

MORE HELPFUL INFORMATION

- As the number of older adults increases, the numbers of people with dementia will increase.
- People with intellectual disability have a normal life expectancy.
- People with Down Syndrome are living longer and experiencing premature aging, specifically Alzheimer disease.
- Each person with dementia has a unique story and individual needs.
- Although there are cognitive deficits, many complex abilities are preserved, which should be identified and cultivated.
- The brain remains plastic and new or compensatory learning can still occur.
- Well-being is not dependent on cognitive or functional ability and should be maximized.
- Work hard to find unmet needs and adapt the care environment to meet those needs as far as is safe and practical.
- Use creativity and collaboration to create a life worth living for people with dementia.



Content material extracted from *Creating Moments of Joy* by Jolene Brackey, *Dementia Beyond Drugs: Changing the Culture of Care* by G. Allen Power, M.D. and the crisis prevention network/dementia care specialists.



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Down Syndrome and Dementia

Down syndrome (DS) is the most common genetic cause of intellectual disability in children. With aging, DS is associated with an increased risk for Alzheimer's disease (AD).

People with DS can begin to show signs of AD as early as age 35. More than 80% may experience dementia by age 65 years.

The information provided includes some signs and symptoms of dementia and strategies that you can use to better interact with individuals with IDD and dementia.

Early detection will enable timely care, planning, and consideration of interventions.

“People with dementia don't operate by a thought process. They operate by how they feel”.

Jolene Brackey

ONSET

- **Gait Dispraxia** (partial loss of the ability to carry out skilled walking movements with control and accuracy).
- Recent literature suggests that declines in gait may serve as an early marker of AD-related dementia in DS.

Seizures

- Individuals with DS may suffer from seizures early in the course of dementia. Dementia often precedes the first seizure.

SIGNS & SYMPTOMS

EXECUTIVE FUNCTION

- Learned skills are lost

BEHAVIORAL SYMPTOMS

- Severe agitation
- Aggression
- Irritability
- Combativeness
- Wandering
- Gait disturbance
- Dysphagia
- Incontinence

PSYCHOLOGICAL

- Apathy
- Lack of motivation
- Stereotyped or ritualistic behavior
- Anxiety
- Depression
- Psychosis
- Suicidal/self-aggression

COMMUNICATION TIPS

- **Gain attention and trust**
Before you speak, make sure you have gained the person's attention. It's also important that the person in your care feels safe with you and that you have his or her agreement and approval to proceed.
- **Approach from the front**
In later stages of dementia, the person's range of vision may become more limited. Make direct eye contact (unless culturally unacceptable)
- **Minimize distractions**
People who live with dementia are often easily distracted by both sights and sounds. Before communicating, try to eliminate all unnecessary sources of stimulation. If you need to handle someone's personal belongings, be sure to ask his or her permission first.
- **Lead with the person's name**
For example: "Hi, Mrs. Turner, I'm Carrie. Are you ready to play cards?" or "George, I'm Becky. How are you feeling today?"
- **Avoid Pronouns**
Avoid words like: it, he she, his, her, them, they, those, etc. as much as possible. What is *IT*? Who is *HE*?
For example: Marvin, when did Arlene leave? (not "she") or "Caroline, please put your shirt in the basket." (not "it") or Tony, let's give the books back to Jerry and Allen." (not "them")
- **Use short sentences**
Keep your sentences short and to the point. For example: "Bob, your son Joe will be here soon"
Or "Mr. Gibson, turn on the water." Or "Barbara, use the towel."

COMMUNICATION TIPS

- **Wait for a response**
In individuals with dementia the response time can be delayed by up to 30 seconds. Therefore, allow time for them to respond. Do not distract the person and **BE PATIENT**.
- **Use visual or tactile cues**
For example while saying "please brush your hair," demonstrate the movement of hair brushing. While saying "Raise your arms," raise your arm to demonstrate and while saying, "It's time to eat," put your hand to your mouth to simulate eating.
- **Watch your nonverbal messages**
Keep you volume at a normal level (unless the person is hard of hearing). Avoid crossing your arms, as this can indicate impatience or tension. Remember that a smile is often contagious.
- **Be patient, supportive, and friendly**
At every stage of dementia, there is a person behind the patient. Let them know that they have your full attention. Focus on the feelings. Use additional forms of communication to express support, such as touches and smiles.



The world of the person with dementia changes over time, and so we must also change and adapt to their evolving needs.