There are many families who are accompanying their loved one with Down syndrome or other Intellectual Disability on the Alzheimer’s (Dementia) journey. It can feel like a lonely path, but it doesn’t have to. Join other family caregivers in regularly scheduled online meetings to discuss your concerns, to share your fears and to learn.

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Alzheimer’s disease is the most common form of dementia and is characterized by gradual onset, inability to remember new information and impaired daily activities. It is caused by an accumulation of amyloid plaques and neurofibrillary tangles which cause the death of brain cells.

Research has shown that the amyloid plaques are created in the 21st chromosome, the same chromosome that is replicated and causes Down syndrome. It is why people with Down syndrome will have more plaque in their brains at an earlier age and why people with Down syndrome are at the highest risk for Alzheimer’s disease than any other special population.

Caring for a loved one who has Down syndrome and Alzheimer's or another dementia can be one of the greatest challenges we face.

**WE DO NOT HAVE TO DO IT ALONE**

**CHALLENGES TO DIAGNOSIS**

Because changes related to Alzheimer’s disease occur over time, subtle changes may not be observed and people with Down syndrome may have difficulty reporting things that are happening to them. In addition, there is often no effective way to measure change from previous levels of functioning. Commonly used assessment tools are not relevant for people with Down syndrome.

**RISK OF DIAGNOSTIC OVERSHADOWING**

Because many medical professionals have little training and experience working with people with Down syndrome, there is a risk of diagnostic overshadowing. Be diligent with professionals who relate the origin of changes in behaviors or health to the person’s primary disability. It is important to explore all the possible causes.

**SIGNS THINGS ARE CHANGING**

People with Down syndrome who have developed Alzheimer’s disease have exhibited medical changes years before any signs of dementia. Watch for Hypothyroidism, and a new onset of seizures. Annual check-ups should include screening for Thyroid disease, hearing loss or vision changes, as well as behavioral problems. All these are signs to be investigated.