

Transforming the Experience of Living with Dementia

Bolstering Purpose in Life Following Diagnosis of Cognitive Impairment

An Empowering Partnership Network Appreciative Inquiry Workshop Sponsored

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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

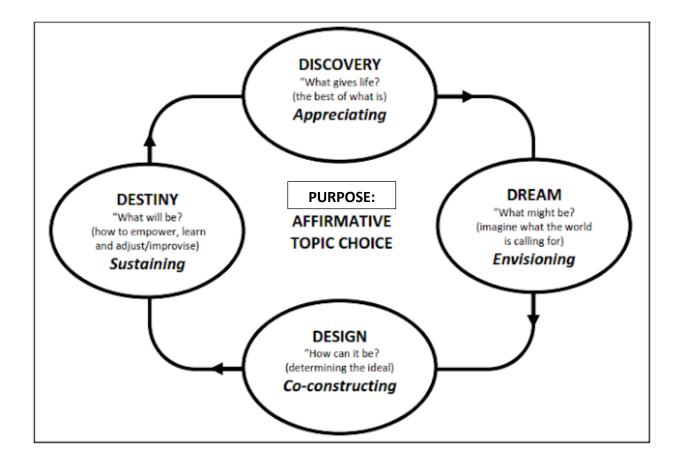
What is an Appreciative Inquiry Workshop?

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 we support persons living with cognitive change to maintain purpose following diagnosis?

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!

Maintaining Purpose: The LiveWell Approach[®] and The Psychologists' Views

The LiveWell Approach[®] empowers persons living with dementia and those that love persons living with dementia to maintain purpose by:

- Identifying what is personally meaningful
- Connecting with something bigger than themselves
- Supporting people to live their values
- Finding opportunities to contribute

Psychologist Views on Purpose:

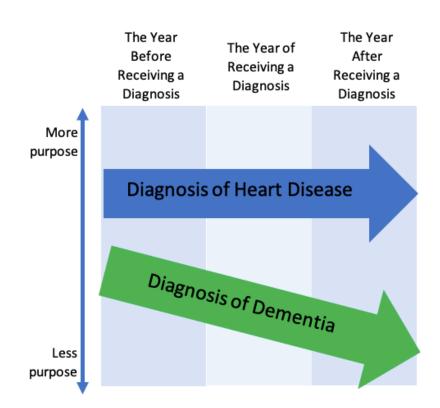
- A part of one's identity
- Motivates one to prioritize time and effort to achieve goals related to purpose
- Long-term commitment
- Influences one's behaviors, decisions, and choices in life
- Can be very specific or very broad
- One may not be fully aware of their purpose or be able to put it in words

Why is Talking About Purpose Important? Psychologists Agree That:

- Those with strong purpose are more likely to feel life is moving in a positive direction
- Purpose supports health and wellbeing
- Purpose supports quality of life
- More research is needed to understand the lived experience of those who report low purpose
- Uncontrollable stressors compromise purpose

Research from Yale and LiveWell: Why We're Here Today

• Our team found that the "stressor" of being diagnosed with dementia led to adults reporting *decrease purpose*



- Persons diagnosed with heart disease did not feel a noticeable change in purpose
- Persons newly diagnosed with dementia reported a decrease in purpose

Knowing that uncontrollable stressors compromise purpose, researchers have identified strategies to bolster purpose including:

- Identifying one's own strengths
- Reducing stigma and stereotypes
- Opportunities for meaningful engagement

How Healthcare Providers Can Help:

- Discover strengths of the individual
- Discover what is important and valued by the individual
- Adapt situations, environments, and tasks for meaningful engagement
- Utilize Occupational Therapists that specialize in working with people living with dementia and their loved ones to support purpose through a strengths-based and person-centered approach

DREAM: IMAGINE WHAT MIGHT BE! Guided Imagery Activity – "Our Deepest Purpose."

What do you know about your deepest hope for purpose in your life?

What helps you continue to have purpose in life?

What does it mean to have purpose in your life?

DESIGN: DETERMINE WHAT SHOULD BE!

Define Purpose: How do you define what purpose means to you?

For a person living with a diagnosis of dementia, how might this definition be different? Are there key words and language that should be used to describe purpose?

Access Purpose: How can we support people in connecting with their purpose?

What support do I need to identify my purpose? What support do I need to connect with my purpose? What will support me to continue to live my life with purpose?

Measure Purpose: How will you measure the impact of having purpose?

How will you know if you are achieving the goal of living your purpose?

• What will it look like? What will it feel like?

How will you know when you are not living your life's purpose?

• What will it look like? What will it feel like?

NOTES:

DESTINY: CREATE WHAT WILL BE!

Why is it important that researchers and persons with lived experiences collaborate in this effort?

How might all parties stay involved in the design and implementation of this research project?

What are the next steps?

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!