Serving People Living with Dementia: Programs and Interventions To Promote Social Engagement

September 19, 2022
Webinar Instructions

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• All participants are muted.

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  – To control closed captions, click on the CC Live Transcript button in the control bar at the bottom of the Zoom window

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USAGing

• USAGing represents and supports the national network of Area Agencies on Aging and advocates for the Title VI Native American Aging Programs that help older adults and people with disabilities live with optimal health, well-being, independence and dignity in their homes and communities.

• https://www.usaging.org/
Overview of engAGED

- National effort to increase social engagement among older adults, people with disabilities and their caregivers
- Administered by USAging
- Funded by the U.S. Administration on Aging, which is part of the Administration for Community Living
- Broad-based Project Advisory Committee
- www.engagingolderadults.org
Presenters

Susan Frick
Social Worker and Education/Recruitment Coordinator, Rush Alzheimer’s Disease Center

Harbhajan Khalsa
Program Director Dementia Capable Southern Arizona, Pima Council on Aging

Janice Lundy, MA, MHA, BSW
Director of Social Work and Geriatric Care Management, Perry County Memorial Hospital
Loneliness and Dementia

Susan Frick, MSW, LSW
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“I feel like I have fallen into a pit, and I don’t know how to get back.”

*Person with Alzheimer’s disease*
People with dementia say they feel . . .

- Left behind
- Ignored
- Disregarded
- Alone
- Isolated
Families share their own feelings of…

- Loneliness
- Abandoned
- Grief
- Anger

“As the disease progresses our social circles get smaller and smaller until it’s just us and our person with dementia.”

Caregiver of person with dementia
Living with dementia is a lonely experience

- Some loneliness comes from the disease process
  - But loneliness can come because of the world around them

We need to look at our own role in reducing loneliness for those living with dementia.
“I love coming here because we are all in the same boat together.”

*Person with dementia*
Creating Community

• Create opportunities for people with dementia to interact with others
• Encourage each person’s ability share their stories without judgment
• Recognize and value for what each person brings to the community
• Purposely consider community in all interactions with people
• Encourage love, laughter, and support
Additional Resources

Artwork from the **Without Warning Support Program**
www.withoutwarning.net

Video clip from the documentary
**Too Soon to Forget: The Journey of Younger Onset Alzheimer’s Disease**
www.toosoontoforget.net

TEDxElmhurst University Presentation by Susan Frick
**Loneliness and Alzheimer’s Disease**
www.youtube.com/watch?v=r_d3jzBU9nI&t=187s
Social Connection

Harbhajan Khalsa (she/her/ella)
Program Director, Dementia Capable Southern Arizona (DCSA)
Pima Council on Aging
Social connection is vital

Social isolation was associated with about a 50% increased risk of dementia.

Additionally, social isolation was shown to increase risk of heart disease by 29% and stroke risk by 32%.

Studies show that those who engage in social activities feel the effects of dementia less rapidly.

By creating a space for fun and connection, you are enhancing the lives of those living with dementia, their family, and caregivers.
Ways DCSA provides social connection

- Options Counseling
- Education
- Caregiver Support
- Dementia Friendly Community
- Memory Cafés
Memory Café

and just enjoy the experience.
What is a Memory Café?
Social gathering for individuals living with memory loss and their care partners

- Social & engaging
- Non-judgmental
- Safe & welcoming
- Personal connection
- Understanding & acceptance
- Shared experiences
Leave the diagnosis at the door

- make music
- share space
- enjoy yourself
- create art
- have fun
- create memories
Memory Cafés in Pima County

“I’ve made new friends. They understand what I’m going through, because they are living it too.”
~ Thomas M. (Memory Café participant)
Memory Café Take Aways

• Café launch party
• Bring a friend
• Connect with a local college or university for volunteers
• Listen to the folks in attendance, this is \textit{their} café
  • Ask core group for feedback
• Percolator Network
  • JF&CS Boston – Beth Soltzberg
Resources

- DCSA website:
  - DCSA.PCOA.org

- Visit www.jfcsboston.org/Percolator to find:
  - Free memory café toolkit and virtual/hybrid supplement, Spanish and English
  - PSA videos (English, Spanish and Portuguese)
  - Percolator Google Group
  - Recorded webinars
  - Quarterly idea exchange meeting archives
  - Sign up for mailing list

- Memory Café Directory
  - www.memorycafedirectory.com
Introduction to Cognitive Stimulation Therapy (CST): Make a Difference for Those with Dementia

Janice Lundy, MA, MHA, BSW

Director of Social Work and Geriatric Care Management
Perry County Memorial Hospital
Perryville, MO
Learning Objective

To introduce Cognitive Stimulation Therapy (CST) as an evidence-based psychosocial intervention for persons with mild to moderate dementia.
Cognitive Stimulation Therapy: Defined

- Cognitive Stimulation Therapy, CST, is an evidence-based group intervention for people with mild to moderate dementia. CST provides guidelines for structuring small, themed-based group sessions aimed to actively stimulate and engage, whilst providing an optimal learning environment and the social benefits of a group.
Background

• Dementia traditionally conceptualized from a medical perspective (Lyman, 1989).
• Considered an organic disease for which assessment, diagnosis and treatment guided by medical interventions.
• 1993: Kitwood: dementia prognosis dependent on environment; interpersonal relationships
• “Tacrine and psychological therapies in dementia: No contest?” (British Journal of psychiatry, Orrell & Woods, 1996)
What is CST?

• A brief group program, for people with mild to moderate dementia, living in a range of settings.
• 14 themed sessions, typically twice a week for 7 weeks. Includes word association / categorization, current affairs, food, and number games.
• Key aims: to improve cognitive functioning using techniques that exercise different cognitive skills.
• Achieved through a variety of means including, executive functioning tasks (e.g. categorization), multi-sensory stimulation, and reminiscence as an aid to orientation.
• Based on concept of ‘use it or lose it’: brain needs to be exercised in order for skills to be retained.
Development of CST

• CST was developed through systematic reviews of literature and pilot study*.

• Combined the most effective elements of different therapies to develop the CST program.
  • Reality Orientation
  • Reminiscence Therapy
  • Multi Sensory Stimulation
  • Validation Therapy

• 14 session program with themed activities (e.g. food, childhood).
• Designed to run twice a week for 7 weeks.
Session Structure

- Introduction
- Theme Song
- Current Affairs
- Main Activity
- Suggested activities for home
- Closure
Key Features of the Program

• 14 sessions, usually twice a week.
• Approximately one hour in length.
• Ideally 5-8 people in groups, run by two facilitators.
• Each session has choice of activities, to cater for interests and abilities of group.
• Group members should ideally be at similar stages of dementia, so activities can be pitched accordingly.
• Attention should be paid to gender mix.
### Key Principles

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<tr>
<td>1</td>
<td>Mental stimulation</td>
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<td>2</td>
<td>New ideas, thought and associations</td>
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<td>Using orientation, sensitively and implicitly</td>
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<td>Opinions rather than facts</td>
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<td>5</td>
<td>Using reminiscence as an aid to the here-and-now</td>
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<td><strong>Physical movement</strong></td>
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<td>7</td>
<td>Providing triggers and prompts to aid recall and concentration</td>
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<td>8</td>
<td>Continuity and consistency between sessions</td>
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<td>Implicit (rather than explicit) learning</td>
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<td>Stimulating language</td>
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<td>Stimulating executive function</td>
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<td>Respect</td>
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<td><strong>Involvement and inclusion</strong></td>
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<td>Maximising potential</td>
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<td>18</td>
<td><strong>Building / strengthening relationships</strong></td>
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How We Think CST Works

• Use it or lose it – taking part in mentally stimulating activities strengthens & creates new neuronal connections.

• Provides complexity, novelty & diversity required for transferrable cognitive gains (Moreau & Conway, 2014)

• Positive reinforcement of questioning, thinking about and interacting with objects

• Social environment is positive & stimulating

• QoL is mediated by improvements in cognition
<table>
<thead>
<tr>
<th>CST session themes</th>
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<tr>
<td>Physical games</td>
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<td>Sound</td>
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<td>Current Affairs</td>
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<td>Faces / Scenes</td>
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<td>Word Association</td>
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Session 6: Faces / Scenes
MCST 15

Level B:
• Prepare multiple (laminated) photographs of famous faces or of local scenes, to stimulate discussion. Give people one or more pictures and ask them to identify and allow discussion of people’s memories.

Level A:
• Give people one or more pictures of famous faces and ask for opinions, such as:
  • Who is the most attractive?
  • What do they have in common?
  • How are they different?
Level B:
• Get one person to pick from a selection of categories (e.g. men’s names) and letters. Get group to think of many words in that category beginning with that letter.

Level A:
• Place objects or pictures of objects on a table and ask the group to categorize them, for example items found in different rooms in the house.
• Place objects or pictures of objects on a table and ask the group to identify the ‘odd one out’.
Individual CST (iCST)

• The individual CST program is delivered by a relative, close friend, volunteer, or professional for:
  • 30 minutes a session
  • 3 times a week
  • over 25 weeks
  • Ideally same time each session
  • Each individual CST session consists of a themed activity (i.e. life story, discussion of current affairs, being creative) and is designed to be mentally stimulating.
  • Centered around fostering relationship
• CST provides guidelines for theme-based sessions aimed to actively stimulate and engage while providing an optimal learning environment with the social benefits of a group.

• The key principles are the foundation of CST and providing person-centered care.

• There are a variety of methods of CST delivery including group, individual, virtual, and with exercise.
Making a difference 1
Also available as a digital download
An evidence-based group programme to offer Cognitive Stimulation Therapy (CST) to people living with dementia
The manual for group facilitators
Almea Spector, Bob Woods,
Clareca M. Stoner & Martin Orrell
SECOND, REVISED EDITION

Making a difference 2
Also available as a digital download
An evidence-based group programme to offer maintenance cognitive stimulation therapy (CST) to people with dementia
The manual for group leaders
Eliza Aguirre, Almea Spector, Amy Streeton,
Juanita Roe, Bob Woods, Martin Orrell

Making a difference 3
Also available as a digital download
Individual Cognitive Stimulation Therapy: A manual for carers
VOLUME THREE
Lizanne West, Martina Klet, Mary Lou Huang,
Amee Bamford, Bob Woods, Vivien Ogilvie

https://hawkerpublications.co.uk/
engAGED Resources

• New! A re-launched and updated Community Awareness Toolkit
• Other resources:
  – Social Engagement Innovations Hub
  – Tips for holding Virtual Events manual
  – Videos
  – Consumer brochures
• Monthly newsletter and blog
• www.engagingolderadults.org
Commit to Connect

• Fostering a nationwide network of champions who are committed to addressing social isolation and loneliness
  – Online discussions
  – Communities of Practice
  – Peer Networking opportunities
  – Newsletter and resources

• Funded by ACL

• USAging serves as the Coordinating Center

https://committoconnect.org/
Questions and Discussion

Please submit your questions or comments through the Q&A.
Thank You!

- Please complete the survey which will be displayed in your browser after Zoom closes. There is also a brief 3-month survey.
- The recording will be available on [www.engagingolderadults.org](http://www.engagingolderadults.org).
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