Apathy and Leisure Activities for Persons Living with Dementia: Preserving Personhood and Dignity

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https://www.nebraskamed.com/nebraska-medical-center

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Overview

1) **Background: apathy overview**
2) Methods
3) Results
4) Discussion

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Background: Dementia

- 7.2 million Americans live with Alzheimer's disease in 2025
- Alzheimer's disease: 60-80% of all dementias
- Other dementia types: frontotemporal, vascular, Lewy body disease, mixed, Parkinson's disease
- Up to **13.8 million** people living with Alzheimer's disease by 2060

Alzheimer's Association (2025)

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Background: Apathy

- The state of being withdrawn, not engaged in activities, loss of interest and motivation

Apathy

Agitation

Often co-occur

For the person	For the caregiver
Social isolation	Stress
Decreased quality of life	Burden
Further cognitive decline	Frustration
Functional decline	
Increased mortality	

Volicer et al., (2018); Lansdall et al., (2019); Tierney et al., (2018); Nijsten et al., (2019); Merrilees et al., (2013)

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Background: Apathy

1) **Apathy**: the most common neuropsychiatric symptom of dementia

- Lack of goal-directed behavior
- Decrease in goal-directed thought content
- Blunted emotions, flat affect

3 domains of apathy (Marin et al., 1996)

2) Often overlooked: not disruption

3) Misinterpreted as "normal" aging or to be expected with dementia

4) Does not cause disruption – does not bring attention

5) Common in long-term care facilities

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Background: Apathy

- Frustrating to caregivers

- *"Do you want to work on a puzzle?"*
- *"Do you want to go for a walk?"*
- *"Do you want to listen to music?"*
- *"Do you want to . . ."*

"No"

- Avolition: not interested in doing things
- Passivity, listlessness
- Loss of spontaneous curiosity
- Different from depression

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Background: Apathy

- Common in **frontotemporal** and **vascular** dementia

- Atrophy of nerves in the frontal and temporal lobes
- Common in persons with young-onset dementia (60% - ages 45-60)
- Changes in personality, behavior > memory impairment

- Damage to brain blood vessels, tissue injury from ischemia and lack of nutrients
- Co-occurs frequently with Alzheimer's disease
- Slowed thinking, impaired decision-making, apathy (fewer emotions), slow gait, poor balance

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Background: Apathy

- Apathy may be assessed with instruments
- **Neuropsychiatric Inventory – Questionnaire** (Kaufer et al., 2000)
- **Apathy Evaluation Scale** (Marin et al., 1991)
- **Passivity in Dementia Scale** (Colling, 1999)

Apathy/Indifference	Does the patient seem less interested in his/her usual activities or in the activities and plans of others?

Yes **No** **SEVERITY:** 1 2 3 **DISTRESS:** 0 1 2 3 4 5

Not at All Characteristic 1	Slightly Characteristic 1	Somewhat Characteristic 3	A Lot Characteristic 4	
__ 1. S/he is interested in things.				+ C Q
__ 2. S/he gets things done during the day.				+ B Q
__ 3. Getting things started on his/her own is important to her/him.				+ C SE
__ 4. S/he is interested in having new experiences.				+ C Q
__ 5. S/he is interested in learning new things.				+ C Q
__ 6. S/he puts little effort into anything.				- B

https://www.tbims.org/aes/aesrat.html

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Methods

- Literature search conducted by the librarian (Dr. Cindy Schmidt)
- 634 articles identified as published in the U.S.
- 18 articles selected as relevant

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Select Results

- Activities that match personality, functional level, or both

Improvement in: engagement, affect, mood, agitation, & passivity (Kolanowski et al., 2011)

Personality match

- High in gregariousness – group activity, choir, reminiscence therapy in a group
- High in aesthetics – arts & crafts, music

Functional level match

- Capable of fine motor activity – ats & crafts
- Good upper body range of motion – table tennis, mini-golf

extraversion | openness

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Select Results

Openness

Fantasy	Need expressed	Activity
High	Needs a rich inner world	Painting, creative writing
Low	Needs to stay focused on a task	Cooking, playing an instrument

Extraversion

Assertiveness	Need expressed	Activity
High	Needs to lead	Be in charge of an activity, whack-a-mole
Low	Needs to be in the background	Not be put in spotlight

Much more precise selection of activities than playing bingo daily!

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Kolanovwski et al., 2011; Kolanowski & Buettner (2008)

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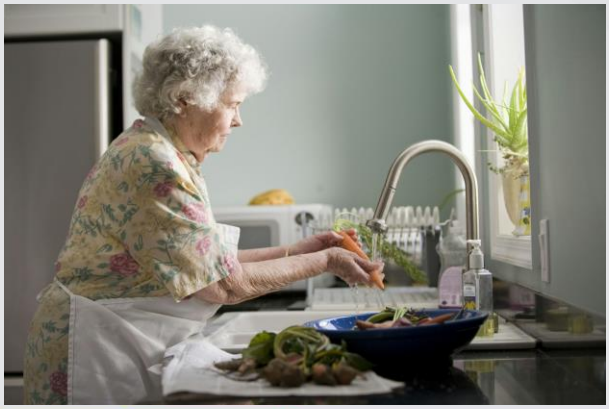
Results

Need-driven Dementia-compromised Behavior model

- Agitation and passivity: result of unmet needs
- Recognition that activity is one of human needs



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Select Results

- PRIDE approach for bathing (Mickus et al., 2002)
  - Privacy
  - Reassurance
  - Information
  - Distraction
  - Evaluation

Instruction for nursing assistants

3 fewer people experienced apathy post-PRIDE *(not statistically significant)*

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Select Results

- Pet therapy (Friedmann et al., 2014)
- Equine therapy (Coil & Kemeny, 2022)
- Feeding the dog, brushing the dog's hair, brushing the dog's teeth, dressing the dog in a bandana, throwing dog a ball, talking to the dog, petting the dog, adjusting dog's collar, feeding the dog

No statistically significant changes in apathy for dog therapy, but slight change in the positive direction

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Select Results

- Therapeutic cooking (Fitzsimmons & Buettner, 2003)

  - Scheduled after lunch: passive or agitated behavior after lunch
  - 2 weeks, 5 days a week
  - Meal planning, shopping, cooking
  - Least restrictive prompts: at least 2 less intrusive cues before actually doing the task

→ Statistically significant decrease in passivity in the intervention group

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Select Results

- Art (Esker & Ashton, 2013)
  - Watercolor painting with guidance
  - Thematic (e.g., beach, winter, autumn)
  - Give advice to the researcher on what to paint if the person does not wish to paint themselves

→ Passive behavior reduced by increasing auditory, visual, and tactile stimulation

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Select Results

- Mobile reminiscing therapy app – Memory Matters (Yu et al., 2019)
  - Play games in a “solo mode” or “social/group” mode
  - Images, music, sounds to evoke autobiographical memories
  - Promotion of reflection, recall, reminiscence
  - Create games or slide shows with personal photographs

→ Not statistically significant improvement in apathy at 12 weeks

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Select Results

- Therapeutic Conversation (counseling) (Tappen & Williams, 2009)
  - Individual treatment 3 times/week x 16 weeks
  - Nursing home residents

→ Statistically significant decrease in passivity in the intervention group

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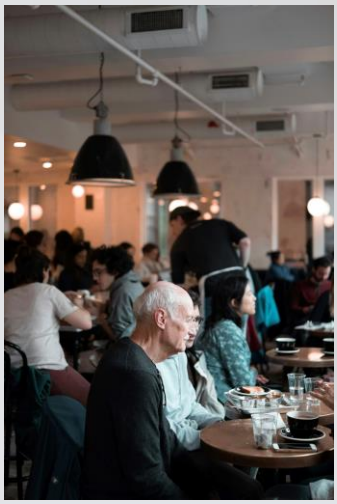
Select Results

- Reminiscence (Politis et al., 2004)
- Cognitive communication stimulation (Chapman et al., 2004)
  - Discussion about important life events
  - Discussion about hobbies, enjoyable activities
  - Education about Alzheimer's disease

3 fewer people experienced apathy post-PRIDE *(not statistically significant)*

→ Improvement in apathy



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Select Results

- Respite Care Adult Day Care Service (Wescott, 2011)

→ Transform apathy into engagement

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Select Results

- Snoezelen – multi-sensory behavior therapy (Staal et al., 2007)
  - 6 sessions

→ Greater reduction in apathy compared to standard psychiatric inpatient care alone

https://snoezelen.info/

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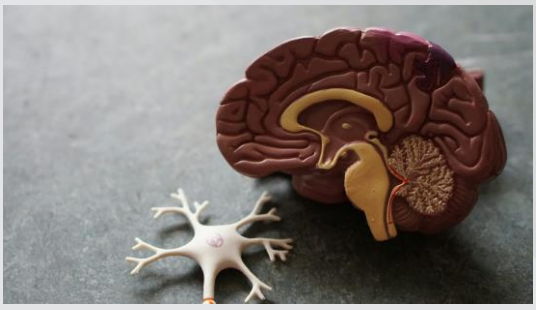
Select Results

- Mentally stimulating activities, brain fitness (Buettner et al., 2011; Sardina et al., 2019)
- Group setting
- Physical challenges: writing with a non-dominant hand, eye-hand coordination,
- Cognitive tasks: word that describes their personality, starting with the first letter of the first name

Cross the midline for left and right hemisphere connection

- Visuospatial skills
- Abstraction
- Sensorimotor function
- Language interpretation
- Executive function
- Body coordination



→ Improvement in apathy

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Select Results

- Kansas Bridge Project (Johnson et al., 2012)
  - Acute neuropsychiatric symptoms
  - Counseling, dementia education
  - Crisis prevention planning
  - Dementia Crisis Support Coordinators

→ Collection of specific information about the crisis

→ Document crisis behaviors using a daily behavior diary

→ Caregivers reported reduction in apathy and reductio in their distress caused by their person's apathy

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Select Results

Whom the activities help?

- Persons with mild cognitive impairment and early stage Alzheimer's disease (Sardina et al., 2019)
- Nursing home residents
- Assisted living facility residents

What do these interventions achieve?

- Improvement in apathy
- Sometimes no difference with control group
- Frequent improvement in mood and other person-centered outcomes

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Select Results

Proposed Interventions (No Outcomes Yet)

- Combination of music therapy and reminiscence, app (Imtiaz et al., 2018)
  - Select an important event in the person's life
  - Use cues: pictures, music, videos
  - Multisensory multimedia presentation

Music that the person enjoys – or select appropriate for the theme

Potential advantages: can be used alone (reminiscence therapy requires a group), may be used in rural settings

Potential limitations: discomfort with using the app

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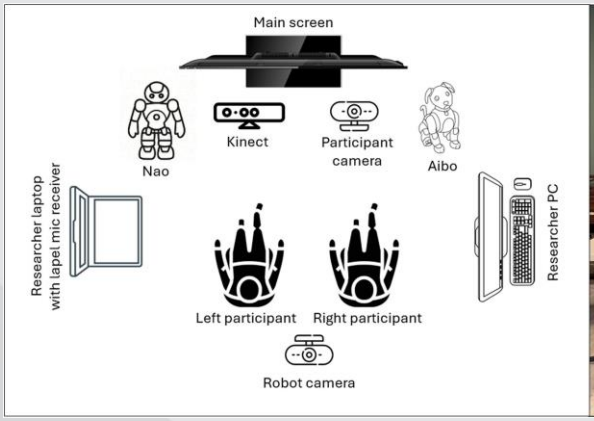
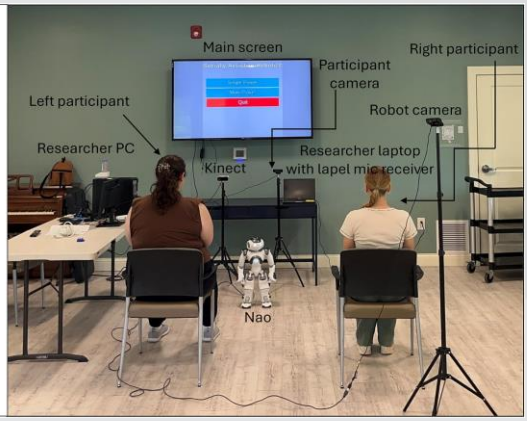
Select Results

Proposed Interventions (No Outcomes Yet)

- Virtual environments, robotics (Tate et al., 2025)





Tate et al. (2025)

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Select Results

Antecedent-Behavior-Consequence (ABC) Model

(A) Antecedent → (B) Behavior → (C) Consequences

Frontal lobe atrophy

Antecedent

Apathy

No initiative, no socialization, no interest in activities

Behavior

How the caregiver reacts? With anger? Irritation? Understanding the antecedent of the behavior? Adjusting activities (e.g., more passive engagement – listening to music, watching the sunset)

Consequence

Merrilees (2007); Smith & Buckwalter (2005); Volicer & Hurley (2003)

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Discussion

- Interventions are often time- and resource-intensive
- Lack of activity triggers agitation, passivity
- Match activity to personality: Extraversion, Openness

- Practical considerations:

  - Costs
  - Who will offer such variety of activities consistently?
  - Other organizational priorities
  - Staffing
  - Values

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Discussion

- Patient outcomes reported
- No caregiver, healthcare utilization, or economic outcomes reported *(whom does apathy affect beyond the person?)*
- Non-pharmacological interventions produce no adverse effects (Kolanowski et al., 2011)
- Pharmacological interventions – frequent adverse effects, modest results
- Enrichment, stimulating environment despite irreversibly progressing dementia
- Adding non-pharmacologic intervention may help even those receiving anti-dementia medications
- Many studies had small sample sizes

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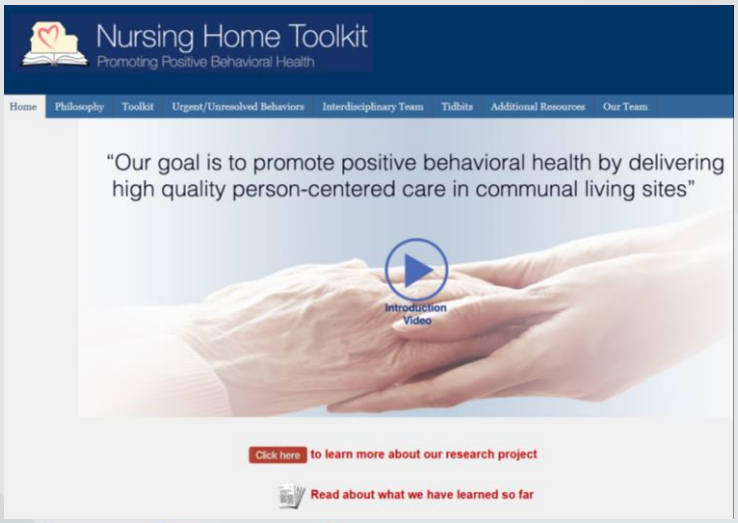
Helpful Resources

Nursing Home Toolkit



nursinghometoolkit.com

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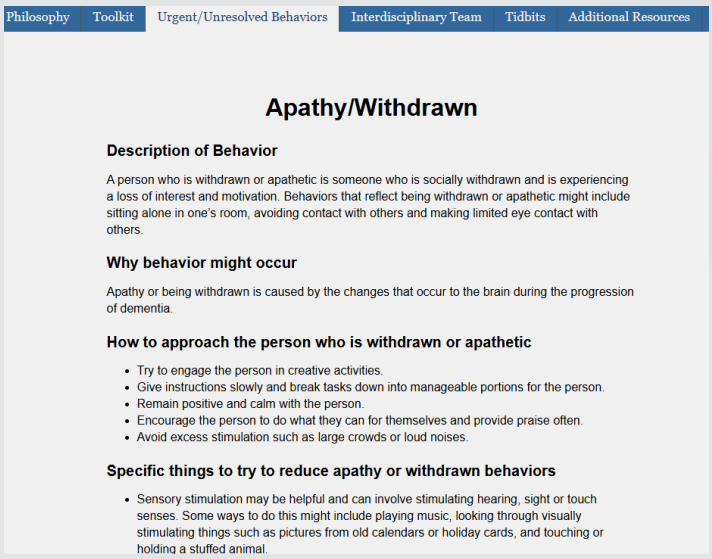
Nursing Home Toolkit



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Pharmacologic Treatment

- Few pharmacologic options available
- **Methylphenidate** (stimulant): may reduce apathy (Alzheimer's disease) (Mintzer et al., 2021)
- Cholinesterase inhibitors *(e.g., donepezil)*
- Atypical antipsychotics
- Dopaminergic agents

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References

Alzheimer's Association. (2025). Alzheimer's disease facts and figures. Alzheimer's & Dementia, 21(4), e70235.

Brownell, C. A. (2008). An intergenerational art program as a means to decrease passive behaviors in patients with dementia. *American Journal of Recreation Therapy, 7*(3), 5-12. https://doi.org/10.5055/ajrt.2008.0016

Buettner, L. L., Fitzsimmons, S., Atav, S., & Sink, K. (2011). Cognitive simulation for apathy in probable early-stage Alzheimer's. *Journal of Aging Research,* 480890.

Chapman, S. B., Weiner, M. F., Rackley, A., Hynan, L. S., & Zientz, J. (2004). Effects of cognitive-communication stimulation for Alzheimer's disease patients treated with donepezil. *Journal of Speech, Language, and Hearing Research, 47*(5), 1149-1163.

Coil, M. H., & Kemeny, B. (2022). Comparative effectiveness of recreational therapy animal-assisted interventions for older adults with dementia. *American Journal of Recreation Therapy, 21*(4), 31-44.

Desai, A. K., Schwartz, L., & Grossberg, G. T. (2012). Behavioral disturbance in dementia. *Current Psychiatry Reports, 14,* 298-309.

Fitzsimmons, S., & Buettner, L. (2003). Therapeutic cooking for older adults with dementia: Effects on agitation and apathy. *American Journal of Recreational Therapy,* 23-33.

Friedmann, E., Galik, E., Thomas, S. A., Hall, P. S., Chung, S. Y., & McCune, S. (2014). Evaluation of a pet-assisted living intervention for improving functional status in assisted living residents with mild to moderate cognitive impairment. *American Journal of Alzheimer's Disease and Other Dementias, 30*(3), 276-289.

Kaufer, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O. L., & DeKosky, S. T. (2000). Validation of the NPI-Q, a Brief Clinical Form of the Neuropsychiatric Inventory. *Journal of Neuropsychiatry and Clinical Neuroscience, 12,* 2, 233-239.

Kolanowski, A., Litaker, M., Buettner, L., Moeller, J., & Costa, P. T. Jr. (2011). A randomized clinical trial of theory-based activities for behavioral symptoms of dementia in nursing home residents. *Journal of the American Geriatrics Society, 59*(6), 1032-1041.

Martindale, B. P. (2008). Effect of animal-assisted therapy on engagement of rural nursing home residents. *American Journal of Recreation Therapy, 7*(4), 45-53.

Mickus, M. A., Wagenaar, D. B., Averill, M., Colenda, C. C., Gardiner, J., & Zhehui, L. (2002). Developing effective bathing strategies for reducing problematic behavior for residents with dementia: The PRIDE approach. *Journal of Mental Health & Aging, 8*(1), 37-43.

Mintzer, J., Lactot, K. L., Scherer, R. W., Rosenberg, P. B., Hermann, N., van Dyck, C. H., Padala, P. R., Brawman-Mintzer, O., Porsteinsson, A. P., Lerner, A. J., Craft, S., Levey, A. I., Burke, W., Perin, J., Shade, D., for the ADMET 2 Research Group. Effect of methylphenidate on apathy in patients with Alzheimer disease. *JAMA Neurology, 78*(11), 1-9.

Nursing Home Toolkit. (n. d.). Nursing Home Toolkit. https://www.nursinghometoolkit.com/

Politis, A. M., Vozzella, S., Mayer, L. M., Onyike, C. U., Baker, A. S., & Lyketsos, C. G. (2004). A randomized, controlled, clinical trial of activity therapy for apathy in patients with dementia residing in long-term care. *International Journal of Geriatric Psychiatry, 19,* 1087-1094.

Sefcik, J. S., & Kolanowski, A. M. (2014). A behavioral health toolkit that can support researchers and practitioners alike. Clinical Nursing Research, 23(2), 115-118.

Staal, J. A., Sacks, A., Matheis, R., Collier, L., Calia, T., Hanif, H., & Kofman, E. S. (2007). The effects of Snoezelen (multi-sensory behavior therapy) and psychiatric care on agitation, apathy, and activities of daily living in dementia patients on a short term geriatric psychiatric inpaitnet unit. *International Journal of Psychiatry in Medicine, 37*(4), 357-370.

Tappen, R. M., & Williams, C. L. (2009). Therapeutic conversation to improve mood in nursing home residents with Alzheimer's disease. *Research in Gerontological Nursing, 2*(4), 267-275.

Wescott, A. (2011). Meeting individual needs in recreational groupwork for people with dementia. *Groupwork, 21*(2), 99-111.

Yu, F., Mathiason, M. A., Johnson, K., Gaugler, J. E., & Klassen, D. (2019). Memory matters in dementia Efficacy of a mobile reminiscing therapy app. *Alzheimer's Dementia, 5,* 644-651.

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