Simple Pleasures: Improving Quality of Life for People with Advanced Dementia

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Objectives

- Discuss the challenges in connecting to people with advanced dementia
- Integrate the use of the Life Story into planning and executing pleasurable activities and connections
- Outline how a simple sensory program can provide meaningful connections for people with advanced dementia
- Document positive and negative findings related to connecting with the person with advanced dementia

Challenges in Making Connections

People With Dementia (PWD) are at increased risk of sensory deprivation due to:

- Severe brain deterioration
- Increased fatigue
- Processing information
- Easily overwhelmed
- Focus on self
- Deterioration of the senses with aging (sound, sight, smell, taste, or touch)
- Apathy and inertia of dementia diminishing the likelihood of self-initiated engagement with sensory pleasures

Lack of stimulation may lead to a variety of negative outcomes (e.g., agitation, anxiety, isolation, boredom…)

Challenges in Making Connections, continued

- Over-stimulation
  - yelling from other residents, loud TV, bed alarms, glare, clutter, group dining
- Unpleasant stimulation
  - noises from pill crushers & PA system, unpleasant odors, soiled brief
- Lack of personally meaningful stimulation
  - impersonal institutions without touches of ‘home’, absence of nurturing touch, bland food with unappealing color and texture

Enhancing Quality of Life through Activities

- The goal of activities is to make personal and meaningful connections in order to promote personhood and improve quality of life.
- The outcomes of activities/connections may include a variety of facial, body, vocal and behavioral observations.
- Making eye contact, change in facial expressions, improved alertness, improved awareness of surroundings, increased verbal comments

Key Concepts of Activities in Making Connections

- To see all activities as purposeful
- To utilize multiple senses
- To promote activities that reflect unique and lifelong preferences
- To balance sensory stimulating with sensory calming activities
- To prevent excess disability by “doing for” the person
KNOW the Person

- Successful activities and/or sensory stimulation must be **customized** to the person’s unique combination of:
  - Cognitive abilities
  - Behavioral concerns
  - Personal preferences

How do we individualize the approach & connections?

- The **Life Story** provides information that honors lifelong pleasures and preferences

Types of Activities

- **Individual** (most successful)
  - One to one
  - Small Group
    - 2 – 3 individuals
  - Large Group
    - > 4 people

Individual Activities

- Activities of Daily Living (ADLs)
  - Bathing, grooming, dressing, feeding
- Vanity Activities
  - Nails, hair, make-up
- Music
- Food
- Massage
- Spiritual/religious
- Reminiscence through “sensory memories”

Small Groups (2-3)

- Individualized activities in a small group setting (such as vanity activities)
- Sensory stimulation**
- Listening/singing/moving to music
- Food activities
- Normalization activities
  - Bread baking
  - Tea time
  - Social hour
### Activity Suggestions

- **Physical Activities**: Balloon toss, bean bag toss, simple range of motion, outdoor walks
- **Music**: Listening, sing-along, movement to music
- **Quiet Activities**: Reading, memory boxes, planned movie time
- **Sensory stimulation**: Lotion/massage; Aromatherapy; Touch; Food**
- **Other**: Spa time; scheduled pet therapy, intergenerational activities

### The SOS Experience

- "Stimulation of Senses" (SOS) provides an "individualized" approach to making connections to the person with advanced dementia
- Contents are standardized and then customized for each person’s experience
- Carried in an SOS bag

### Contents of the SOS Kits

**Front pocket:**
- Antiseptic Cleansing Gel
- Laminated ‘SOS Quick Tips Guide’
- Music ‘Quick Tips Guide’ & lyrics for CD

**Side pockets:**
- Lemon essential oil and spray solution (energizing)
- Lavender essential oil and spray solution (calming)

### Contents of SOS Kit (cont’d.)

**Main section of bag:**
- Scented lotion
  - Sunshine On My Face book
  - Lydia Burdick (author)
- CD player with sing-along CD
- Squishy ball
- Bubbles, balloons/inflatable beach ball
- Chocolate kisses and See’s lollipops
- Readings/prayers for spiritual support

### Essential oil sprays (olfactory cues)

- Lemon essential oil and spray solution (energizing)
- Lavender essential oil and spray solution (calming)
- Responses to aromas vary.
  - Discover personal favorites-vanilla, cinnamon, Old Spice, White Shoulders, rosemary, basil, baby oil, flowers, etc.
- Cue the person and help them focus in on the aroma

### Scented lotion (Tactile and Olfactory cues)

- Human touch is a basic need, but for PWD most of the touch is related to attending to bodily needs.
- Holding the hand of a person with dementia can communicate love, warmth and safety.
- A gentle hand or foot massage can create a unique connection.
- Use in conjunction with conversation, music/singing, direct eye contact, smiling or simply by itself.
Sunshine On My Face Book
(Visual & Auditory cues)
- Visual cues can help recall memories of treasured experiences.
- The shared viewing of this book or photos can create a sense of joy, humor warmth and love.

CD player and Sing-along CD
(Auditory cues)
- Select songs with pleasant memories that have been heard repeatedly over a lifetime.
- Sing with or to the person. Hold hands, tap the rhythm and try to draw the person into the experience.
- Success does not depend on the quality of your singing voice. Focus on conveying comfort and tenderness.
- Sing-along CD for advanced dementia: Guides the recommended approach: slow tempo, lower keys & repetition of songs

Tactile and Kinesthetic Cues
Tactile stimulation
- Squishy balls provide interesting tactile stimulation.
- Explore objects that the person finds pleasurable to touch or that invoke favorite memories (baseball mitt, fabrics, stuffed animals).

Kinesthetic stimulation
- Bubbles, balloons and inflatable beach balls provide motion cues and help raise the person’s awareness to the surrounding environment.
- In addition they provide gentle range of motion exercise along with a sense of fun.

Chocolate kisses and See’s lollipops
(Taste cues)
- Food continues to be enjoyed until the last days of life IF it provides pleasure and comfort for the PWD.
- Taste and texture are important considerations. Soft and sweet are usually preferred ‘comfort foods’ (ice cream, shakes, yogurt, bananas, applesauce, peanut butter and jelly, mashed potatoes and gravy).

Cues for spiritual connections
Explore which sensory approaches support and honor the person’s spiritual preferences:
- The sights, sounds & smells of nature via fresh flowers or going outdoors can touch the soul.
- The sounds of short favorite passages from a book of faith or favorite sacred songs can bring comfort and awareness of the Divine.
- Touching & looking at religious symbols (e.g., rosary beads, prayer shawl, holy pictures) or smelling incense or candles can assist the person to sense the presence of God.
- Tasting the sacraments

Preparation for the SOS Experience
- Schedule for the person’s best time of day. Be flexible.
- Create a calm, uninterrupted environment (turn off TV & radio)
- Assess & provide for any unmet needs that may cause distraction (pain, hunger, thirst, toileting, change of position, etc.)
- Use sensory aids as needed (glasses, hearing aids, etc.)
Conducting the SOS Session

- Consult the ‘About Me’ to customize sensory approaches for each person
- Baseline Assessment
  - facial expressions, body language, muscle tension
- Determine goal: Stimulate? Calm? Connect?
- Gently encourage responses to the sensory activities
- Frequently reassess responses & stop if any negative effects are noted

Baseline Assessment
- Baseline sensory data
  - Facial expressions
  - Body language
  - Muscle tension

Determine goal: Stimulate? Calm? Connect?
- Set goal for each session based on individual needs
  - Stimulate
  - Calm
  - Connect

Gently encourage responses to the sensory activities
- Use gentle encouragement to elicit positive responses
- Modify approaches based on individual preferences

Frequently reassess responses & stop if any negative effects are noted
- Continuously monitor and reassess
- Stop if negative effects are noted

Evaluating the Impact of SOS

At the conclusion of the session...

- Do you notice any positive changes in the person?
  - Non-verbal (direct eye engagement)
  - Verbal (singing, ‘Yes, it’s good’)
  - Physiological (slow, deep respirations)
  - Behaviors (mimicking, kissing back)

Key Points for Success

- Target lifelong preferences and pleasures (Consult the ‘About Me’) 
- Provide one-to-one attention
- Length of intervention is determined by person’s ability to comfortably tolerate and pay attention (usually 5-10 minutes for PWAD)
- Demonstrate/cue activities and convey ongoing positive verbal and non-verbal support.

Suggestions for Documentation

TWO essential components:
1. Sensory interventions implemented
2. Patient responses

Example
- “Provided 5 minutes of sensory stimulation using soft touch with scented lotion while singing ‘You Are My Sunshine’. Patient demonstrated increased alertness and relaxation by prolonged direct eye contact, deep sighs, smiling and humming along. Stated, ‘That was beautiful’.

Caregiver Feedback

SOS Kits evoke a wide range of positive physical and emotional responses
- Increased alertness
- Increased awareness of environment
- Positive changes in affect
- Increased verbalizations & social behaviors
- Improved periods of relaxation
- Distraction from pain, fear, anxiety, depression
- Non-threatening form of reality orientation

Examples

- CNAs report with bath/shower care:
  - Decreased aggressive self-protective behaviors
  - Increased positive interactions & verbalization
  - Improved participation in self-care and social behaviors

- Family and Friends Visits
  - Visitors report PWD is more alert and engages in more meaningful exchanges
Additional Caregiver Benefits

SOS Kits encourage positive regard towards future visits and caregiving experiences.

Caregivers continue to use these SOS skills and creatively adapt the methods as needed to support the person’s deteriorating condition.

Why is the SOS Kit appropriate for PWD?

- Cost-effective
- Easy to replicate
- Non-invasive
- Non-pharmacological
- Integrates and honors lifelong preferences
- Celebrates the person’s residual abilities to experience beauty and meaning every day
- Optimizes comfort and enhances quality of life

Summary

- It is still possible to make meaningful connections with person with advanced dementia
- Individualized and sensory activities that honor preferences are likely to produce engagement and connection in order to promote quality of life

References