

Getting Connected!

DEMENTIA PEER



COALITION

*Bob Savage,
President & Co-
Founder, Dementia
Peer Coalition*

*Stephani Shivers,
COO, LiveWell
Co-Founder,
Dementia Peer
Coalition*

LiveWell

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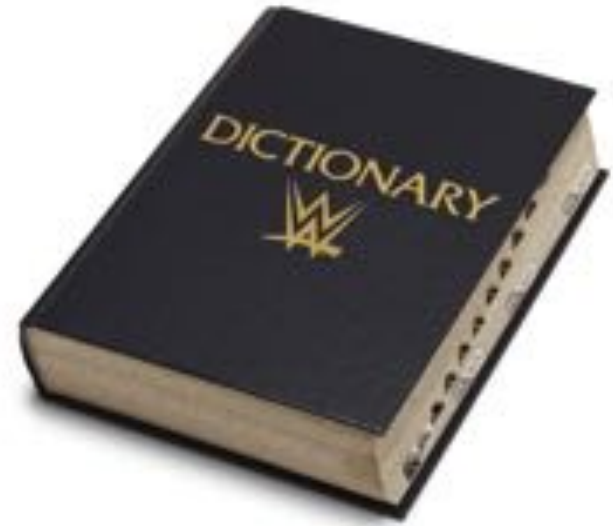
Who's in the room?

- ▶ Name
- ▶ How do hear about the DPC and today's session?
- ▶ Is there something you are particularly interested in learning?



If you prefer not to share just say “Pass”

Peer - What does it mean?



Peer *noun*

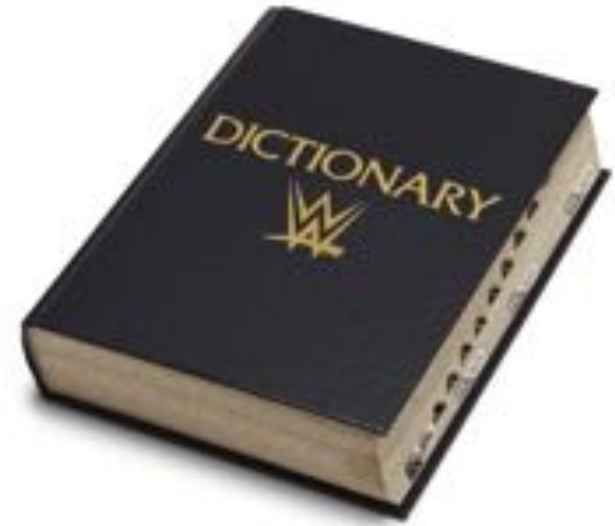
- ▶ Person of the same age, status, or ability as another specified person

Peer *verb*

- ▶ Make or become equal with or of the same rank

New Oxford American Dictionary

Coalition - What does it mean?



Coalition *noun*

- ▶ A union or association formed for mutual benefit and for combined action

New Oxford American Dictionary

Peer Coalition - What does it mean?



COALITION

- ▶ people of the same status or ability
- ▶ becoming equals with one another
- ▶ and joining together for mutual benefit and combined action

*Who has been an important
peer to you?*

Colleague? Friend? Sibling?

*How were they helpful in
your life?*

Peer Advocates





run by people with dementia



European Working Group
of People with **Dementia**
ALZHEIMER EUROPE



DEMENTIA
ALLIANCE
INTERNATIONAL

**SEE THE PERSON
NOT THE DEMENTIA**

dementia
australia
advisory
committee



DEMENTIA PEER



COALITION

“A group of resilient people living well with the changes attributed to various forms of dementia who are joining together into a local peer coalition run by and for people with dementia.”

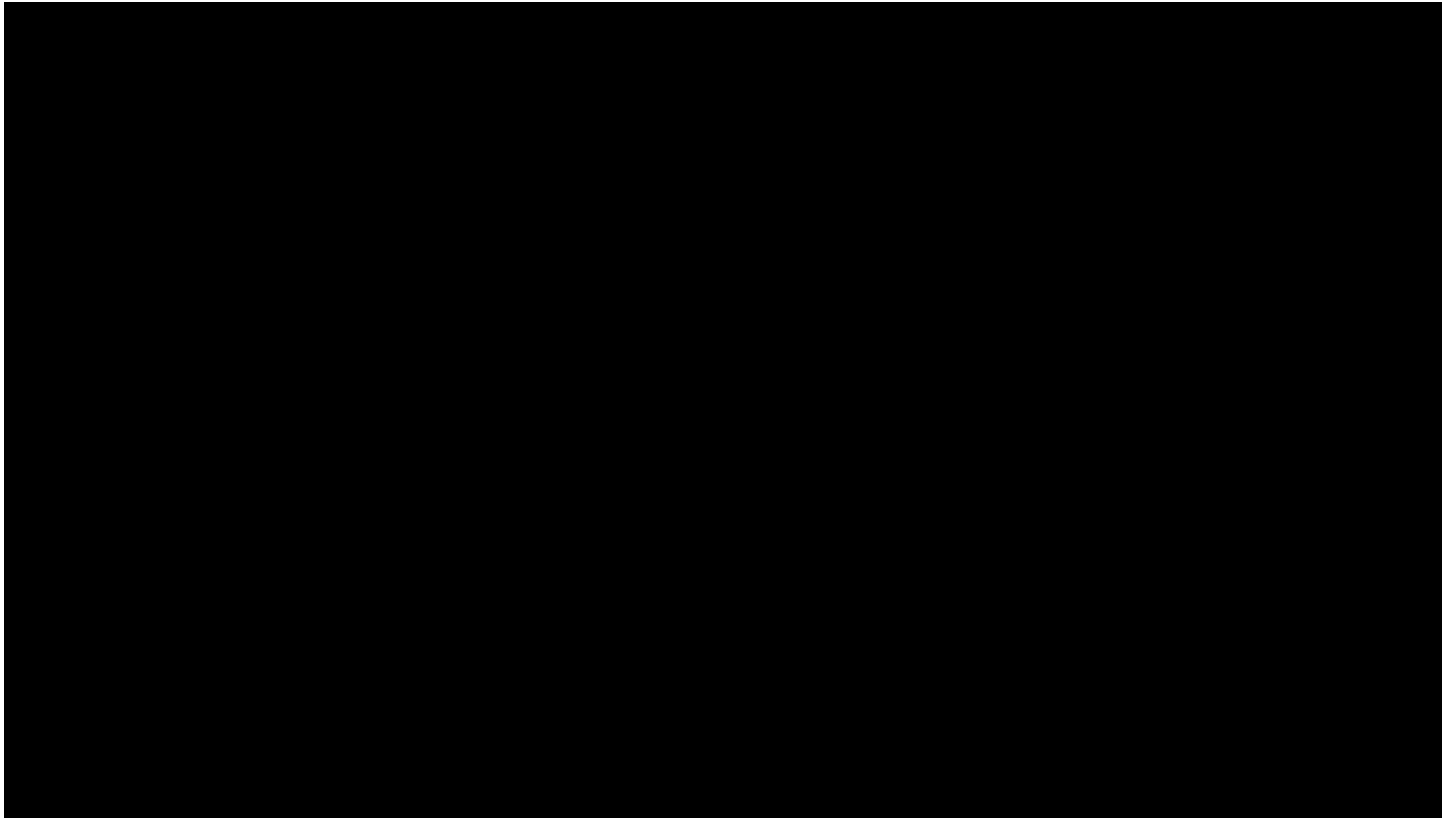
FOUNDING PRINCIPLES

- ▶ Empowerment, Equality, Inclusion, Access, Resilience, Meaning, Purpose

FOCUS AREAS

- ▶ Peer Support, Advocacy, Community Education & Research

www.dpc-ct.org



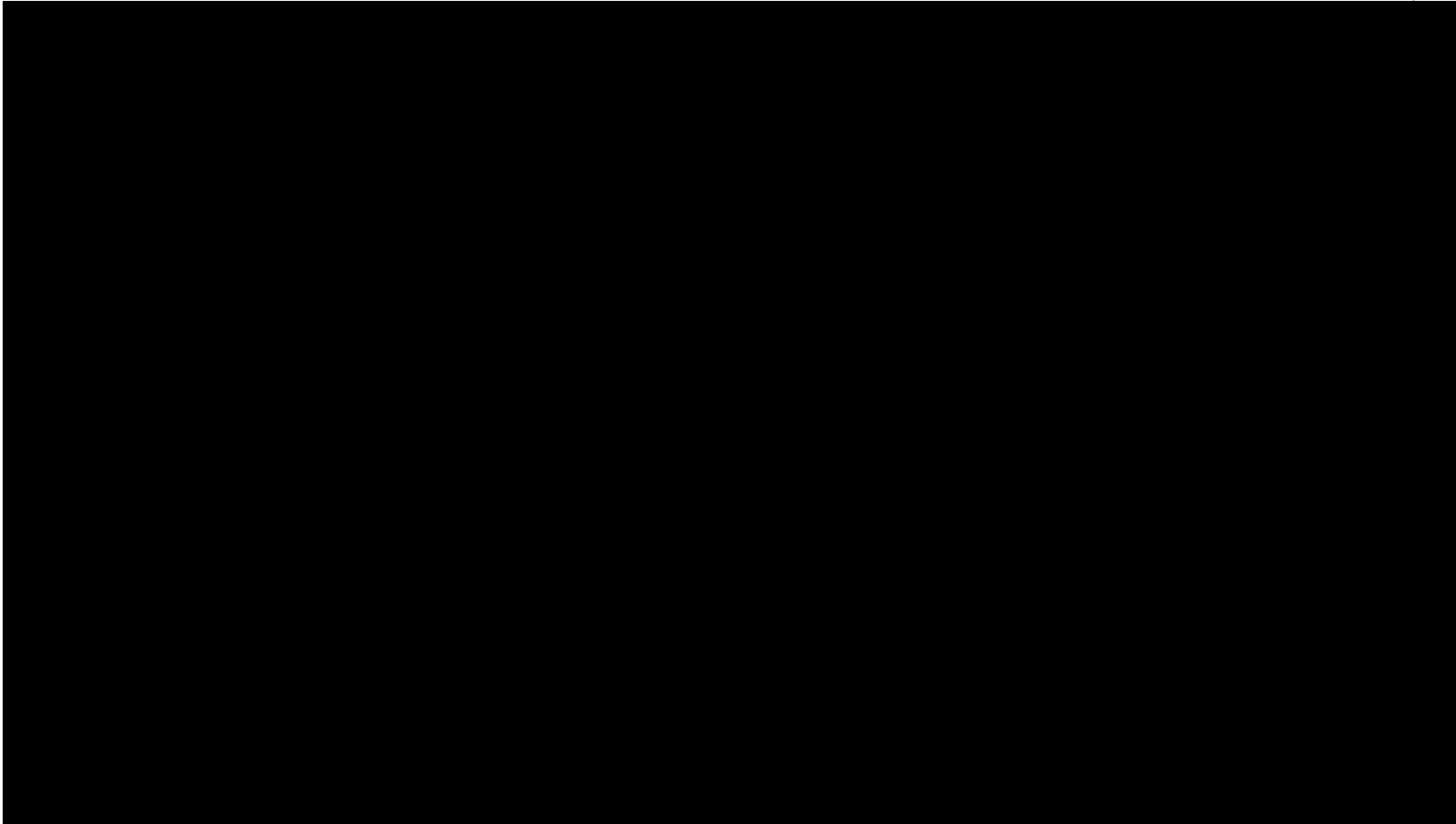
Bob Savage



Thoughts on Empowerment

- ▶ Why do we need to talk about empowerment?
- ▶ How do you shift your thinking from caring to empowering?
 - ▶ Reduce Stigma
 - ▶ Change perceptions
 - ▶ Ensure our human rights
 - ▶ Increase access, inclusion and disability rights
 - ▶ Empower us

Empowerment - Charles Michalak



DPC - Support Groups

- ▶ Peer Support Groups
 - ▶ Southington Senior Center: 1st Mondays
 - ▶ Bristol: Dr. Reyes's office - 2nd Wednesdays
 - ▶ Farmington: Last Tuesdays
 - ▶ Hamden: July 25th, 4th Thursdays
 - ▶ Zoom Video Conference: 3rd Wednesdays
- ▶ Based on Alcoholics Anonymous format

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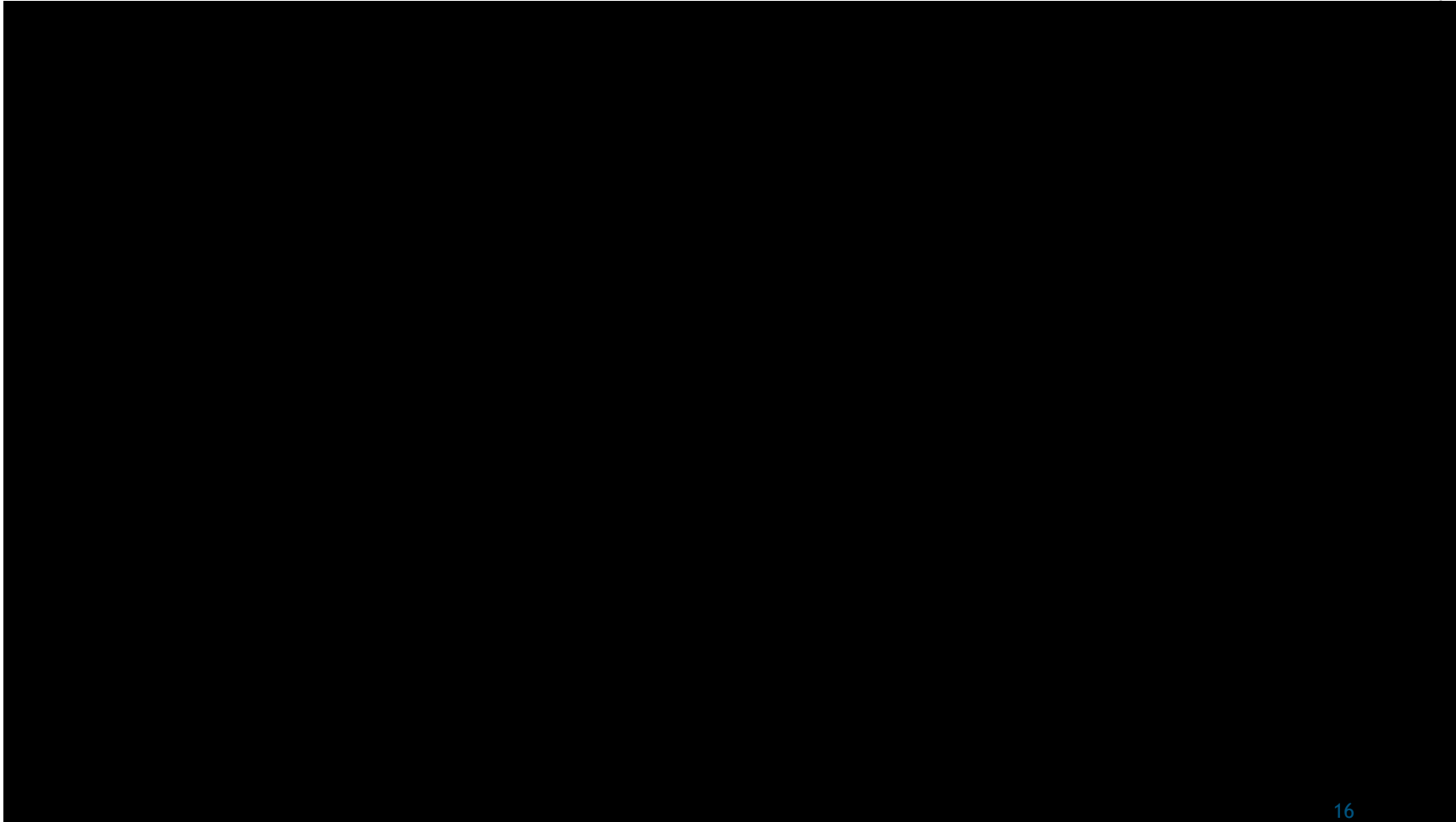


Peer Support Group - format

- ▶ Standardized group format (similar to AA)
- ▶ 4 meetings per month - 3 in person, 1 Zoom Video Conference
- ▶ In Person Meeting Format
 - ▶ Review Meeting format (rotate peer leader)
 - ▶ 5 minutes of sharing issues people are facing
 - ▶ Choose 1-2 issues for additional exploration
- ▶ Zoom Meeting Format
 - ▶ Review Meeting format (rotate peer leader)
 - ▶ 1-2 themes based on previous meetings
 - ▶ Each meeting participant is invited to share (up to 5 minutes) their experiences and perspectives on the topic



On Peer to Peer Support



DPC - *REACH*

Research, Education, Advocacy, Community Happenings

- ▶ Bi-Monthly Meeting: 1st Friday September, November, January, March, May, July , 11:00-12:30 pm
LiveWell, 1261 S. Main St. Plantsville, CT and via Zoom
- ▶ Focuses on opportunities in:
 - ▶ Research
 - ▶ Community Education & Public Awareness
 - ▶ Advocacy
 - ▶ Social Events - upcoming memory cafes, etc.

(not a support group)

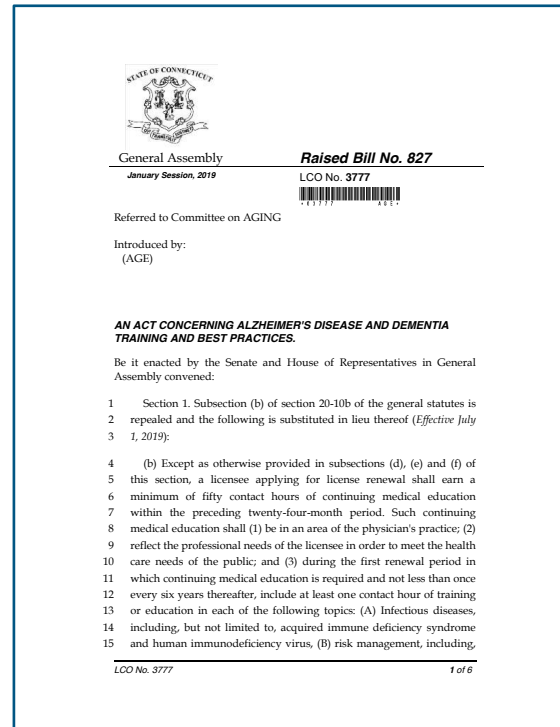


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DPC - Advocacy Efforts

- ▶ Testimonies at Legislative Office Building
- ▶ Letters to local and national government officials
- ▶ Lobby days

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Public Awareness and Education Events



Living with Alzheimer's

Presented by:
Geri and Jim Taylor
Alzheimer's Activists and Nationally
Noted Speakers



**Thursday,
November 16th
7:00PM**

Stolba Center
Alzheimer's Resource Center
1261 South Main Street
Plantsville, CT 06479

Admission is free.
Please register by calling:
(860) 628-9000

Geri Taylor, diagnosed five years ago with Alzheimer's, and her husband Jim share their moving, positive story of living with the disease and a full, rewarding life. The Taylors' story was featured titled in the *New York Times* (5/1/16) *Fraying at the Edges*. Geri's career as a health professional provides unique insights into living fully with dignity and determination.



Dementia Friendly Efforts



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To whom I may concern®



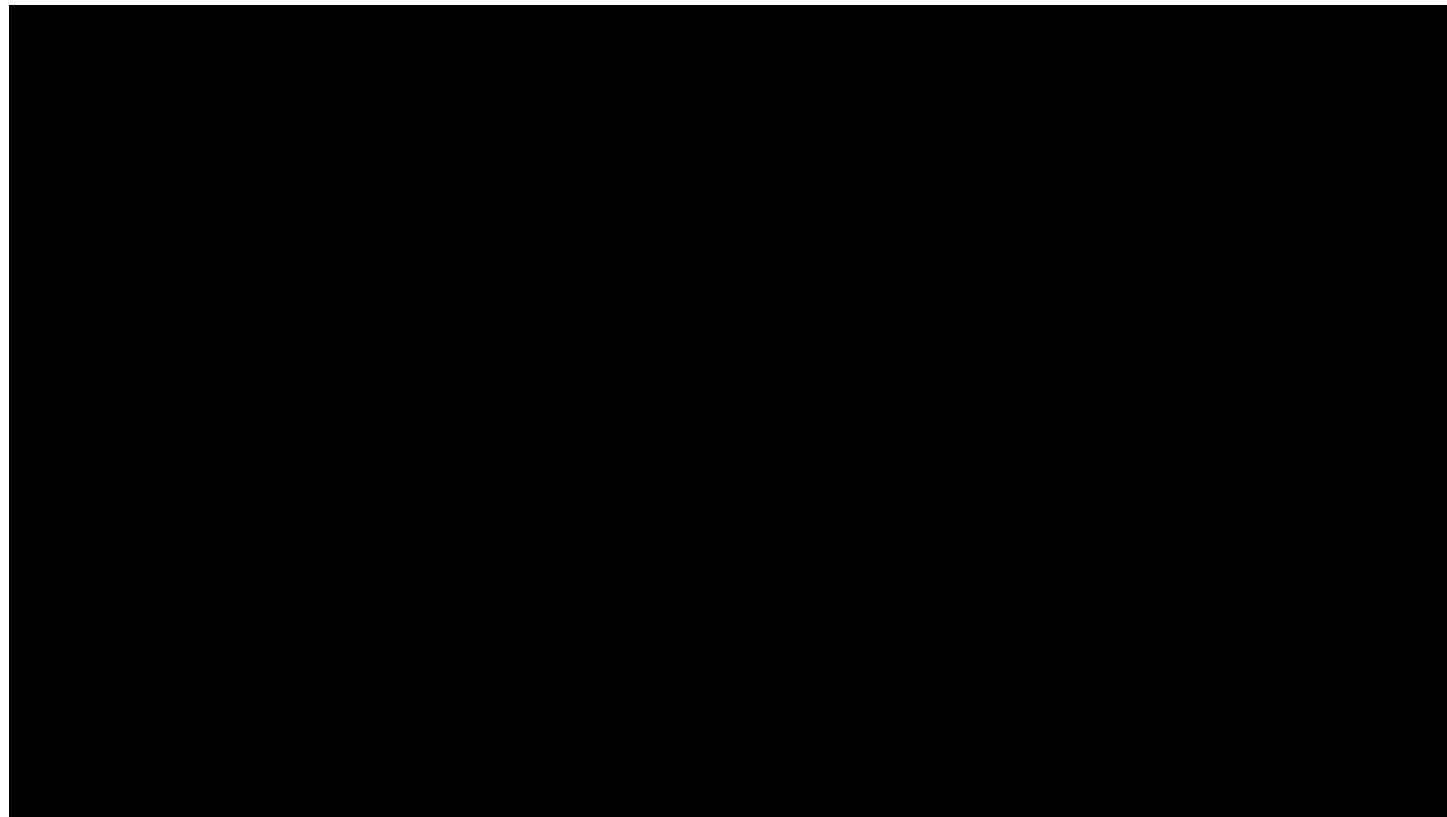
An interactive theater program designed to give voice to people in the early stages of dementia by creating their own script of stories, expressing their fear, anger, frustration, hope and determination – often with humor and love. Group members then share their stories and experiences with audiences made up of family members, peers, friends, care partners, and professionals.

www.towhomimayconcern.org

<https://vimeo.com/livewellct>



To whom  may concern®



<https://vimeo.com/livewellct>

DPC - Research

- ▶ Empowering Partnerships Training
- ▶ A-List and Surveys
- ▶ Advisors on research projects



**Empowering
Partnerships**

*Preparing People with Dementia
to Partner with Researchers*



The world's largest survey on attitudes
around dementia is now open!



**Alzheimer's Disease
International**
The global voice on dementia

Join us at ALIST4research.org



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Eugene Washington PCORI Engagement Award

September 2018 - August 2020

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Who is PCORI?

Patient Centered Outcomes Research Institute

<https://www.pcori.org>

Mission:

PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

PCORI is funded through the Patient-Centered Outcomes Research Trust Fund (PCOR Trust Fund), which was established by Congress through the Patient Protection and Affordable Care Act of 2010.

PCORI Engagement Principles

- ▶ Reciprocal relationships
- ▶ Co-learning
- ▶ Partnership
- ▶ Transparency, honest, and trust



**Empowering
Partnerships**

*Preparing People with Dementia
to Partner with Researchers*

What is a Eugene Washington Engagement Award?

Supports projects that...

encourage active integration of patients, caregivers, clinicians, and other healthcare stakeholders...

as integral members of the research process



Our 2-year project

Build the capacity of people living with dementia and their caregivers to engage in research:

1. Expand and strengthen the Dementia Peer Coalition
2. Provide a training program that prepares persons living with dementia, care partners and researchers to **partner in research**

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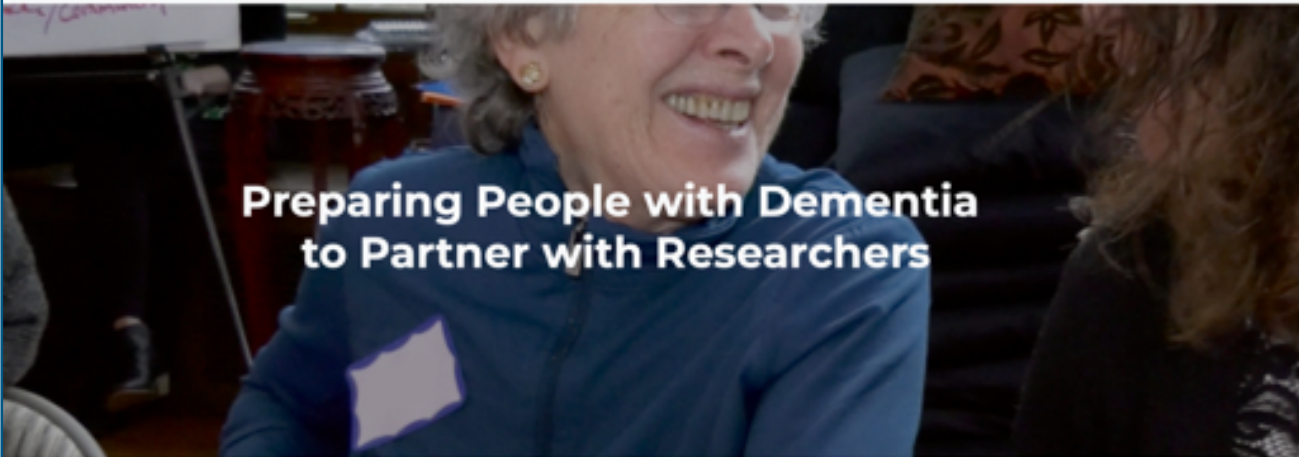
COALITION



Our 2-year project

3. Create and prioritize a list of research topics - what matters to you!
4. Take what we learn and share it with others!





Preparing People with Dementia to Partner with Researchers

[Training Events](#)[Project Background](#)[Project Team](#)[Co-Research](#)[Dementia Peer Coalition](#)[Eugene Washington PCORI
Engagement Award](#)[News](#)[FAQ](#)[Contact Us](#)[Find us on Facebook](#)

Empowering Partnerships engages individuals with dementia and caregivers as co-researchers

Empowering Partnerships is designed to build a network of people living with dementia throughout Connecticut who are prepared to engage in the research process. Join us this Fall for a 2-day training program to learn about research and ways to promote partnership – not just participation. Identify and prioritize research topics that support well-being, and learn ways to include people living with dementia in all aspects of research – study design, implementation and dissemination.

The goal of this project is to empower persons living with dementia to align the direction of research with their priorities and issues of concern – “Nothing about us, without us!”. By training persons living with dementia, caregivers and researchers in ways to co-partner in research design and methods, new services to support living well with dementia can ultimately be created.

This project will strengthen the Dementia Peer Coalition – a growing peer coalition of people in the early stages of dementia – and grow their capacity to engage in patient-centered outcomes research and clinical effectiveness research by:

www.empoweringpartnerships.livewell.org

Partnering in Research



**Empowering
Partnerships**

*Preparing People with Dementia
to Partner with Researchers*

Traditional Research

- ▶ Persons with dementia are the subjects of research

Research Partnerships

- ▶ View persons living with dementia as experts of the lived experience of dementia who can participate in all aspects of research on dementia care and services by:
 - ▶ Planning studies
 - ▶ Conducting studies
 - ▶ Sharing the results of studies

Benefits of Partnering in Research



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- ▶ Opportunities to:
 - ▶ Share what matters to YOU
 - ▶ Advance research related to dementia
 - ▶ Socialize with others
 - ▶ Give back and help others
 - ▶ Reduce the stigma about abilities of persons living with dementia to contribute to society
 - ▶ Improve self-esteem and self-worth

Shaping research questions



Why Participate in Research?

Quotes from Researchers



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- ▶ “I think it’s important for me as a researcher to know what’s important to the people who are enrolling in my studies. If we could listen carefully to what they tell us that could benefit so many families who are living with dementia.”
- ▶ “There have been more pioneering researchers who have engaged persons living with dementia in the design of their studies, but they’ve been few and far between.”



Why Participate in Research?

Quotes from Persons Living with Dementia

- ▶ “I was comfortable in contributing my knowledge because I knew I had something valuable to offer.”
- ▶ “To develop trust, researchers need to stop making assumptions about what the person with dementia can contribute. Researchers may find themselves surprised at how much they can gain just by asking the person with dementia.”



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An Invitation: Empowering Partnerships Training



- ▶ If you are a person living with dementia or a care partner, we invite you to learn about how to partner with researchers. You are **EXPERTS** with lived experiences with so much to offer!
- ▶ *Empowering Partnerships* will bring persons living with dementia together with researchers for a 2-day training session designed to help all participants learn how to best **PARTNER** with one another to leverage the expertise of **ALL** participants

Commitment and Cost of the Training



Empowering Partnerships

Preparing People with Dementia to Partner with Researchers

What is the Commitment?

- ▶ Attend a Welcome & Orientation session, and 2-day Empowering Partnerships training.
- ▶ Participate in surveys and interviews before and after the trainings

No Cost to Participate in 2 day training!

- ▶ Participants are paid \$50 per day, meals are included during the 2-Day Training are included, and transportation will be provided if needed.

Dementia Alliance International

“It is imperative that there is nothing about us without us. It is our undisputed human right. Quite simply this means that anything about people with dementia should involve people with dementia. And not just one person with dementia - as many as possible.”

*John Sandblom, DAI Founding Member
ADI Conference, Chicago, 2018*



NEXT STEPS

- ▶ If you are a person living with dementia, inquire about joining the Dementia Peer Coalition. Or, if you know someone living with dementia, let them know about the DPC!
- ▶ Attend a Welcoming/Orientation Session to learn more about Empowering Partnerships in Research!

Sign-up sheets available

Questions

- ▶ What resonates with you?
- ▶ What questions do you have?
- ▶ What more do you want to know?

Save these dates!



**Empowering
Partnerships**

*Preparing People with Dementia
to Partner with Researchers*

Welcoming & Orientation Sessions
August 26, 28 & 29

2 Day Training
October 9 & 10

More info? Want to get involved?

www.dpc-ct.org

info@dpc-ct.org

860-628-3080



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