

# Empowering Partnership Network



*Transforming the Experience of Living with Dementia*

## ***A Strength Based Approach to Measure Living Well with Dementia***

An Empowering Partnership Network  
Appreciative Inquiry Workshop

Sponsored

By

**LiveWell**



**NIA IMPACT**  
COLLABORATORY  
TRANSFORMING DEMENTIA CARE

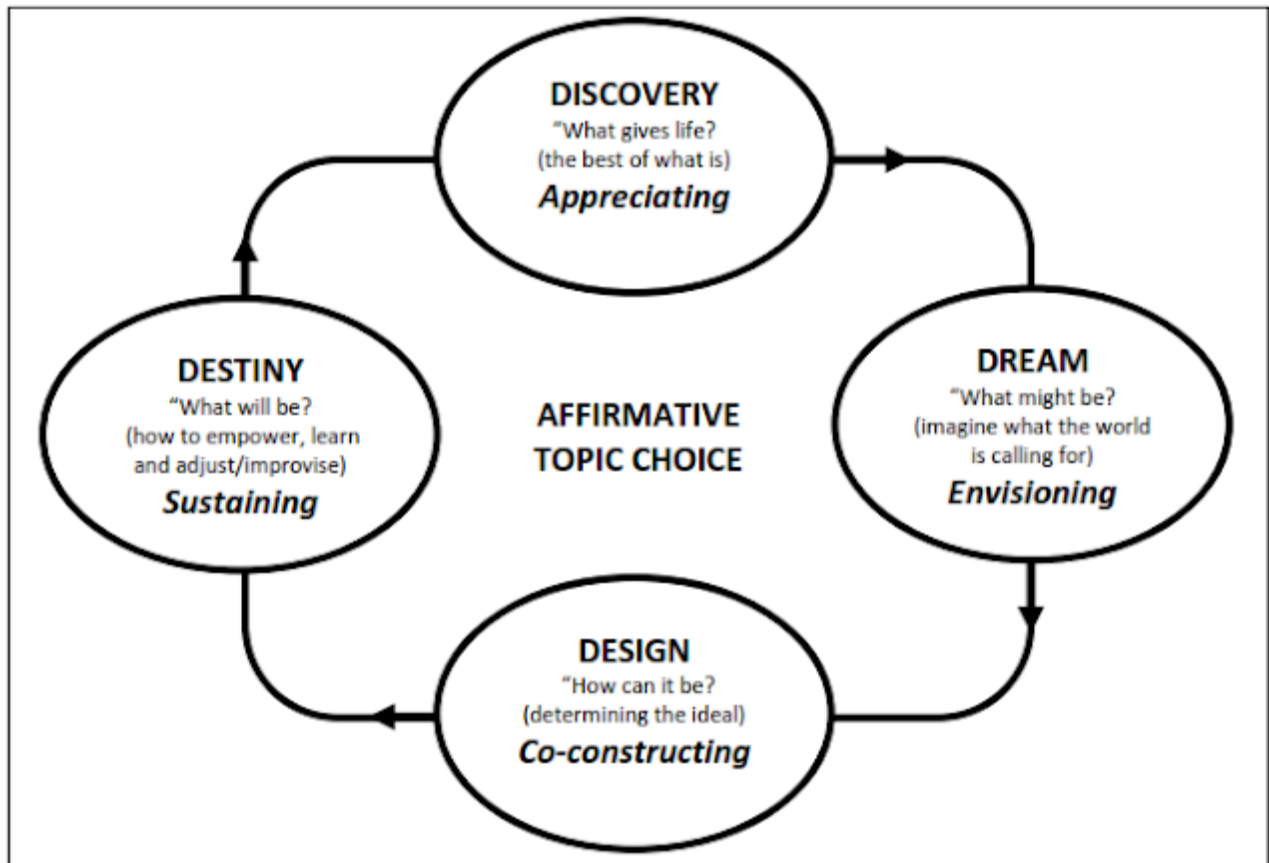
## What is an Appreciative Inquiry Workshop?

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 create a strength-based measurement tool that can be utilized for care planning?***

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



**Introductions and Sharing:**

Find something in your home to share that reflects who you are as a person. Introduce yourself and share.

**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

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## **DISCOVERY: APPRECIATE WHAT IT**

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### **WHAT IS THE PURPOSE OF THE LIVEWELL WITH DEMENTIA INVENTORY?**

The questionnaire focuses on practices that contribute to wellbeing for persons with cognitive change or dementia.

The measure is intended to be used in two ways:

1. A research tool to evaluate new ways of supporting people with cognitive change.
2. A planning tool to guide new practices and approaches to living well with cognitive change.

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### **HOW WAS THE SURVEY DEVELOPED?**

- The **Living Well with Dementia Inventory** was initially created from focus group interviews with individuals living with dementia who were asked “What does living well mean to you?”
- The 55-question questionnaire was reviewed and refined by persons living with dementia, care partners and researchers.
- Two independent groups judged the clarity and importance of each question and the items that received the highest ratings were used in the next phase of survey testing.
- A group of 17 people living with dementia took the survey and provided additional feedback.

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## WHAT WAS LEARNED DURING INITIAL TESTING OF THE SURVEY?

- Participant felt the questionnaire was clear and easy to use.
- Most people felt that the questionnaire should be used in future studies.
- Individuals shared more detailed information and stories in response to the questions.
- These findings suggest that the Living Well with Dementia Inventory is useful for future planning and supporting wellbeing.

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## WHAT CHALLENGES CAME UP DURING INITIAL TESTING?

- Some participants struggled with multiple choice responses and used “yes/no” responses instead.
- Some of the questions were duplicative and/or not as statistically strong.
- Some questions were not clear to all participants
- Some items were more likely to show agreement between care partners and persons with cognitive change.



## WHAT IS OUR HOPE FOR THIS WORKSHOP?

- The questionnaire has been revised and shortened to 20 questions.
- We would like your feedback on:
  - Wording of some questions and response options.
  - Clarity and importance of some of the revised questions.
  - Importance and usefulness of questions for people living with more advanced levels of cognitive change.
  - How might the questions support planning for wellbeing

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**SEE BELOW:**  
**REVIEW THE DRAFT LIVING WELL WITH DEMENTIA INVENTORY AND PLANNING TOOL**

## Living Well with Dementia Inventory |

The Living Well with Dementia Inventory was developed with feedback from persons with cognitive impairment and dementia, family partners, researchers, and others.

**At the workshop**, we will ask for your feedback on the Living Well with Dementia questions; we will not ask how you would answer each question.

1. Overall, are you living well with cognitive change / dementia?	
2. Are you able to do the normal, everyday activities that you would like to do?	
3. Are you satisfied with the amount of physical activity or exercise that you get?	
4. Are you satisfied with other things you do to stay healthy, such as healthy diet, enough sleep, keeping your brain active, spiritual practices, meditation, or other things?	
5. Are you satisfied with your ability to help others?	
6. Are you satisfied with the amount of time you spend doing things you really <u>love</u> to do?	
7. Do you feel as productive as you would like to be?	
8. Do you feel included by others in your social group?	
9. Are you able to get help from others if you need it?	
10. Do you feel a sense of meaning and purpose in your life?	
11. Do you manage stress well?	
12. When you are faced with a challenge, do you feel you can do something to improve your situation?	
13. When you cannot remember something or you struggle with a task, do you give yourself positive messages?	
14. Do you feel gratitude each day for what is good in your life?	
15. Do you have people in your life who value you for who you are?	
16. Do you have more positive experiences each day than negative experiences?	
17. Are you confident that you can improve your well-being?	
18. Are you confident that you can stay connected to people who are important to you?	
19. Are you confident that you can make new friends?	
20. How would you complete this sentence – “When I am unable to do something that I used to be able to do...”	<input type="radio"/> It does not bother me at all.
	<input type="radio"/> It bothers me but I move on quickly.
	<input type="radio"/> It bothers me for hours.
	<input type="radio"/> It bothers me a lot and spoils my whole day.

## Living Well with Dementia Inventory Planning Tool

The Living Well with Dementia Inventory may be used as a planning tool to support people to live well with dementia. **At the workshop**, we will ask for your feedback on the questions *below*, we will not ask how you would answer each question.

- 1) How has your condition affected (a) your ability to do things; (b) you feeling about yourself; and (c) your relationships with others?
- 2) Are there other everyday activities you would like to do?
- 3) What types of physical activity would you like to do?
- 4) Are there other things you would like to do to stay healthy?
- 5) What else would you like to do to help others?
- 6) What do you love to do?
- 7) What helps you to feel productive?
- 8) Do you feel included by others in your social group?
- 9) What else is important for others to know about helping you when needed?
- 10) What helps you to feel a sense of meaning? What helps you to feel a sense of purpose?
- 11) What helps you to manage stress?
- 12) When you are faced with a challenge, do you feel you can do something to improve your situation?
- 13) When you cannot remember something or you struggle with a task, do you give yourself positive messages?
- 14) Do you feel gratitude each day for what is good in your life?
- 15) Do you have people in your life who value you for who you are?
- 16) What are some recent positive experiences? What are some recent negative experiences?
- 17) Are you confident that you can improve your well-being?
- 18) Are you confident that you can stay connected to people who are important to you?
- 19) Are you confident that you can make new friends?
- 20) How would you complete this sentence – “When I am unable to do something that I used to be able to do...”



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## WHICH QUESTION IS WORDED BETTER?



Do you feel included by others in your social group?

**OR**



I feel included by others in my social group.

Also, which wording is better for someone with more advanced cognitive change?

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## WHICH QUESTION IS WORDED BETTER?



Do you feel as productive as you would like to be?

**OR**



I feel as productive as I would like to be.

Also, which wording is better for someone with more advanced cognitive change?

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## ARE THESE QUESTIONS CLEAR?



Are you confident that you can improve your wellbeing?



Are you confident that you can make new friends?

Also, can they be answered by someone with more advanced cognitive change?

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## LOOKING AT THE QUESTIONS ON THE LIVING WELL WITH DEMENTIA INVENTORY

- Asking about frequency, as in ....
  - Never
  - Not often
  - Some of the time
  - Most of the time
  
- Asking about agreement, as in ...
  - Strongly disagree
  - Disagree
  - Agree
  - Strongly agree



## IS THIS QUESTION USEFUL? WHY OR WHY NOT?

How would you complete this sentence: “When I am unable to do something that I used to be able to do...”

■ Response Options:

- It does not bother me at all.
- It bothers me but I move on quickly.
- It bothers me for hours.
- It bothers me a lot and spoils my whole day.

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**DREAM: IMAGINE WHAT MIGHT BE!**

You are filling out a survey that will assist you with evaluating and taking steps to enhance your wellbeing.

Describe the experience that will support your ability to take the survey.

Describe the process that will give you the support and confidence to take steps toward planning for your wellbeing.

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**DESIGN: DETERMINE WHAT SHOULD BE!**

**Wellbeing Questions:**

Are the revised questions important and clear? Which items are suitable for persons with moderate dementia?

What is the format of questions and answers? ( identify whether items should be worded in the first person (“I”) as opposed to the third person (“you”); and if response options of no/yes vs. disagree/agree)

Should items query “confidence” as opposed to “ability”?

**Experience of Survey:**

How long does it take to fill out the survey?

How am I filling out the survey?

What is an immediate follow up step upon completion?

**Planning Tools:**

What measures are useful for changing behavior or habits?

How might measures support an actionable plan? What information do I want to see to inform my plan? How will I prioritize what matters most to me?

Do I work with a peer, my care partner, and/or clinicians to create a plan? What would this process look like?

**NOTES:**

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**DESTINY: CREATE WHAT WILL BE!**

**Why is it important that researchers and persons with lived experiences collaborated in the design of this research intervention?**

**How might we stay involved in the design and implementation of this research intervention?  
What are the next steps?**

**NOTES:**

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**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!**