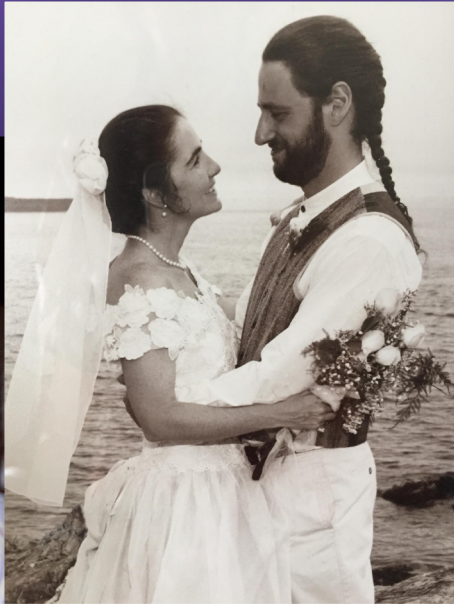


- +
- • Tips from the Trenches: A Care Partner's Reflection on Resources that can Help Families Prepare for the Dementia Journey



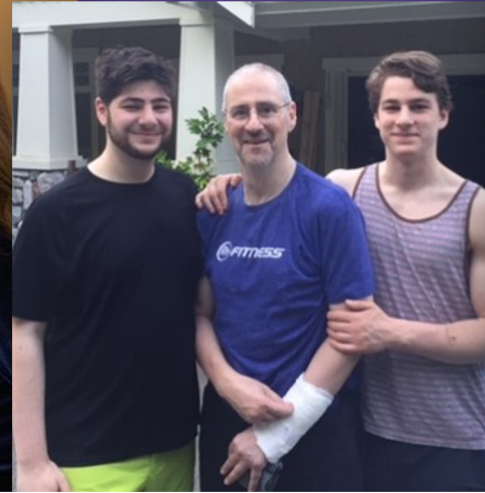
Evan Joseph Schrier



June
1995



March
2012
Diagnosed with FTD



June
2018



August
2018

The Road to Diagnosis

6 years + 2 psychiatrists + 5 therapists +
1 neurologist + 1 neuropsychologist + 2
charlatans + MRI at 3 years (misinterpreted) +
Neuropsych evals at years 3 and 5
(misinterpreted) =

Diagnosis: **Adult onset ADHD**





Delivery of correct diagnosis following PET scan at end of Year 6:

“Mrs. Schrier, I’m afraid your husband has something called Pick’s Disease. I’m so sorry. Here’s a printout from the internet that’ll tell you more about it.”



Career Shift

Earned certifications to teach Dementia classes to family and professional care partners.

Facilitate family support groups

2020 winner of Maude's Award for Supporting Family Care Partners

January 2020 UW Memory and Brain Wellness Center to support Project ECHO Dementia

Families might benefit from their health providers sharing tips about how to:



Get prepared



Get connected



Get educated

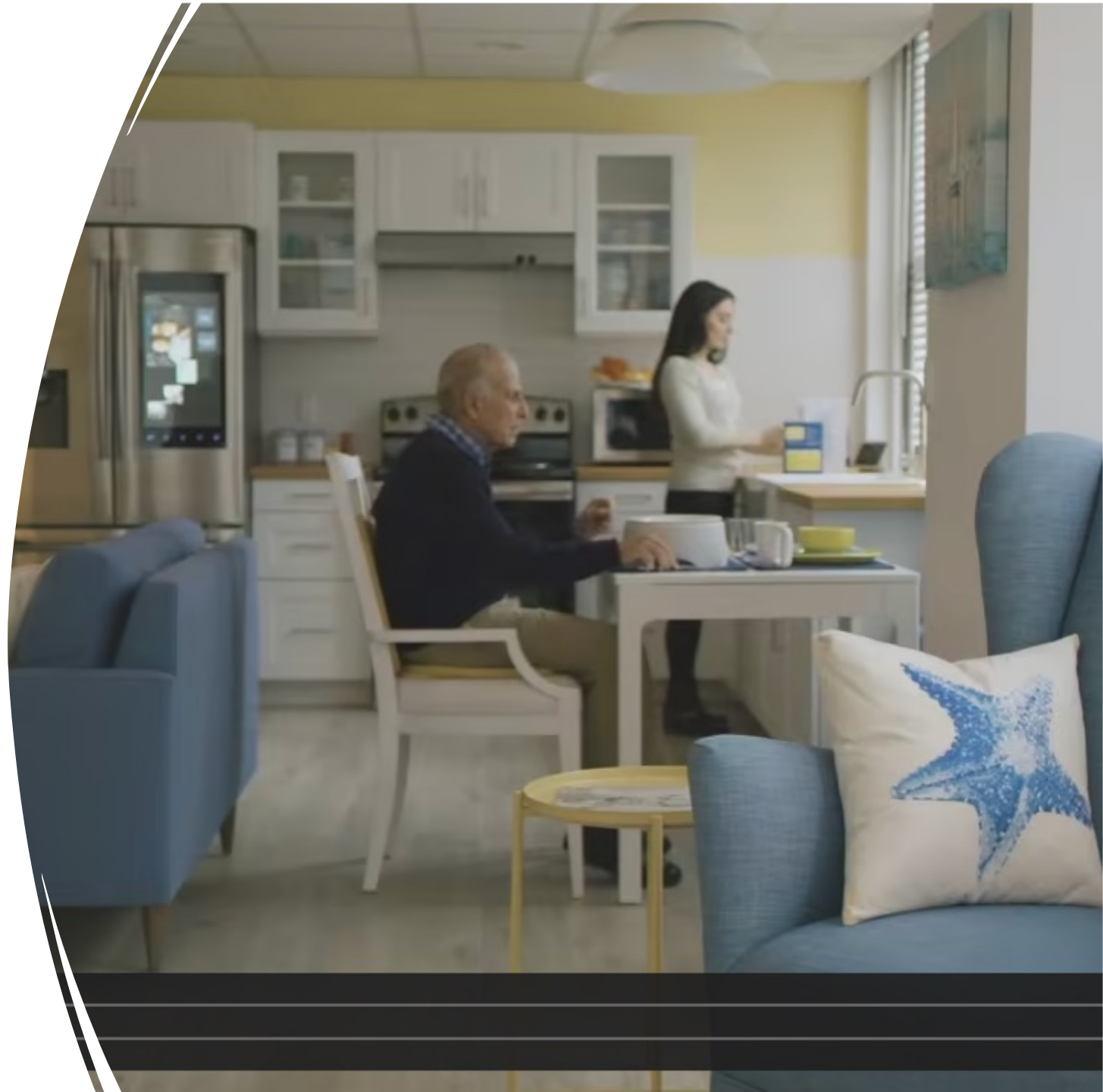


Links to Resources are included at the end of this deck and in a separate handout.

Get Prepared

- **DSHS Dementia Roadmap**
- **DSHS Legal Planning** for People with Dementia
 - Advance Directives
 - Dr. Barak Gaster's Advance Directive for Dementia
 - Video: Advance Care Planning a la mode
 - ECHO Dementia didactics of July 10 and 14, 2020
- **Social Security Disability and Dementia** (Alz Assn website)
- **VA Services** for people with a diagnosis

The Alzheimer's Foundation: A Guide to Creating a Dementia Friendly Home



Additional Resources for Education Skill Building: Family Caregiver Alliance



資源 | 자원 | Recursos | Pagaaring yc

Connecting Caregivers Caregiver Resources

Caregiving 101: On Being a Caregiver

By Donna Schempp, LCSW



In Depth Audio
10 minutes

 Order this publication

 Print/download

 Email

Get Connected

- **Connect with your community: Sharing the Diagnosis to build a support network**
 - Be a Stigma Buster!
 - Let potential support network know
 - Outliers can be instrumental
 - **Alzheimer's Association has how-tos**
- **Join a support group (for care partners / those with diagnosis / family)**
 - AARP Article: **How to Find a Caregiver Support Group That's Right for You**
 - **Randomized wondering and sharing**
 - Alzheimer's Association
 - Alzheimer's Foundation of America
 - Association for Frontotemporal Dementia
 - Lewy Body Dementia Association
 - Veterans Administration
 - Dementia Alliance International (only for people with a diagnosis)
 - Refer back to ECHO Dementia didactics of 10/8/2021 and 9/11/2020
 - **Care partner self-care (Keep from burning out; understand process)**
 - Teepa Snow's Caregiver Support Series and Ask me Anything
 - Powerful Tools for Caregivers

Get Connected: Programs for the Person Living with a Diagnosis:



The National Council of Dementia Minds (NCDM) is a not-for-profit organization led by persons living with dementia whose vision is to transform the worldview of living with a Neurocognitive Disorder (NCD).



[Dementia Alliance International](#) is a registered non-profit organisation whose membership is exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world . We seek to represent, support, and educate others living with the disease, and the wider dementia community. We are an organization that strives to provide a unified voice of strength, advocacy and support for our rights, individual autonomy and improved quality of life.

Get Connected on Social Media

- Search on Facebook and join a PRIVATE group to avoid being marketed to.
- Good solution for those hesitant to join a more intimate group.

Dementia/Alzheimers Family Caregiver Support

🔒 Private group · 35.6K members

 Join group



Frontotemporal Dementia (FTD) Info and Support

🔒 Private group · 2.3K members

 Join group



Lewy Body Support Group

🔒 Private group · 7.5K members

 Join group



Get Educated.

- Understanding Dementia (set of symptoms)
- Understanding the Diagnosis (the disease)
 - It is brain changes, not laziness/willfulness at work/ **“they are doing the best they can”**
- Understanding how dementia affects a loved one’s lived experience?
 - **Increase empathy**
- Skill building

Our Didactics are for EVERYONE

A	B
2/12/21	Best Practices for Appropriate Prescribing (Part II)
2/26/21	Hearing Loss and Dementia
3/12/21	Disease Modifying Drugs for Alzheimer's--The Current Landscap
3/26/21	Food for Thought: The Emerging Role of Whole Food, Plant Based Die
4/9/21	Wound Care for Patients in Long-term Care Communities
4/23/21	Fall Prevention and Dementia
5/14/21	Psych Meds in the Management of Dementia Symptoms
5/28/21	Behavioral Approaches to Managing Behaviors
6/11/21	Issues with Elder Abuse
6/26/21	Cognitive-Communication Intervention for Neurocognitive Disorders
7/9/21	Artificial nutrition/hydration in advanced dementia
7/23/21	An Overview of Dementia with Lewy Bodies
8/13/21	An Overview of Frontotemporal Dementia
8/27/21	Comprehensive Care Planning Visit Utility and Value
9/10/21	Difficult Conversations: Giving a Diagnosis of Dementia
9/24/21	Capacity Evaluations: Driving and Dementia
10/8/21	Resources for Practitioners, Patients and Families
10/22/21	Managing Mild Cognitive Impairment

UW Medicine
MEMORY & BRAIN
WELLNESS CENTER

Search

SEARCH ▾ / CLINIC ▾ / BE INVOLVED ▾ / THE MEMORY HUB ▾ / **ECHO ▾** / BIENVENIDOS ▾

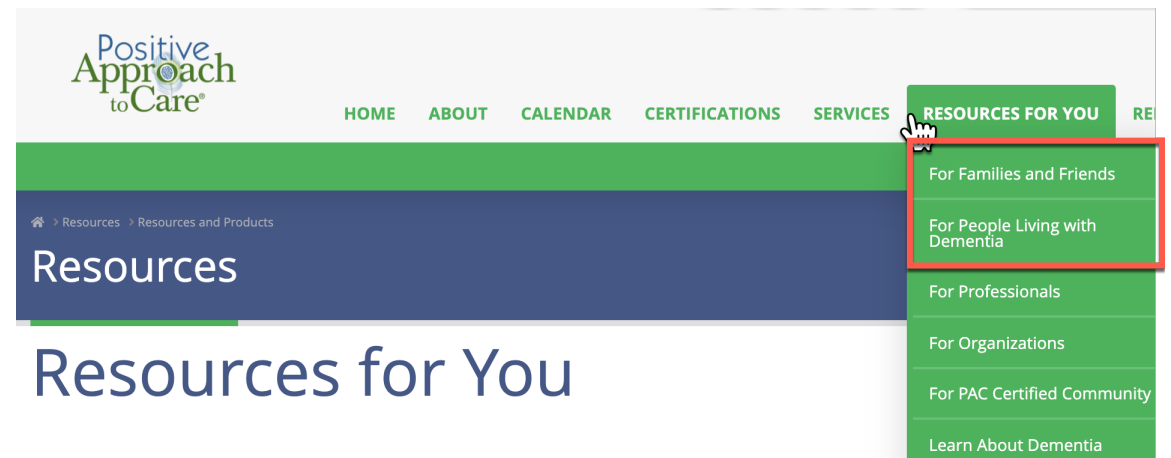
Project ECHO® Dementia

of those living with memory loss

ECHO Session Resources & Recordings

Teepa Snow

- Support groups
- Videos
- Ask Teepa Anything



Challenging Behaviors



Challenging Behavior



Watch later



Share

CHALLENGING BEHAVIORS



Teepa's GEMS®



Teepa's GEMS



Watch later



Share



TEEPA'S GEMS™



Dementia 101



Dementia 101



Watch later



Share

YOU'RE NOTICING
CHANGES



Brain Changes



Brain Changes



Watch later

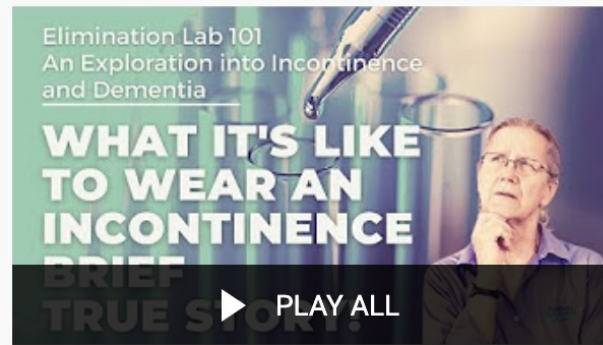


Share

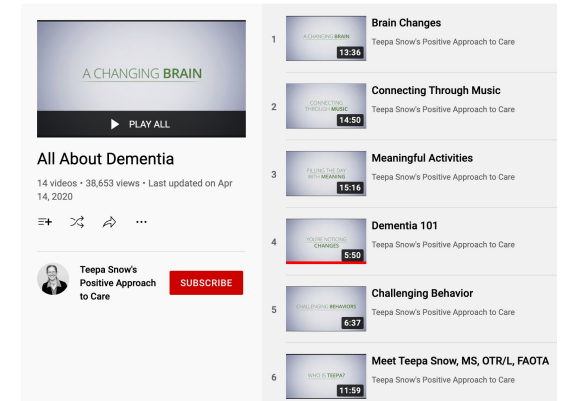
A CHANGING BRAIN



Teepa Snow on YouTube



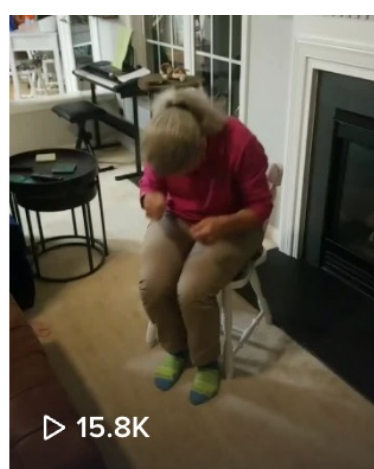
Elimination Lab 101:
Dementia and Incontinence



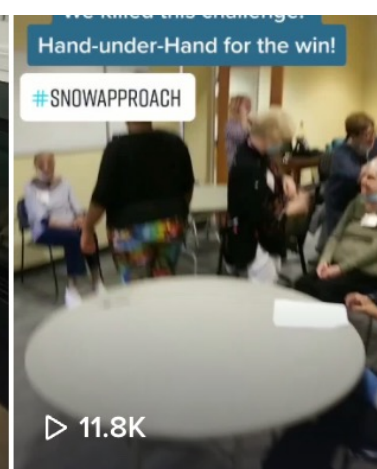
Dementia Problem Solving

Teepa Snow **Dementia Care Partner Talk Show Podcast** (also available on YouTube)

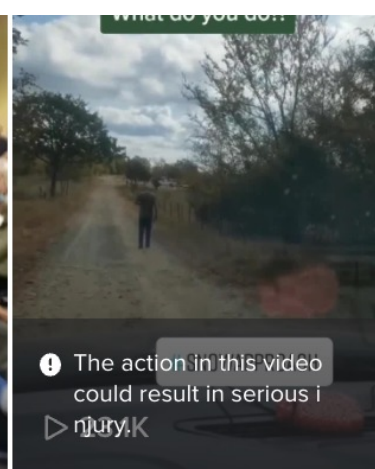
- How to Maintain Dignity and Minimize Aggression in Dementia Care
- What to Know About Dementia and Incontinence
- What to Know About Hoarding and Dementia
- How to Handle a Loved One That Constantly Wants to Leave the House



▶ 15.8K

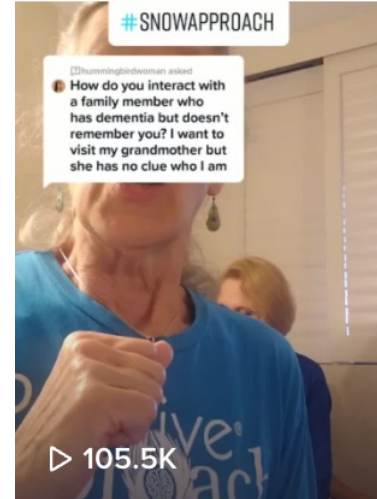


▶ 11.8K



▶ 11.7K

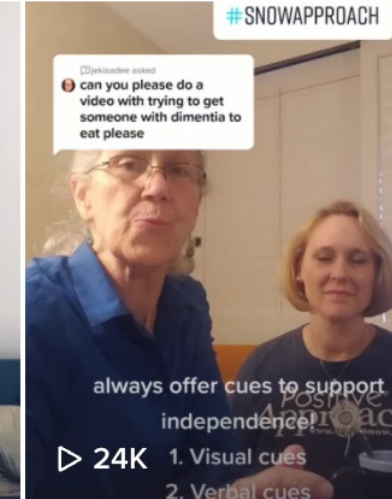
Teepa on Ticktok



▶ 105.5K



▶ 24.4K



▶ 24K



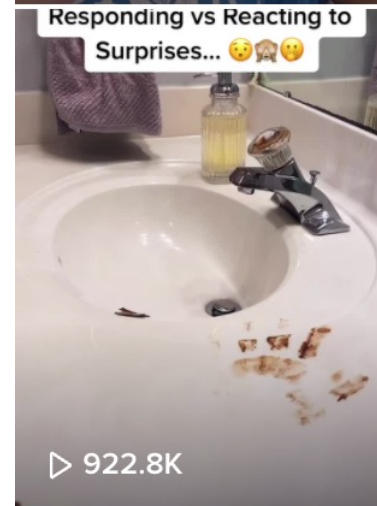
▶ 57K



▶ 20.9K



▶ 17.6K



▶ 922.8K



▶ 52.9K



▶ 547.3K



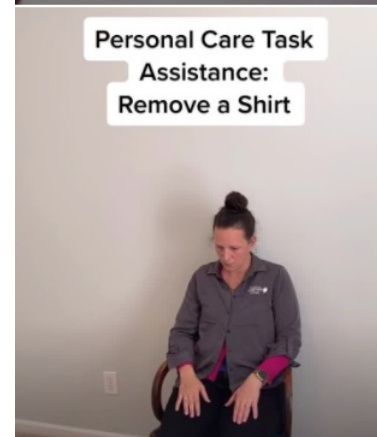
▶ 51.7K



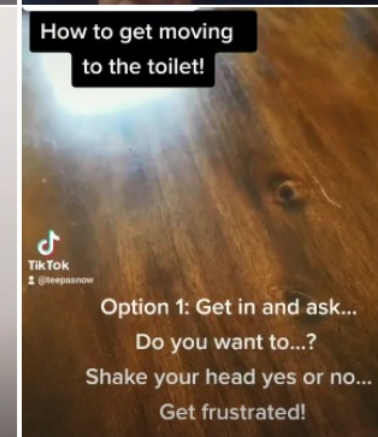
▶ 26.8K



▶ 19.3K



Personal Care Task Assistance: Remove a Shirt



How to get moving to the toilet!

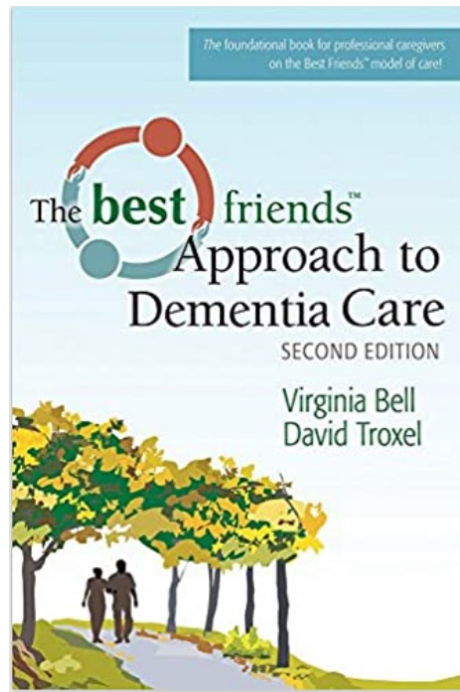
Option 1: Get in and ask...
Do you want to...?
Shake your head yes or no...
Get frustrated!



What's the difference between Alzheimer's and dementia?

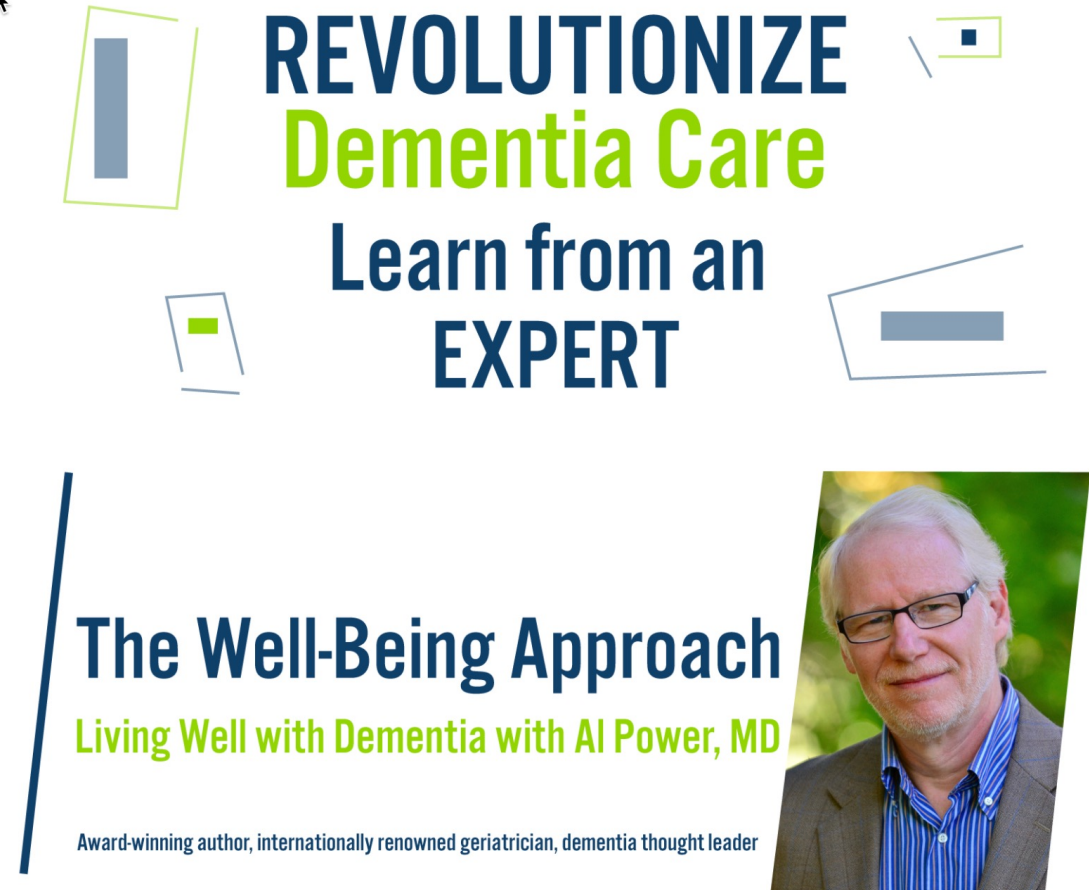
David Troxel

- YouTube videos -- excellent primers about:
 - What is dementia
 - How it impacts a person's lived experience
 - Changes care partners need to make to provide support and avoid conflict



Dr. Al Power and the Eden Alternative

- Books:
 - Dementia Beyond Drugs
 - Dementia Beyond Disease
- Pre-emptive Approach
 - Cognitive Ramps
 - Dementia Domains of Well-Being




REVOLUTIONIZE
Dementia Care

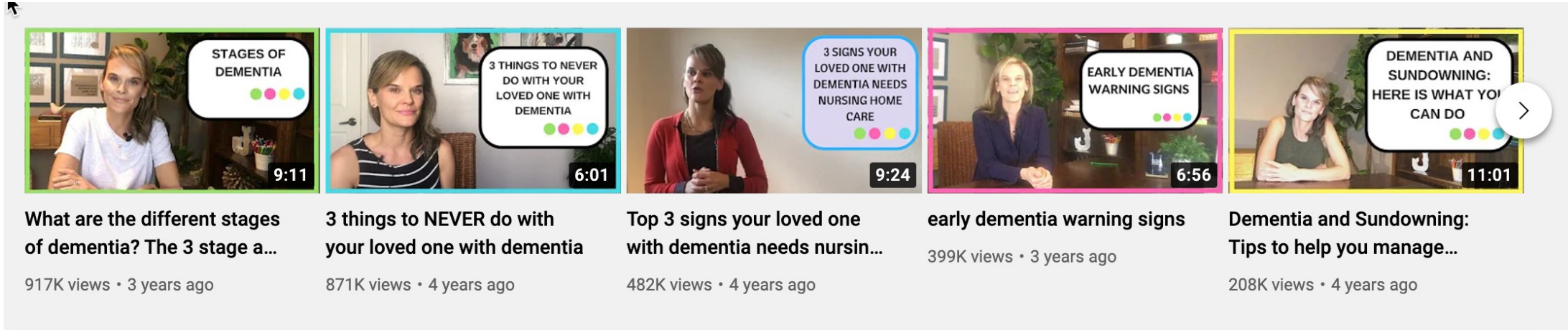
Learn from an
EXPERT

The Well-Being Approach
Living Well with Dementia with Al Power, MD

Award-winning author, internationally renowned geriatrician, dementia thought leader



Additional Resources: Dementia Careblazers



This row contains five video thumbnails. Each thumbnail features a woman speaking, a title card with a list of topics, and a duration in the bottom right corner. The titles and view counts are as follows:

- STAGES OF DEMENTIA** (9:11): 917K views • 3 years ago
- 3 THINGS TO NEVER DO WITH YOUR LOVED ONE WITH DEMENTIA** (6:01): 871K views • 4 years ago
- 3 SIGNS YOUR LOVED ONE WITH DEMENTIA NEEDS NURSING HOME CARE** (9:24): 482K views • 4 years ago
- EARLY DEMENTIA WARNING SIGNS** (6:56): 399K views • 3 years ago
- DEMENTIA AND SUNDOWNING: HERE IS WHAT YOU CAN DO** (11:01): 208K views • 4 years ago

HOW TO HANDLE DIFFICULT DEMENTIA BEHAVIOR ▶ PLAY ALL



This row contains five video thumbnails. Each thumbnail features a woman speaking, a title card with a list of topics, and a duration in the bottom right corner. The titles and view counts are as follows:

- DEMENTIA & HOW TO HELP** (8:26): Simple tip when helping someone with dementia
- IMPROVE YOUR LIFE AS A DEMENTIA CAREGIVER** (12:44): How to change your life as a dementia caregiver: A simpl...
- LET THEM HELP** (7:35): How to help someone with dementia (HINT: let them...
- EMBARRASSING DEMENTIA BEHAVIOR** (4:53): How to handle difficult dementia behaviors in publi...
- DEMENTIA CHEATING ACCUSATIONS** (6:31): Dementia and being accused of cheating

Additional Resources for Education and Skill Building: UCLA


- Caregiver Education ▾
 - ACES Webinars
 - Caregiver Training Videos ▾**
 - Aggressive Language and Behaviors
 - Agitation and Anxiety
 - Depression and Apathy
 - Hallucinations
 - Home Safety
 - Refusal to Bathe
 - Refusal to Take Medications
 - Repetitive Behaviors
 - Repetitive Phone Calls
 - Repetitive Questions
 - Sexually Inappropriate Behaviors
 - Sleep Disturbances
 - Sundowning
 - Wandering
 - Common Challenges: Alcohol Abuse
 - Common Challenges: Driving
 - Common Challenges: Lack of

English [Español](#)

U Caregiver Training: Introduction

Alzheimer's & Dementia Care Videos

Introduction

Watch on  YouTube

Part I: Introduction

Additional Resources for Education and Skill Building: UCSF

Dementia & You ▾

Caregiving & Support ▾

Clinical

[Home](#) > [Caregiving & Support](#)

Caregiving & Support

Being a caregiver can be both extremely rewarding and extremely challenging. Learning to take care of yourself, making smart choices about your environment and behavior, and finding support can help you manage the challenges of caregiving.

10-Step Planning Process

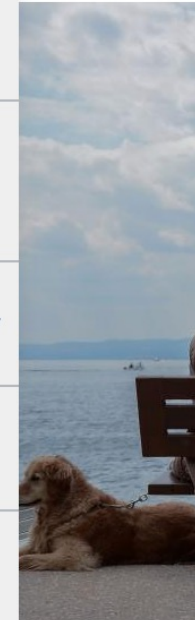
Everyday Advice

Behavior & Personality
Changes

Working with Your Family

Support Options

Caregiver Well-Being



Additional Resources for Education and Skill Building: UCSF website links to videos @ Family Caregiver Alliance

- Caregiving & Support ▾
- Clinical Services ▾
- Research & Clinical Trials ▾
- About ▾

General Tips for Supporting a Person with Dementia with Daily Tasks	>
When to Seek Outside Help	>
Communication	>
Balancing Safety & Independence	>
Being in Public or Social Situations	>
Helping with Bathing & Grooming	>
Incontinence	>
Eating Changes & Challenges	>
Sleeping Changes & Challenges	>



Family Caregiver Alliance®

資源 | 자원 | Recursos | Pagaaring yaman | Tài nguyên [Donate](#)

[Connecting Caregivers](#) [Caregiver Resources](#) [Research & Policy](#) [About](#)

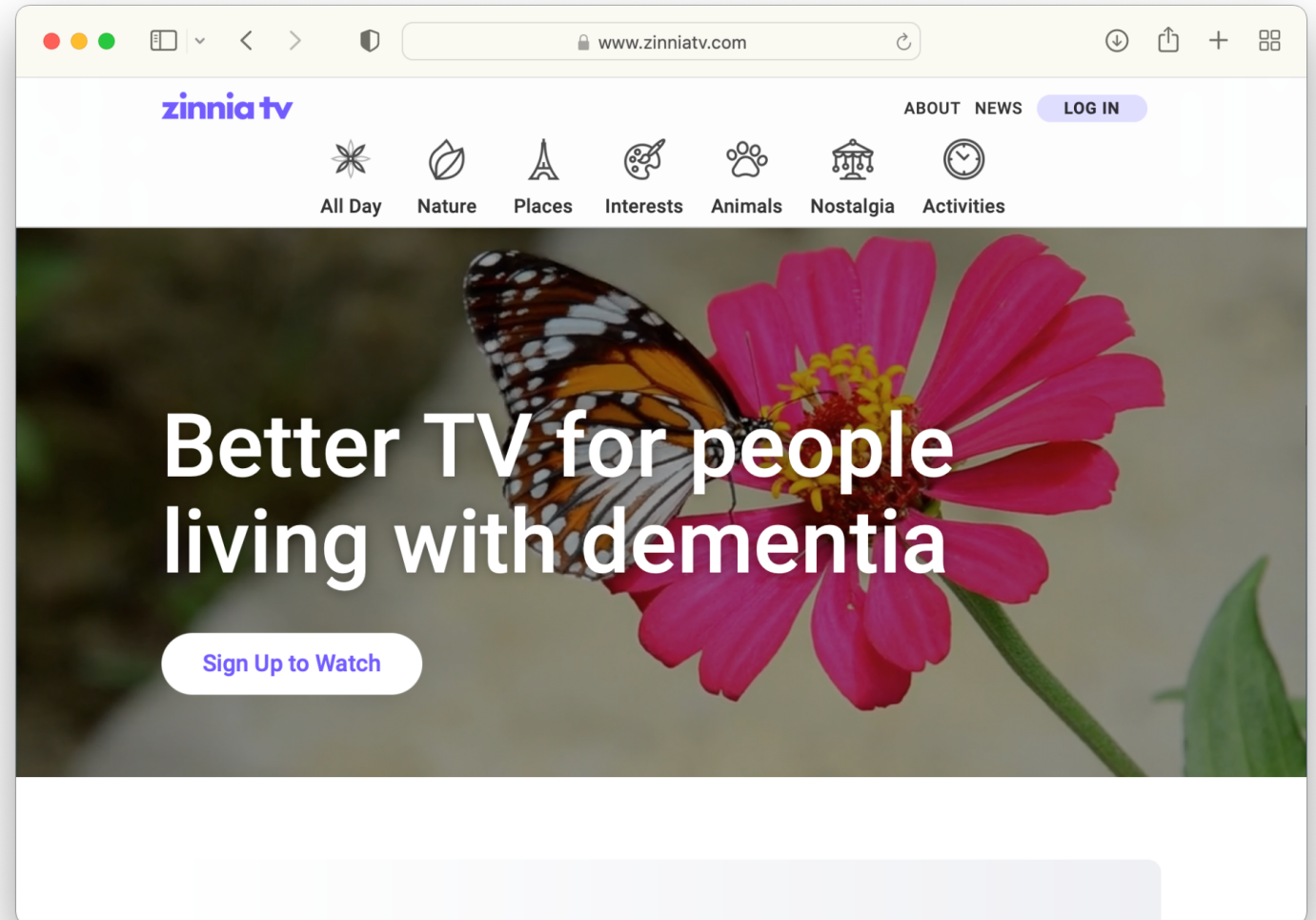
Caring for Another

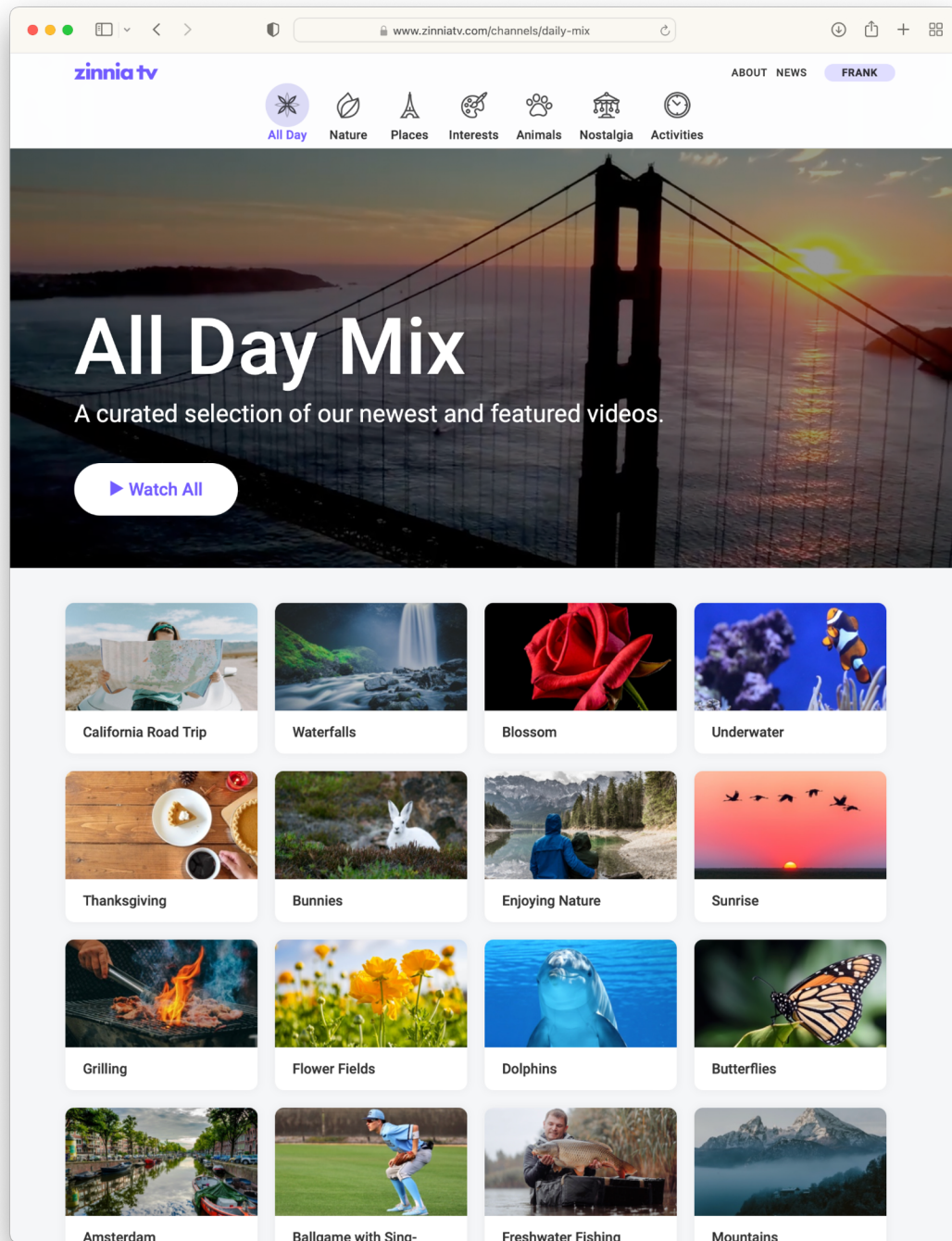
Find in-depth information and tips on a wide variety of caregiving topics.

- Advanced Illness and End of Life
- Legal and Financial Planning
- Out of Home Care
- Caring at Home

Co-founder Zinnia
Technologies Inc

Caregiver.com's
Visionary
Caregiver of 2020





Gently-paced, visually stunning, plot-free programming that promotes connection and engagement between people with mid to late-stage dementia and those who care for them.

Get Prepared:

Dementia Roadmap:

<https://www.dshs.wa.gov/sites/default/files/AL TSA/stakeholders/documents/AD/Dementia%20Road%20Map%20-%20A%20Guide%20for%20Family%20and%20Care%20Partners.pdf>

Social Security Disability and Dementia:

<https://www.alz.org/help-support/caregiving/financial-legal-planning/social-security-disability>

DSHS Dementia Planning Legal Tool Kit: https://www.washingtonlawhelp.org/files/C9D2EA3F-0350-D9AF-ACAE-BF37E9BC9FFA/attachments/801D6207-79DB-46D8-B806-D3EDB0FE85BB/9605en_dementia-legal-planning-toolkit.pdf

Advance Directives:

Learn about Advance Directives specifically for people with a dementia diagnosis: <https://dementia-directive.org/>

Watch the video Advance Care Planning a la mode: <https://www.youtube.com/watch?v=1s20HXeO2HU>

Alzheimer's Foundation of America's video **A Guide to Creating a Dementia Friendly Home:**

<https://alzfdn.org/theapartment/>

Caregiver 101: On Being a Caregiver: <https://www.caregiver.org/resource/caregiving-101-being-caregiver/>

Get Connected:

Sharing Your Diagnosis

Alzheimer's Association ideas about how to share your diagnosis: https://www.alz.org/help-support/i-have-alz/know-what-to-expect/sharing-your-diagnosis?_gl=1*bt93th*_ga*NzlxMDI1NzcuMTYzNjMyMjE5Ng..*_ga_9JTEWVX24V*MTYzNjMyMjE5Ni4xLjEuMTYzNjMyMjcyMy4w&_ga=2.193748397.1090238355.1636322196-72102577.1636322196

Support Groups for care partners, people with a diagnosis and families:

AARP Article, **How to Find a Caregiver Support Group That's Right for You**: <https://www.aarp.org/caregiving/life-balance/info-2021/support-groups.html?intcmp=AE-CAR-R5-C3-CO> RONA

Alzheimer's Association: <https://www.alz.org/help-support/community/support-groups>

Veteran's Administration: https://www.caregiver.va.gov/help_landing.asp

The Association for Frontotemporal Degeneration: <https://www.theaftd.org/living-with-ftd/aftd-support-groups/>

Lewy Body Dementia Association: <https://www.lbda.org/local-support-groups/>

Dementia Alliance International: <https://www.dementiaallianceinternational.org/services/online-support-groups/>

Alzheimer's Foundation of America: <https://alzfdn.org/caregiving-resources/2860-2/>

Care partner support (structured to help care partner keep from burning out)

Teepa Snow Care Partner Support Series: <https://teepasnow.com/services/consulting/care-partner-support-series/>

Teepa Snow Ask Teepa Anything Webinars: Find an upcoming date on the PAC website (<https://teepasnow.com/events/>) and find past webinars on YouTube.

Powerful Tools for Caregivers: <https://www.powerfultoolsforcaregivers.org/>

Get Connected:

Support/advocacy groups for people living with dementia:

National Council of Dementia Minds: <https://dementiaminds.org/>

Dementia Alliance International: <https://www.dementiaallianceinternational.org/>

Facebook Groups:

Simply go to Facebook and search for the support you are after. Alzheimer's Support Group. FTD Support Group. Lewy Body Support Group. Note that you probably want a group that's PRIVATE and requires that you join. This is the only way to keep from getting bombarded by people trying to sell you things.

Get Educated:

UW Memory and Brain Wellness Center recordings of previous Project ECHO Dementia didactics: <https://depts.washington.edu/mbwc/resources/echo-recordings>

Teepa Snow:

- Teepa Snow's Positive Approach to Care: <https://teepasnow.com/>
 - Take a look at Family Resources tab for videos, support groups, education
- YouTube and TikTok for a huge assortment of EXTREMELY useful videos

David Troxel:

Dementia Related Behavior – Managing Challenging Moments with Confidence:
<https://www.youtube.com/watch?v=luahDBX2Y-I>

Webinar hosted by the Alzheimer's Association:
<https://www.youtube.com/watch?v=eVvafXWWGAA>

Dr. Al Power:

- Education: Dr. Al Power and The Eden Alternative: <https://www.edenalt-evolve.org/courses/the-well-being-approach-creating-a-life-worth-living-with-dementia>
- Dr. Power lecturing: <https://www.youtube.com/watch?v=42DvFgXEPKk>

Additional Resources:

Dementia **Careblazers**: An online resource for family care partners

<https://www.careblazers.com/>

Many Careblazers 'how-to' videos on YouTube:

<https://www.youtube.com/channel/UCVgK5-w1dilMx7bPVB5yNug>

Care videos on the **UCLA Website**: <https://www.uclahealth.org/dementia/caregiver-education-videos>

Excellent care specifics on the **UCSF website**:

Family Caregiver Alliance: https://www.caregiver.org/resource/caregiving-101-being-caregiver/?gclid=Cj0KCQjw8p2MBhCiARIsADDUFVG-JEOYUsUxv984aFAOdiSFliU9CHiTE80GNCjKT1xr4MdZOos1wLkaAvUMEALw_wcB

Zinnia TV: <https://www.zinniatv.com/>