modifiable risk factors for dementia?
- What are some of the barriers to people learning about brain health? How do we break down the stigma that might prevent people from learning more? How do we increase access to the latest scientific and medical discoveries?
- How do some of the people profiled in the film show a range of healthy behaviors? What do you think keeps them surfing, playing music, making art, etc.? What are some of the barriers to making lifestyle changes? What specific changes can you make in your own life to support your brain health?

Theme: Inclusion & Acceptance

Helen Rochford-Brennan tells us, “I started talking to whomever wanted to hear my story. Whoever wants to write about my story. I think with the illness of Alzheimer’s is very much a family illness as well. The more I can talk about this, the easier it is for other families. ...today I’m advocating for my own rights. Our voices are really important, and our voices should be heard.”

“Today I’m advocating for my own rights.”

—Helen Rochford-Brennan

Karin Diamond adds, “Every one of us has a story to tell. And some of us need our story heard... The power of the family’s story of dementia can start building compassion and understanding for what families are going through.”

- What stories in your community aren’t being heard?
- What can be done to help people feel brave enough to share their stories? And how can an audience be created to hear them?
- What does telling your story do for the storyteller? How does it help heal?

Theme: Connection & Resilience

“There is still a person there.”

—Jill Harmon

Jill Harmon shares, “The point that I really want to strongly make is that the person is still there. The context can be different. The behavior can be different, but there’s a human being there. There is still a person there.” She also says, “I’m, like, foolishly in love with him. I don’t dwell on it, but I really miss him. To lose some part of your heart, which he is to me, is really hard.” Dr. Dana Walrath describes her perspective as a medical anthropologist as, “Biomedicine focuses in just on the one sick person, whereas other medical systems recognize that it’s the whole family unit that’s experiencing something. Family members know things that other people don’t know, so they are the ideal carers, but they need absolute support.” And goes on to add, “So many people get anti-psychotics thrown at them instead of the rest of us first trying to figure out how we can meet them where they are.”

- How might you respond to a change in someone’s behavior? What are some ways to try to understand what is driving the behavior?
- What are ways that people can be ostracized and become lonely when they don’t behave as expected? How can we change this?
- How can we shift our thinking and actions, so we meet the person living with dementia where they are, without dwelling on the losses?
- How can we support care partners and their health? Are there ways to provide companionship, respite or services to help promote wellness?

Theme: Policy & Public Health

“The development of a resilient brain is tightly linked to the social determinants of health.”

—Victor Valcour, MD, PhD

The film opens with Dr. Walt Dawson’s story about a family struggling to pay for the care his father needed, and his journey to change health care policy. Later in the film, Dr. Victor Valcour states, “We know that the largest number of dementia cases around the world will be occurring in low- and middle-income countries because those populations are aging. It’s critically important for us to address a public health approach to preventing dementia in any way we can... Stress is not good for the brain.... The development of a resilient brain, which is what we think is necessary to prevent dementia, is so tightly linked to the social determinants of health. Where you’re born, what communities you live in. It’s a very tight link to equity. And it’s a bit of a humanitarian crisis.”

- Consider the elements in your community that support or degrade brain health for the people who live there.
- What can you do to help create a more supportive and resilient community? How can behaviors and lifestyles that support brain health be fostered?
- What actions can you take with your local and federal government leaders to advocate for the rights of people with dementia, and better supports for families?

About the Filmmaker



CYNTHIA STONE | PRODUCER/DIRECTOR

Cynthia Stone has been creating social justice documentary-style pieces for nearly three decades. Based in the San Francisco Bay Area, her work has appeared regionally on KQED, and nationally on PBS, The BBC/PRI, and The Discovery Channel, among others. She has won multiple regional Emmy, Society of Professional Journalists, and Press Club awards. Having covered education, the environment, health, poverty, and equity issues, she's inspired to highlight people and programs finding solutions to seemingly intractable problems. The wisdom and humor of those in this film helped her better connect with, and care for, her own mother throughout her aging process from her vital active years through her memory loss. Teaming up here with award-winning Oakland-based, feature-film editor and co-producer, Linda Peckham.

About the Author



CAROLINE PRIOLEAU | WRITER & DESIGNER

Caroline Prioleau writes and designs content for the UCSF Memory and Aging Center and the Global Brain Health Institute. She also co-leads the hear/say oral history project that focuses on collecting and sharing personal stories about the experience of aging, dementia, and caregiving. The hear/say team teaches classes and workshops and has produced two books of stories, with more to come. The project focuses on ethically collecting, preserving, and sharing these stories – which is how this film got started.