

Monthly newsletter for people caring for those affected with Alzheimer's disease or other forms of dementia.



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Dementia in Adults with Intellectual Disabilities

Marcy Maler

Caregivers play an important role in the overall wellness of individuals they support including those who care for adults with intellectual disability. The needs of people living with IDD and dementia are sometimes similar to other people with dementia but often call for unique skills, assessments, and approaches. As individuals with an intellectual or other developmental disability age, you may see changes that are confusing and upsetting. It can be frightening not knowing what is happening to them or how to best support him or her. Your support is extremely important to your loved one. Sometimes, it can be difficult finding answers when life begins to change. As people with intellectual disability age, changes will occur and the best thing you can do is learn as much as you can, advocate whenever it's needed, and support your loved one to live his best life.

Typically, a developmental disability interferes with a child's normal development. Your loved one may be identified as having an intellectual disability that creates limitations in intellectual functioning (intelligence) and in adaptive behavior (everyday social and practical skills). Or, he may have a developmental disability. Examples of a developmental disability include autism, cerebral palsy, developmental delay, Down syndrome, epilepsy, intellectual disability, Prader-Willi syndrome, spina bifida and other genetic conditions that impair growth and development.

With advances in healthcare, people with intellectual disability are also living longer. For example, people with Down syndrome, a chromosomal condition that may be associated with intellectual disability and some health complications, are often living well into their 60s and beyond. They are a



special population at higher risk for developing Alzheimer's because of the extra copy of the 21st chromosome. People with other types of intellectual and developmental disability have only a slightly higher risk.

Dementia in adults with intellectual disability will generally be the result of Alzheimer's disease, but they may also have dementia due to other causes. Early signs may include changes in health, in some cases, the development of later-age seizures. Other changes may include the loss of skills for dressing, self-care, and completing multiple-step tasks. Loss of language skills and memory are other signs that changes may be connected to dementia. However, in a person with an intellectual disability, these are typically seen later in the progression of the disease. Learning about the different characteristics of dementia, including diagnosis and care, along with the stages of the disease, is a good way to prepare and plan for your loved one's care as he or she ages.

Although the information can be overwhelming at times, it can also give you more control to handle the challenges you will face. It is helpful to understand the importance of preparing, reaching out to community resources, and putting a plan in place.

A healthcare advocate can help present information to a healthcare provider in

Tips & Tools

Dementia Symptoms in Persons with Intellectual and Developmental Disabilities

- Increased inability to stay focused
- Exaggeration of longstanding behavioral traits (most often stubbornness)
- Change in prior daily routine, sleeping, or eating habits
- Inability to make clothing decisions
- Getting lost in familiar environments
- Not remembering names of people previously known
- Increased aggression, unjustified fears, sleep problems
- Increased difficulty with visual/motor coordination
- Increased accidents and falls
- Difficulty learning new tasks
- Loss of language and other communication and social skills
- Progressive loss of prior activities of daily living
- Late onset seizures
- Frequent choking incidents
- Changes in hearing and vision

support of a person with whom they have a trusted relationship. For someone with an intellectual disability, a healthcare advocate may share the individual's medical history, changes in functioning, and symptoms that are related to the reason the person has a medical appointment.



Even without a medical background you can be a good healthcare advocate for your loved one. Families are the greatest source of information about their loved ones with intellectual disability. You are the expert on your family member, having spent a lifetime with him. Your knowledge will help identify what is happening and lead the medical professionals to the most accurate diagnosis. As you continue to develop a partnership with your healthcare provider you will feel more confident in the importance of the information you provide.

Keep a list of questions you have and make notes of concerns you have. The more information you can give to the healthcare provider, the better he will be able to determine what needs to be done. Speak with others who provide care for your loved one or those who spend time with her, such as other family members. They may have observations that you are unaware of and that would be helpful to share. Pay close attention to subtle changes in behavior and any changes in communication skills (such as losing the ability to carry on a conversation). Watch for significant changes in functioning, such as skill loss including activities of daily living, loss of appetite and/or weight loss, refusal to participate in previously preferred activities and events, as well as changes in social interaction such as forgetting the names of people who your loved one has known for years. All behavior is a form of communication and much can be learned from changes in typical daily behavior.

Some families have struggled with how much they tell their loved one or whether they should say anything about the diagnosis. It is a very personal decision and one that only you and your family can make. Consider these factors as you make this decision:

- Will my relative understand?
- How will I tell him or her?
- How much information should I share?
- How can I keep the message simple, and not scary?

Understand that each day will be different, and that your role as a caregiver will change over time. You may need to seek help from others in your family with the caregiving demands. Your loved one will benefit from a well-developed Dementia Care Plan. This may be a new and separate plan of support or it could be a revision of an existing plan. The foundation of the plan must be person-centered and focused on the current and changing needs of your loved one. It should include his wishes, likes and needs to ensure that his journey through the disease is well supported to provide a good quality of life.

Don't forget to make time to take care of yourself and be open to getting help. If you are tired or irritated, your loved one will sense and may mirror your feelings, even if your words say something different. Caregiver stress and burnout are real and the risk becomes greater as the care demands increase. Many caregivers have difficulty asking for help for themselves, but you need to take care of yourself as you are the most important medicine your loved one receives. Most family members want to know how they can help. Your honesty and direct requests will be appreciated as they try to support you and your loved one.