

Empowering Partnership Network



Transforming the Experience of Living with Dementia

**Developing an Attachment Based Communication (ABC) Intervention
for Persons Living with Early-Stage Dementia and their Adult Children**

An Empowering Partnership Network
Appreciative Inquiry Workshop

Sponsored

By

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Welcome to the Empowering Partnership Network Appreciative Inquiry Workshop!

What is the Empowering Partnership Network?

The Empowering Partnership Network is a diverse peer network of partners:

- Leading a 'dementia positive' movement
- Promoting cognitive health
- Transforming the experience of living with dementia

The vision of this network is to make impact that matters through:

- Research
- Policy
- Practice

By participating in this workshop today, you have joined this movement by:

- Changing how research is traditionally done
- Becoming a partner in research
- Lending your voice and contributions to advance how a research intervention is designed and implemented

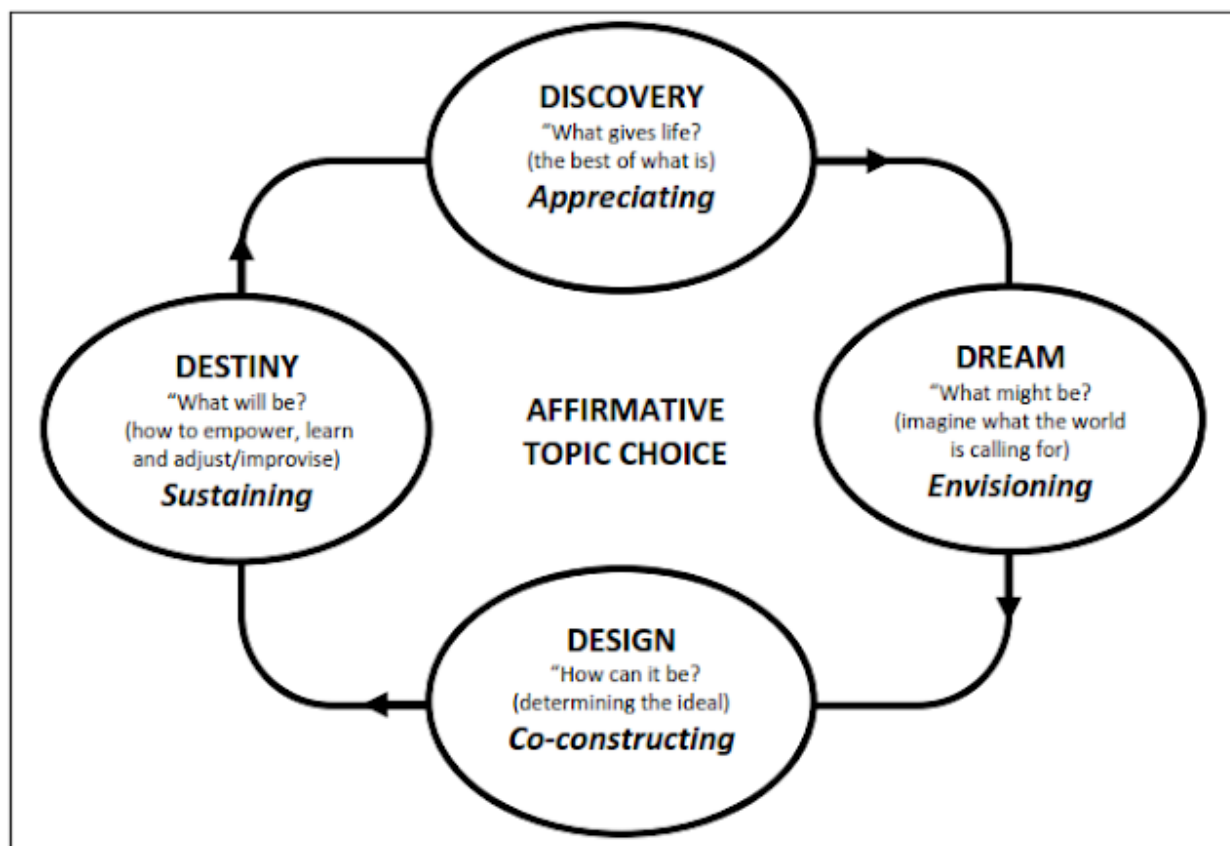
What is an Appreciative Inquiry Workshop?

An Appreciative Inquiry Workshop is created for a diverse group of people who care, to come together around an affirmative topic to:

- Address *important questions* to make positive change
- Design something better and more meaningful
- Propel curiosity, confidence, and hope

Appreciative Question: *How might a virtual, group-based intervention for parents living with early-stage dementia and their adult children assist with maintaining emotional communication and relationship quality?*

We will address this topic and question through the Appreciative Inquiry Process that entails the **4 steps of DISCOVERY, DREAM, DESIGN, DESTINY:**



Introductions and Seeing Strengths

In pairs at your table, introduce yourself.

Think of a time when you made a difference in the life of another person. Tell your partner a two-minute story.

Be specific. What happened? Why is this experience important or meaningful for you?

Partners listen and write down two strengths, values, or skills they hear in the story.

Guiding Principles for Our Time Together: How can we help each other be at our BEST?

Recommendations provided by person living with dementia (PLWD) have included:

- Empowering the person with dementia to respond first
- Resisting the urge to speak on behalf of people living with dementia
- Giving people living with dementia extra time to process and respond to questions (20- 90 seconds)
- Ensuring that when someone was speaking, that there not be side conversations
- Speaking clearly and projecting one's voice
- Paying attention to the speed with which people speak

Please share other recommendations with the full group.

DISCOVERY: APPRECIATE WHAT IS!

Why is this intervention important?

- In our society, post diagnosis of dementia we receive no information/guidance about how to emotionally communicate in relationships between adult children and older adult parents in ways that help prepare a care partner and care recipient and maintain the parent-child emotional bond.
- Parents and children may have to deal with difficult histories in these relationships and be faced with being a care partner or care recipient.

How will the Attachment Theory be useful in informing the invention?

- Attachment theory was first developed by John Bowlby to explain why infants become attached to their caregivers and emotionally distressed when separated from them. This theory suggests that in healthy parent child relationship, the child knows they can go to their parent in times of stress and they can count on the parent to be a secure base when they go out to explore.
- Support seeking and caregiving behaviors become important when partners are faced with one person's dementia. For parents with dementia, seeking support from their adult children may be confusing, as this is a role reversal.

What prior data has informed this project?

In a recent study “Attachment Behavior in Parent Child Dyads Coping with Early-Stage Alzheimer’s Disease and Related Dementias” the Yale project team enrolled 146 parent-child dyads in which the parent was living with early stage ADRD.

- In this study, both parents and children completed survey about their parent-child relationship. They also answered questions about their health and well-being and social networks. We also videotaped parents and children playing a game together, talking about their plans for the week, and how they had been managing the covid pandemic shutdown together. In addition, both the parent and the child each shared their concerns about the future given the parent is in the beginning stages of living with dementia. All of this was done at year 1 and year 2, so we can look at changes over time.

Key study findings include the following:

Changes from baseline evaluation to the one year follow up:

The Child	The Parent
Perception of relationship quality with the parent significantly declined	Perception of relationship quality stayed the same.
Depressive symptoms stayed the same	Depressive symptoms significantly increased

What was related to better relationship quality for both children and parents?

The Child	The Parent
Asking for emotional and practical support from their parent	Asking for emotional and practical support from their child
When the child is better at being an emotional caregiver	When the child and the parent are better at being emotional caregivers
Not using distraction as a coping style	Planning for the future

Based on the study findings, we suggest the following topics be covered in the group-based intervention over six virtual sessions:

- Introduction & understanding emotions and underlying needs in the self and other
- Communicating emotions and needs to another
- Regulating emotions and reactions to the other
- Offering responsive support
- Receiving responsive support
- Summary and Wrap-up

DREAM: IMAGINE WHAT MIGHT BE!

Create the ideal experience:

What will give you the highest level of motivation to participate in this virtual class experience?

What will give you the highest level of confidence to fully participate in this virtual class experience?

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DESIGN: DETERMINE WHAT SHOULD BE!

RECRUITMENT OF PARTICIPANTS:

What would entice you to participate? What is the language used? How is it described?

What is the best day and time? How would the group first meet?

What would you have to know about the outcomes?

MATERIALS/INFORMATION:

What materials are being provided? How are they presented? How do I prepare?

How will I know what to expect for each session?

What information will continue to entice and engage you as a dyad?

THE EXPERIENCE:

What is happening before the training begins?

What is important to know about creating virtual experiences?

What will support an ideal group experience and relationships with participants other than my child?

What will make the experience fun?

What happens when the program is over? How might the support and conversations continue?

NOTES:



Kate Swaffer

Thank you, Volume 2, 2016

*Two simple words
So often forgotten
Stalwart of my youth
For fear of tongue lashing
Seemingly less important
Today than then
But just as meaningful
And worthwhile
A smile and a thank you
Fills others' hearts with goodwill
Just a bucket full of love
To complete the wonder*

**Our deepest appreciation for participating in and joining the
Empowering Partnership Network movement!**