DICE in Action

Non-Pharmacological Support in Home and Community

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Disclosures

National Alzheimer’s Project Act Advisory Council
• **Describe** a behavior that challenges; who, what, where, when, and how the behavior occurs

• **Investigate** thinking like a detective and explore the person with dementia, the caregivers, and environment for possible clues to triggers underlying possible causes of behavior

• **Create** a prescription in collaboration with your team to help prevent and manage behaviors

• **Evaluate** and review prescription effectiveness, and modify or restart the process as needed
DICE in Action

DICE in Research: Caregiver Burden Intervention Study
- Telephone-based support for caregivers navigating behavioral challenges

Community-Based Applications
- Adult Day Health Programs
- Assisted Living Memory Care Programs
- Workshops, Trainings and the DICE Manual

Opportunities and Challenges
- Education and empowerment for caregivers
- Adjusting for education and understanding
DICE in Action

Caregiver Burden Intervention Study

**Participants**: Primary caregivers of loved ones with MND and behavioral challenges. Primary caregivers of loved ones with behavioral variant FTD. Intervention and waitlist groups.

**Intervention**: 7 phone calls (4 weekly, 2 bi-weekly, 1 monthly) scheduled for 1 hour each.

**Surveys**: Pre-survey, 1 month, 3 month and 6 month

“The telephone intervention was a life saver! I started the calls with Katie within 60 days of initial diagnosis of my wife. Katie was able to calm me down and provide sound advice about resources, support groups and most importantly, what to expect as the disease progresses. I can't thank you enough for this service.”
DICE in Action

Caregiver Burden Intervention Study

**Patient**: 51-year-old male, bvFTD, living at home with his wife (50), son (13) and daughter (10)

**Caregiver**: Employed full-time

**Targeted Behavior**: Nightly organization of clothes, emptying of all master bedroom drawers and closet, excessive requests for laundry to be done

**Other Issues**: Grief, parenting while caregiving, daycare, transportation, safety, financial, paperwork overwhelm and caregiver burnout
Behavioral Management

**Patient:** 81, M  
**Diagnosis:** PPA  
**Caregiver:** Spouse, 77, F

**Describe:** Changes in behavior impact relationship, ADLs and caregiver stress. Kicked out of ADH after aggression.

**Investigate:** Identifying triggers and times of day and activities of highest stress for caregiver.

**Create:** Multiple care plans that addressed strengths and weaknesses.

**Evaluate:** Patient behaviors continue to worsen, caregiver feels empowered.

**Resource Referral**

**Patient:** 68, F  
**Diagnosis:** PPA  
**Caregiver:** Son, 38

**Describe:** Son shares caregiving with wife and brother and utilizes an ADH five days a week. In need of 24/7 care.

**Investigate:** Reports that mother has high apathy and is compliant for all personal care.

**Create:** Referral to ALZ for local resources

**Evaluate:** One resource was secured, not longer needed study

**Emotional Support**

**Patient:** 53, M  
**Diagnosis:** bvFTD  
**Caregiver:** Spouse, 51, F

**Describe:** Caregiver reports high levels of grief and sadness over diagnosis.

**Investigate:** Caregiver a dementia practitioner. Reports that behaviors are manageable. Already incorporates non-pharma.

**Create:** Shared grief resources and scheduled ADH training.

**Evaluate:** Caregiver reports increased coping.
**Describe:** 69 yo, female, bvFTD, SCI does not want to participate in an adult day health program

**Investigate:** Caregiver reports that their loved one says “everyone sleeps there” and “I don’t do anything there” Staff report that she had a negative affect at the program. Caregiver interview reveals that patient used to evaluate healthcare programs before retirement due to health issues.

**Create:** Worked with ADH staff to develop a meaningful (and easy) Community Ambassador Program

**Evaluate:** Patient reports that she is working at the ADH program and is willing to attend ADH and while there is engaged in activities. Caregiver reports reduced stress.

KAREN ZANDER

Karen Zander is a powerful patient making a difference at her adult day health program, Julia Ruth House, located in Westwood. Karen is an amateur classical musician and was a member of the New Philharmonia Orchestra for 40 years. Now she plays the piano for attendees at Julia Ruth House two days a week. For the past four decades, Karen has worked in healthcare, first as a psychiatric nurse, and then as a hospital consultant in case management. She is a Fellow of the American Academy of Nursing. Karen and her husband, Bernie, have been married for 62 years and have raised two daughters, Elise and Vicki. At Julia Ruth House, Karen is a Dickerson Community Ambassador. When we asked Karen “What are you showing us through this experience?” Her response was immediate: “Hope matters.”

Newphil.org
TheJuliaRuthHouse.com
DICE in Action

Memory Care Assisted Living Program

Describe: 75 yo, female, dx PPA with minimal verbal communication skills eloped during an outside walk with a memory care staff member, crossed street and entered supermarket. Difficult to coax back. Exercise removed from routine due to wander risk.

Investigate: Memory care director reports that patient is "more aggressive" pushing other residents and "escaped" from staff member on walk and communication is not possible. Memory staff member reports that patient was upset about non-working watch and inpatient with slow-moving residents to get to desired group activity and meals and that patient responds to written notes.

Create: Building on patient strengths, develop written daily schedule with times, communicate with written notes, keep working back-up watch available, allow to join group activities first.

Evaluate: Staff report that patient is no longer pushing residents and continues to enjoy outdoor walks without elopement.

Update: Patient has lost the ability to tell time and has sleep disturbances. Recommendation to create picture-based schedule, wake-up and sleep routines set to music and increased mid-day walks to promote nighttime sleepiness.
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PRESCRIPTION FOR LEAVING HOME

DESCRIBE THE BEHAVIOR

On 1/17/2019 Carol went for a walk on the Whitney Place property with a staff member and ended up walking across the street to the Shaw's Plaza. At the time, it was unclear why Carol was so determined to walk into Shaw's, and the staff was very concerned because she was incredibly difficult to direct back to Whitney Place. In general, Carol shows strong exiting behaviors anytime another person leaves the neighborhood. Carol will pace and repeat "It is really bad" over and over while trying to head to the door.

INVESTIGATE WHY THE BEHAVIOR MAY OCCUR

PERSON:
- Confusion as to what to do
- Difficulty communicating
- Difficulty recognizing, holding or using objects
- Discomfort or unmet need (hunger, thirst, boredom, full bladder, fatigue, lack of exercise, social isolation, need for attention, sensory stimulation)
- Disorientation (time or place)
- Feeling fearful, insecure, anxious, or paranoid
- Feelings of failure, loss of control or frustration
- Health (pain, fatigue, poor vision, hearing loss, constipation, infection, medication effects)
- Inhibition
- Inversion of personal space
- Too much/too little sleep
- Unable to start, organize, or complete the task
- Unable to follow directions
- Other: Possible UTI, staff working on sample

CAREGIVER:
- Expectations too high
- Feeling stressed and/or frustrated
- Lack of or change in daily routine
- Rushing routines
- Too many choices offered
- Verbal communications too complex
- Other: All staff must know that Carol needs written cue

PHYSICAL ENVIRONMENT:
- Cannot distinguish between objects
- Difficulty finding room or location
- Objects not in sight or hard to find
- Over stimulation (too noisy or too many people)
- Under stimulation
- Unfamiliar or uncomfortable environment
- Poor lighting
- Poor seating
- Too hot/too cold
- Too many objects
- Other: Carol is triggered by others leaving

ABILITIES:
- Carol knows what day and time it is. She seems to enjoy following a pre-set schedule.
- Carol can read and seems to respond to scheduled times for activities as well as the idea that it is "too cold to go outside".
- Carol loves art. This can be a wonderful activity to distract her from distress she feels when she wants to exit.

CREATE A PRESCRIPTION EFFECTIVELY

What to do:
- Place written notes in very visible locations, such as "Stay at home" or "Do not enter".
- Stay calm, listen to Carol, and try to solve the problem.
- Communicate with neighbors, if you plan on leaving for a period of time.
- Other: Compassionate Listening paired with redirection

What to avoid doing:
- Expecting Carol to remember where they should not go without providing some type of visual cue.
- Raising your voice, yelling, or dismissing Carol's feelings or perceived need to leave the home.
- Leaving Carol home alone, even for a brief period of time, without telling someone who can check in on them.
- Other: Carol needs written notes and cues for success

MODIFY YOUR HOME AND MAKE IT SAFE

What to do:
- Install a door alarm.
- Use a medical alert and/or identification bracelet.
- Lock exterior doors or use safety door knob covers.
- Remove unnecessary objects, minimize distractions.
- Other: May not be applicable to WP neighborhood

What to avoid doing:
- Relying on being able to hear open the door.
- Expecting Carol or someone else to remember their home address or other important information if they are lost.
- Relying on a closed door to prevent from going through it.
- Keeping a lot of objects and knick-knacks in Carol's living space; or entertaining a large group of people in the home at the same time.
- Other: May not be applicable to WP neighborhood

SIMPLIFY THE WAY YOU SET UP DAILY ACTIVITIES AND ROUTINES

What to do:
- Create a master calendar for Carol to refer to. Place it in a prominent place, like on the refrigerator.
- Take regular walks with Carol with a specific goal in mind, such as getting the newspaper.
- Provide Carol something to manipulate or explore that is enjoyable or interesting to them (i.e. a box of old photographs, costume jewelry, etc.)
- Other: Create a large daily calendar with Carol

What to avoid doing:
- Expecting Carol to remember a daily schedule without providing a written, visual reminder.
- Avoiding or limiting going out in the community with Carol.
- Having long periods of time where Carol is not involved in some type of activity, as this may contribute to boredom and/or restlessness.
- Other:

ENHANCE ACTIVITY PARTICIPATION

What to do:
- Look into attending a senior day program that includes supervision as well as activities.
- Refer to an activity list so you can redirect Carol to art or to a simple activity if they become upset.
- Other:

What to avoid doing:
- Assuming is better off staying at home without first checking into available community programming.
- Assuming Carol needs "down time" in order to become calm.
- Other: May not be applicable to WP neighborhood

STRATEGIES FOR YOU

- Try to relax, use a deep breathing technique if you feel stress or tension.
- Feel good about yourself — you are doing a great job!

EVALUATE

Keep track of the strategies you try and how things go as you practice them. This will help to make adjustments and find the best strategies for you.

STRATEGY 1: Educate all staff in the Whitney Place neighborhood about Carol’s strong connection with her watch. Staff should check if the watch is missing or broken as a first approach when Carol is agitated. Ask Carol’s family to bring in a back-up watch for Carol.

STRATEGY 2: Carol has a strong understanding of time. Create a daily schedule for Carol that includes group and individual activities such as walks and Art Time. Make the schedule large and hang it in her room so that staff may refer to it to let Carol know what is coming next in her day.

STRATEGY 3: Carol is able to respond to written notes and prescribed times. Anytime a staff member takes her for a walk, they should take a written note with them for Carol stating when the walk begins and ends and what comes next. Example: 3:00 Walk Outside 3:30 Art in the neighborhood.

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Discussion

Staff Availability and Expertise
◦ Staff must be dynamic, flexible and experienced

Baseline Knowledge and Education of Participants
◦ Adjustment for caregivers at different stages

Benefits of Workshops, Trainings and DICE Manual
◦ It doesn’t have to be all or nothing

“They went great I especially liked the weekly calls and I wish that she and I still had the weekly calls because things are getting a bit harder for me.

And just knowing that there was someone that was going to call helped me.”
ProgramForPositiveAging.org/diceapproach

Helen Kales, MD
Laura Gitlin, PhD
Constantine Lyketsos, MD MHS

ALS Association

Alzheimer’s Association

Association for Frontotemporal Degeneration

Boston-area FTD Support Group

Patients, Family Caregivers & Professional Care Providers in our Dementia Community