

The Conversation Project: Including Alzheimer's-specific Programming Into Your Work

October 17, 2018



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Naomi Fedna

WebEx Quick Reference

Welcome to today's session!

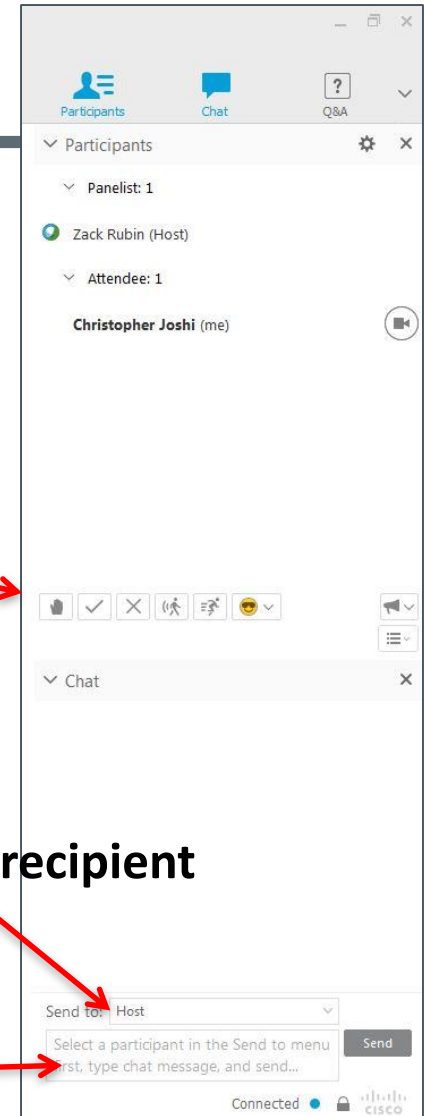
Please use Chat to “All Participants” for questions

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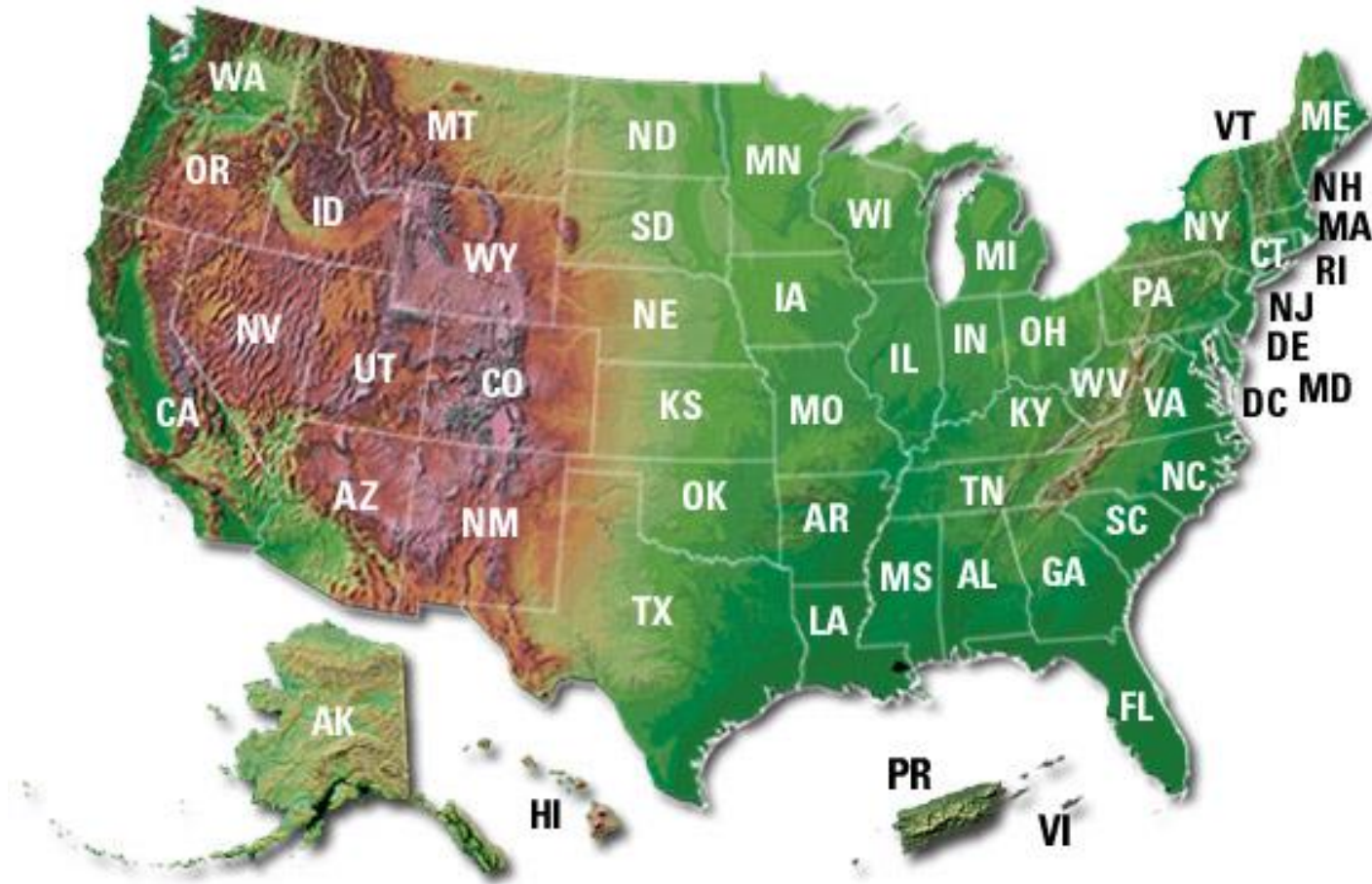
Ice Breaker Question

Type into the chat box your response to the following question:

How did you learn about this call?

Make sure you send your message to “All Participants.”

Where are you located on the map?



Chat

- What type of ACP/TCP-related work you are doing right now?
- What experience do you have with integrating dementia/Alzheimer's-specific programming into your ACP work - **Newbie, Seasoned, Somewhere in between?**

Session agenda and objectives

- Background & what we've learned
- Community highlight: PeaceHealth, Bellingham, WA
- Q&A
- Discussion: Share strategies
- Additional resources, upcoming calls and events



A public engagement campaign dedicated to assure
that everyone's wishes for end-of-life care are
expressed and respected.

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What
Matters TO
Me?

As Well As

What's the
Matter with
Me?

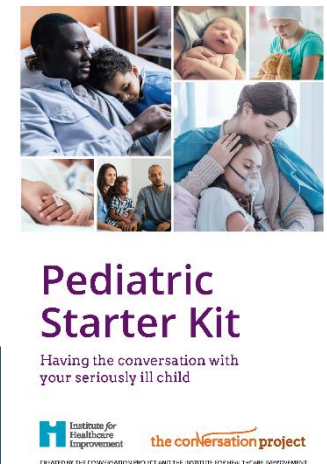
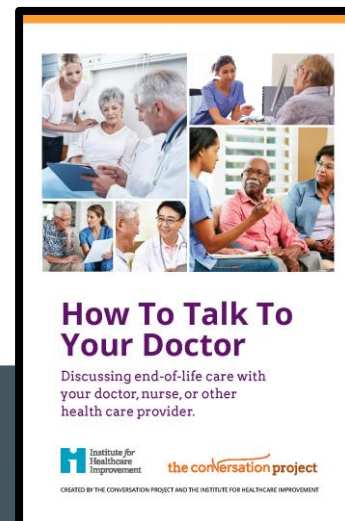
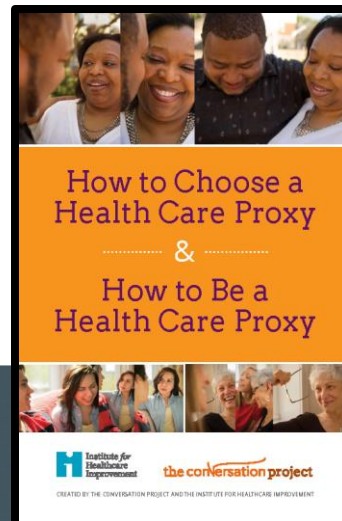
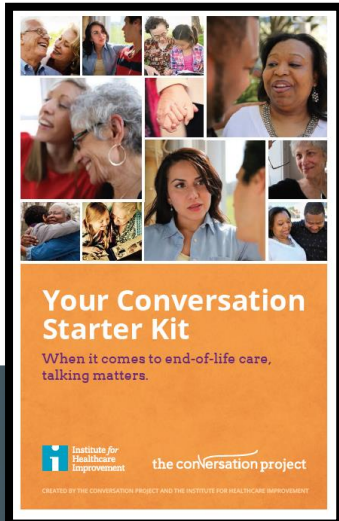
Public Awareness Community
Engagement

Health Systems Transformation



Our Tools

- Conversation Starter Kit
- Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia
- How to Choose/Be a Health Care Proxy
- How to Talk to Your Doctor Starter Kit
- Pediatric Starter Kit for Parents of Seriously Ill Children





Your Conversation Starter Kit

For Families and Loved Ones of People
with Alzheimer's Disease or Other
Forms of Dementia



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CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

What have we learned?

- Using the AD/dementia starter kit in a workshop setting works well!
- Camaraderie forms between family/caregivers as you walk through kit together



What have we learned?

- Can use the Starter Kit along the spectrum
 - Upon Diagnosis – Affected person engaged
 - Mid-Stage – Moments of connection
 - Later-Stage – Building consensus with circle of care around patient's values

What have we learned?

- Remind caregivers to keep your loved one at the center
 - Focus on what she would want
 - What he would say if she were able to?
 - *How would Mom answer this question?*
 - *“What mattered most to Dad?”*
- Encourage caregivers to bring their loved ones in the room

What have we learned?

IS ADVANCED DEMENTIA A TERMINAL ILLNESS?

Yes, dementia is a terminal illness. This means that patients with advanced dementia commonly die from complications caused by this disease. Some people have a hard time understanding that dementia is a terminal illness. It may help to imagine a patient who died with widespread cancer. If this patient had pneumonia or eating problems in the last few weeks of life from the weakened state caused by the cancer, most people would still consider cancer the underlying cause of death. In the same way, the bodily functions and defenses of patients with end-stage dementia are weakened. As a result, they often get pneumonia or eating problems near the end of life, but advanced dementia is still the underlying major illness leading to these complications and death.

From "Advanced Dementia: A Guide for Families," created by an interdisciplinary team from Hebrew SeniorLife and Beth Israel Deaconess Medical Center: Susan L. Mitchell, MD, MPH, Angela G. Catic, MD, Jane L. Givens, MD, MSCE, Julie Knopp, APRN, MSN, and Julie A. Moran, DO.

What have we learned?

- Take time to acknowledge the caregivers
 - Focus on kindness, compassion and courage
- Acknowledge the barriers they may feel
 - Unkind, denial, fear, loss, anger
- Emphasize the Conversation lets their loved ones know they will be there for them
- Caregivers find the process of considering what their loved one might want very helpful



A close-up photograph of a person's hand holding a dandelion seed head. The person is wearing a blue jacket. The background is a field of tall, green grass. The image is used as a background for a text overlay.

ACP+D

.....*Advance Care Planning for those with Dementia*

THE **IMPORTANCE** OF ADVANCE CARE PLANNING

- Makes my wishes for treatment known
- Empowers family members and provides a road map for care
- Reduces conflict among loved ones
- Eliminates painful doubts and questions that can never be answered after a loved one dies

PLANNING AHEAD FOR DEMENTIA: TOOLS YOU CAN USE

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Planning for living w/ dementia

Road Map

EOL-WA's "Dementia Directive"

Conversation Starter Kit

Planning for dying w/ dementia

Dr. Gaster's "Health Directive for Dementia"

EOL-WA's "Instructions for Oral Feeding and Drinking"

HOW DOES DEMENTIA CHANGE THE ACP PROCESS?

The person with dementia may

- Not be aware of their condition
- Not understand the disease or how it progresses
- Forget what you discussed or change their mind often; surprise you with new ideas or values
- Tell different people different things
- Become distrustful
- Refuse to talk about their health . . . let alone dying
- Refuse to sign anything
- Agree with anything anyone tells them

HOW (ELSE) DOES DEMENTIA CHANGE THE ACP PROCESS?

- Someone will likely have to be part of the support and decision-making process much **earlier** and much more **actively**
- Why? Possibly to:
 - Deal with the pharmacy & oversee medications
 - Observe and get treatment for things that the person with dementia has a hard time identifying or denies
 - Oversee doctor visits and hospital stays
 - Make decisions about what to treat, and how
 - Steer the person to get diagnosed in the first place
 - Deal with many non-medical issues that come up, such as . . .

A TOOL FOR EXPLORING ISSUES

ALZHEIMER'S DISEASE/DEMENTIA MENTAL HEALTH ADVANCE DIRECTIVE

- Outside caregivers
- Out-of-home placements
- Financing future care
- Future intimate relationships
- Care of pets
- Participation in research
- Driving



A TOOL FOR GETTING THE CONVERSATION STARTED

.....

Step 1 Get Ready

“Should I have the conversation with my loved one?”

- What if he insists that “there’s nothing wrong” with him?
- What if she says she doesn’t want to have the conversation?

We know how hard it can be to start conversations about end-of-life care with a loved one. The primary reason we give for postponing the conversation is telling ourselves that “it’s too soon.” But as we say in The Conversation Project, “It’s always too soon until it’s too late.”

This is especially true when the people we love begin to lose their memory, their cognitive ability — word by word, step by step — along with their ability to function in the world. And at no time is the need to have these conversations greater.

A TOOL FOR CONSIDERING QUALITY OF LIFE ISSUES

Dr. Gaster's Health Directive for Dementia

A simple 5-page document that helps you match goals for medical care to the stage of the disease and the symptoms being experienced.

So for each stage . . .

- ▶ Mild**
- ▶ Moderate**
- ▶ Severe**

You can indicate which level of treatment you'd want

- ☐ **To live for as long as I could.** I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.
- ☐ **To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine.** Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.
- ☐ **To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill,** and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.
- ☐ **To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness.** I would not want any care that would keep me alive longer.

WHAT IF YOU DON'T WANT TO LIVE WITH DEMENTIA?

- Fingers crossed!
- Modify diet and behavior?
- Early diagnosis, medication, participate in research?
- Voluntarily Stopping Eating and Drinking (VSED)
- Possible “off ramps”
 - Opt out of or discontinue life-saving treatments (pacemaker, dialysis)
 - Infection (UTIs are common)
 - Pneumonia
 - Complications following a fall
- People with dementia are unable to qualify for the Death with Dignity Act because by the time they are eligible to receive a terminal diagnosis with a six-month prognosis, they are no longer deemed mentally competent.

TOOLS FOR THE CONVERSATION

- Dementia Road Map: Guide for Family and Care Partners
 - Search “AL TSA Dementia Road Map” on the Internet and click on the link that is a pdf
- The Conversation Project’s “Starter Kit”
<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf>
- End of Life Washington’s “Dementia Directive”
<https://endoflifewa.org/alzheimersdiseasedementia-advance-directive/>
- Dr. Gaster’s “Health Directive for Dementia” <https://dementia-directive.org>
- End of Life Washington’s “Instructions for Oral Feeding and Drinking”
 - <https://endoflifewa.org/documents/>

FOR ADDITIONAL INFORMATION

Contact Adrienne Doucette and Denise Weeks,
Creators of ACP+D course in Bellingham, WA
acpdementia@gmail.com

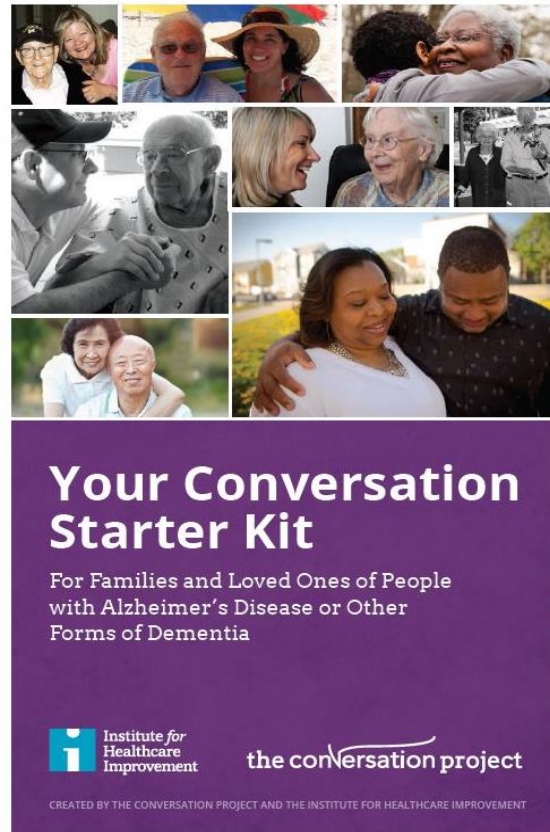
Discussion

- Comments, thoughts, what's resonating?
- Share your strategies, ideas – what is working, not working?
- What questions are you hearing?

Additional Resources, Upcoming Calls and Events

TCP: Conversation Starter Kit (free download)

www.theconversationproject.org



Compilations

● Recent TCP blog:

- <https://theconversationproject.org/tcp-blog/promoting-the-importance-of-care-conversations-with-individuals-with-dementia-or-alzheimers-12-articles-resources-to-put-on-your-radar/>

● NY Times article: Leading an Active Life With a Diagnosis of Dementia

- <https://www.nytimes.com/2018/10/05/business/-active-life-diagnosis-of-dementia.html?smprod=nytcore-ipad&smid=nytcore-ipad-share>

12 Articles/Resources About Sparking Conversations and Caring for Dementia & Alzheimer's Disease

Posted on 10/03/2018



There's been a buzz lately: a steady stream of interesting stories in the news and articles being published about caring for those with dementia and, specifically, Alzheimer's Disease. And, in The Conversation Project's own backyard, the State of Massachusetts has become the first-in-the-nation to have legislation on Alzheimer's. Read more [here](#) on how this pioneering law will boost Alzheimer's care. Improving the diagnosis and treatment of an illness afflicting 5.7 million Americans. As this topic is top of mind for TCP and many others, below is a sampling of recent articles and resources that have sparked our interest.

- **Community-wide resources to become dementia friendly:** Check out the **Dementia Friendly Massachusetts** grassroots movement and the adaptable resources (videos, checklists, etc.) they have for making communities safe, inclusive and respectful for persons with Alzheimer's disease, or a related dementia.
- **Targeted approach to dementia care:** This recent National Public Radio **article** highlights a behavioral approach to dementia care designed by a geriatric psychiatrist at the **Program for Positive Aging** at the University of Michigan in Ann Arbor. This approach emphasizes training and support for caregivers as the bedrock of support for the patient.
- **Targeted advance directives:** Read about the rise of advance directives that are targeted specifically towards individuals with dementia/Alzheimer's disease. Including the **Advance Directive for Dementia** created by Dr. Barak Gaster at

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Ellen Goodman
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Health Professionals

The New York Times

RETIRING

Leading an Active Life With a Diagnosis of Dementia



Alzheimer's Association Care Planning Toolkit (pgs. 50-51)

<https://www.alz.org/careplanning/downloads/care-planning-toolkit.pdf>

END-OF-LIFE CHECKLIST

50

Questions	Yes	No	Resources
Have wishes or desires for end-of-life care been discussed?			<p>Aging with Dignity Five Wishes agingwithdignity.org Provides resources for end-of-life planning.</p> <p>The Conversation Project theconversationproject.org Offers a guide for how to talk about the end of life.</p>
Is a power of attorney in place for financial needs?			<p>Alzheimer's Association* alz.org/care/alzheimers-dementia-common-costs.asp Provides information on costs to expect and tips for financial planning.</p>
Is a power of attorney in place for health care decisions?			<p>National Association for Elder Law Attorneys naela.org Offers a directory of elder law attorneys.</p>
Is palliative or hospice care appropriate for the patient?			<p>National Hospice and Palliative Care Organization nhpco.org/find-hospice Provides information about hospice and palliative care and local hospice and palliative care organizations.</p>

PATIENT AND CAREGIVER RESOURCES

51

Caregiving

Administration on Community Living
alzhimers.gov
 Supports individuals living with Alzheimer's disease or other dementias and their caregivers by increasing access to community resources.

Aging Life Care Association
aginglifecare.org
 Locate a geriatric care manager.

ALZConnected*
alzconnected.org
 Online community that connects individuals facing the disease and provides online support.

Alzheimer's Association*
alz.org
800.272.3900
 Provides disease education, support groups, and personalized care consultation in person, online and through a free 24/7 Helpline.

Alzheimer's Disease Education and Referral (ADEAR)
nia.nih.gov/alzheimers
800.438.4380
 Offers disease information online or by phone for individuals with Alzheimer's or other dementias and their families.

Community Resource Finder
alz.org/CRF
 Find local programs, resources and support services.

Family Caregiver Alliance
caregiver.org
 Offers support for family and friends providing long-term, in-home care.

Eldercare Locator
eldercare.gov
 Connects older adults and their caregivers with local services and provides resource referrals and contact information for state and local agencies on aging.

Safety

Aging Life Care Association
aginglifecare.org/ALCA/About_Aging_Life_Care/Find_an_Aging_Life_Care_Expert/ALCA/About_Aging_Life_Care/Search/Find_an_Expert.aspx?key=7b6cb03-e912-4993-9b68-df1573e9dbaf

Alzheimer's Association Dementia and Driving Resource Center
alz.org/driving

Alzheimer's Association Safety Center
alz.org/safety

American Occupational Therapy Association
myota.aota.org/driver_search

Car Safety Guides
thehartford.com/resources/mature-market-excellence/publications-on-aging

If You Live Alone
alz.org/fi-have-alz/fi-you-live-alone.asp

Medication Management: A Family Caregiver's Guide
nextstepincare.org/uploads/7file/Guides/Medication/Medication_Management_Guide/Medication_Management.pdf

Medication Safety
alz.org/care/dementia-medication-drug-safety.asp

Medi-Cog
pharmacy.umaryland.edu/practice/medmanagement/assisted_living/Tools-to-Assess-Self-Administration-of-Medication/

Simple Solutions: Practical Ideas and Products to Enhance Independent Living
thehartford.com/resources/mature-market-excellence/publications-on-aging

Staying Safe brochure
alz.org/national/documents/brochure_stayingsafe.pdf

Steady Materials for Health Care Providers
cdc.gov/steady/materials.html

Wandering and Getting Lost
alz.org/care/alzheimers-dementia-wandering.asp

End-of-Life

Aging with Dignity Five Wishes
agingwithdignity.org
 Resources for end-of-life planning.

Alzheimer's Association
alz.org/care/alzheimers-dementia-common-costs.asp
 Provides information on costs to expect and tips for financial planning.

The Conversation Project
theconversationproject.org
 Offers a guide for how to talk about the end of life.

National Association for Elder Law Attorneys
naela.org
 Offers a directory of elder law attorneys.

National Hospice and Palliative Care Organization
nhpco.org/find-hospice
 Provides information about hospice and palliative care and local hospice and palliative care organizations.

Upcoming events

- **Conversation Sabbath: Oct 26- Nov 4 #ConvoSabbath**
Hundreds of congregations sharing each faith's teachings on this critical topic and supporting congregants in having the conversation in familiar settings, and not during a medical crisis in the ICU.
- **Reimagine End of Life NYC, Oct. 27 - Nov. 3**, is a citywide, week-long collection of events exploring death, dying, bereavement, and celebrating life through the arts, spirituality, healthcare, and innovation.
- **Hospice and Palliative Nurses Association Campaign:**
#ISaidWhatIWant encourages all nurses to lead by example by establishing their own advance care plan.

Upcoming Community Calls

The next Conversation Project Community Call will take place on:

Wednesday, Nov 14th, 3:00-4:30 pm ET

Date and Time	Topic
Wednesday, Nov 14 th , 3:00 – 4:30 pm ET	Special interest: Ensuring equity, reaching diverse communities
Wednesday, Dec 19 th , 3:00 – 4:00 pm ET	Community Planning 101
Wednesday, Jan 16 th , 3:00 – 4:00 pm ET	Community Planning 201

We want your feedback!

- After this call you will be redirected to a Survey Monkey form

Please take a few moments to answer the following questions:

- How useful was this session on a scale from 1-5?
- Given today's topic, what would you like to learn more about?
- Any other comments on today's session?