Care Management Resources & Advancing Dementia in the Home

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DISCLOSURE

I do not have any financial relationships or conflicts of interest with the organizations mentioned in this presentation.

I am solely focused on sharing knowledge, information, and resources to support individuals living with dementia and their caregivers.

OBJECTIVES

- Challenges Faced by Caregivers
- Addressing Caregiver Burnout
- Creating a Sustainable Life at Home
- Practical Strategies for Caregiver Management
- Resources to Share with Families

CHALLENGES FACED BY CAREGIVERS

Behavioral

- Memory Loss
- Agitation
- Paranoia
- Fear
- Poor Decision Making
- Wandering
- Inappropriate Behavior

Financial

- Medical Appointments
- Emergency Department Visits
- Cost of Day Cares and Care Sitting Agencies
- Cost of Assistive Technology

Emotional

- Role Confusion
- Divergence from Life Planning
- Ambiguous Loss, Continuous Grief
- Compassion Fatigue

Physical

- Sleep Disruption
- Assistance with Activities of Daily Living
- Nutrition and Meal Preparation
- Hypervigilance

ADDRESSING CAREGIVER BURNOUT

- Recognize Causes of Burnout
  - Unrealistic Expectations
  - Lack of Control
  - Lack of Support (social and financial)
- Recognize Signs of Burnout
  - Physical
  - Emotional
  - Behavioral
  - Cognitive
  - Interpersonal

QUESTIONS TO ASK PATIENTS AND CAREGIVERS

For Patients Living with Dementia

- What activities do you enjoy doing?
- What helps you feel comfortable and safe?
- Who do you like to spend time with?
- How do you prefer to communicate or express your needs and preferences?
- Do you feel that you can express to others how you're feeling?

For Caregivers

- Who are the key members of your support network, such as family, friends, neighbors, coworkers, or community resources?
- Have you talked with anyone else about your loved one's cognitive changes? If so, how did they respond?
- Does anyone in your community have experience with dementia? Have you connected with them?
- How do you prioritize self -care and well -being while balancing caregiving responsibilities?

BUILDING A SUSTAINABLE LIFE AT HOME

Qualities of a Sustainable Caregiver

- Resilient
- Patient
- Self-Aware
- Flexible
- Compassionate
- Open to Support and Help

What can we do as a neurology clinic to make their journey as smooth as possible?

PRACTICAL STRATEGIES

Diagnosis Education

Behavioral Strategies

- Communication Strategies
  - Acknowledge, validate, empathize
  - Speak in simple, clear language
  - Attend to nonverbal cues
- Environmental Modifications
  - Security (Cameras, Alarms, etc.)
  - Locks
  - Lighting
  - “Safe Space”
  - Accommodation via Technology
- Redirection and Distraction

MANAGING AGITATION TIP SHEET

Tip Sheet: Managing Agitation and Irritability in Dementia

1. **Stay Calm**: Keep your own emotions in check. If you remain calm, it can help diffuse the situation and prevent escalating agitation.
2. **Avoid Arguing or Correcting**: Trying to reason with someone experiencing agitation may worsen the situation. Instead, provide reassurance and understanding.
3. **Validate Feelings**: Show empathy and validate your loved one's feelings, even if you don't fully understand the cause of their agitation.
4. **Identify Triggers**: Pay attention to what triggers your loved one's agitation. Is it certain environments, activities, or specific times of the day? Knowing triggers can help you avoid them or plan accordingly.
5. **Create a Calm Environment**: Keep the environment quiet and free from excessive noise or distractions that may agitate your loved one.
    - If the person becomes agitated by their reflection, cover or remove mirrors temporarily.
6. **Stick to Routines**: Establish and maintain a daily routine as much as possible. Familiarity and predictability can help reduce agitation.
7. **Use Gentle Touch**: Physical touch can be comforting but be mindful of your loved one's response. Some individuals may not appreciate touch during moments of agitation.
8. **Offer Distractions**: Engage your loved one in calming activities or redirect their attention to something enjoyable, like looking at family photos or listening to soothing music. See the following pages for more information.
9. **Monitor Personal Comfort**: Check for discomfort or pain that may be contributing to agitation, such as hunger, thirst, or needing to use the restroom.
10. **Limit Caffeine and Sugar**: Be cautious with stimulants like caffeine and sugary foods, as they can exacerbate agitation.
11. **Maintain Personal Space**: Respect your loved one's need for personal space, especially if they are feeling agitated.
12. **Use Simple and Clear Communication**: Speak slowly, use short sentences, and avoid complex language. Be patient and allow time for your loved one to process information.
13. **Consider Professional Support**: If you find caregiving challenging, consider seeking assistance from professional caregivers or respite care services to give yourself breaks and prevent burnout.

REDIRECTION AND DISTRACTION

Distractions and redirections can be valuable techniques to manage agitation and refocus the attention of individuals living with dementia. Here are some examples of distractions and redirections:

Distractions:

1. **Sensory Items**: Provide items with different textures, such as a soft blanket, stress ball, or fidget spinner, to keep hands occupied and promote relaxation.
2. **Art Activities**: Engage the person in simple art activities like coloring, drawing, or painting.
3. **Music Therapy**: Play familiar and soothing music or songs that the person enjoys.
4. **Handheld Games**: Offer simple handheld electronic games or puzzles that the person can play with.
5. **Reading**: Read aloud from a favorite book or share short stories together.
6. **Watching Nature**: Sit near a window or in a garden to watch birds, butterflies, or other natural elements.
7. **Cooking or Baking**: Involve the person in simple cooking or baking activities, like mixing ingredients or rolling dough.
8. **Reminiscence Activities**: Look at old photos, family albums, or mementos together.
9. **Pet Interaction**: If there are pets around, encourage gentle interaction with them.
10. **Virtual Travel**: Show pictures or videos of places the person has visited or places they find interesting. YouTube has thousands of traveling videos that may interest your loved one.

Redirections:

1. **Changing the Topic**: If the person starts to fixate on something distressing, gently switch the conversation to a different topic.
2. **Moving to a Different Room**: If the environment seems to be causing agitation, move to a quieter or more comfortable room.
3. **Offering a Snack or Drink**: Providing a snack or drink can be a simple way to redirect focus and create a calming experience.
4. **Outing or Walk**: Suggest going for a short walk or outing to change the environment and provide a distraction.
5. **Looking at a Clock or Calendar**: Drawing attention to the time or date can help redirect focus and provide context.
6. **Engaging in Simple Tasks**: Involve the person in simple tasks like folding clothes or arranging items on a table.
7. **Use Humor**: Light-hearted humor can help defuse tension and shift focus.
8. **Gardening**: If possible, spend time together in a garden or with potted plants.

FIND WAYS TO ENGAGE

Engaging Activities for People Living with Dementia

The following list encompasses a diverse range of activities suitable for individuals at various stages of the dementia journey, offering options tailored to both earlier and later stages of the condition. Whether engaging in indoor pursuits, outdoor adventures, creative outlets, physical games, or sensory experiences, these activities aim to provide meaningful stimulation and enjoyment for individuals living with dementia.

Indoor Activities:

1. Puzzles: Jigsaw puzzles or puzzle books are great for cognitive stimulation.
2. Board Games: Choose games with simple rules and large pieces, like Scrabble, Bingo, or Memory.
3. Arts and Crafts: Painting, coloring, or simple crafting activities can provide creative outlets.
4. Music Therapy: Listen to familiar songs or create personalized playlists to evoke memories and emotions.
5. Reminiscence Therapy: Look through old photos or memorabilia to stimulate conversation and reminiscing.
6. Baking or Cooking: Simple recipes allow for participation and sensory stimulation through smell and taste.
7. Reading: Enjoying books or listening to audiobooks can provide mental stimulation and relaxation.

Outdoor Activities:

1. Gardening: Planting flowers or tending to a vegetable garden can provide sensory and therapeutic benefits.
2. Nature Walks: Take leisurely strolls in parks or gardens to enjoy fresh air and nature.
3. Birdwatching: Set up bird feeders and observe the wildlife in the backyard or local park.
4. Picnics: Pack a lunch and enjoy a meal outdoors in a peaceful setting.
5. Outdoor Games: Play gentle games like bean bag toss, ring toss, or balloon volleyball.

Creative Outlets:

1. Drawing or Sketching: Provide drawing materials for artistic expression and creativity.
2. Poetry or Storytelling: Encourage writing or verbal storytelling to express thoughts and feelings.
3. Sculpting: Work with clay or Play-Doh to create sculptures and shapes.
4. Music Making: Experiment with simple musical instruments like tambourines, shakers, or keyboards.
5. Dance Therapy: Move to music to promote physical activity and emotional expression. There are plenty of videos on YouTube to choose from!

Physical Games:

1. Gentle Exercise: Engage in activities like stretching, chair yoga, or seated exercises to promote mobility and flexibility.
2. Balloon Games: Keep balloons afloat or play catch with soft, lightweight balls for coordination and fun.
3. Bowling: Set up a makeshift bowling alley using plastic bottles and a soft ball for gentle competition.
4. Indoor Golf: Create a mini-golf course using household items like cups, cardboard tubes, and soft balls.
5. Tai Chi: Practice slow, flowing movements to improve balance, coordination, and relaxation. You can search for videos on YouTube to follow an instructor.

Sensory Activities:

1. Aromatherapy: Use essential oils or scented candles to create a calming atmosphere.
2. Massage Therapy: Offer gentle massages using lotion or hand massages to promote relaxation and sensory stimulation.
3. Sensory Boxes: Fill boxes with various textured materials like fabrics, feathers, or ribbons for tactile exploration.
4. Bubble Play: Blow bubbles or use bubble machines for visual and tactile stimulation.
5. Aural Stimulation: Play soothing sounds like nature sounds, white noise, or calming music to promote relaxation.

CONNECT TO RESOURCES

- Home Health, Palliative Care, and Hospice
- National Council on Aging
- Senior Centers
- Adult Day Programs
- Care Sitting and Personal Care Agencies in the NOLA area
- Support Groups and Education Series
- Educational Reading/Viewing Materials
  - National Institute on Aging: Free Publications
  - The 36 Hour Day by Mace and Rabins
  - Loving Someone Who has Dementia: How to Find Hope While Coping with Stress and Grief by Pauline Boss, PhD
- Caregiver Action Network (CAN)- Family Caregiver Toolbox
- Family Caregiver Alliance (FCA)

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