

CAREGIVER NEWS

Volume 1, Issue 1

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SUPPORT FOR FAMILIES AND CAREGIVERS OF PEOPLE WITH INTELLECTUAL DISABILITIES AND ALZHEIMER'S DISEASE

Welcome to the first issue of the Caregiver News. This publication has grown out of the NTG's Family Caregiver Online Support Group for those who are caring for, or have cared for, loved ones with Alzheimer's and intellectual disabilities.

Once each month, we open the airwaves to share what is happening in our lives and with our loved ones. To keep the group effective for support to the families, we limit participation to those who have loved

ones with dementia or are direct caregivers. As we identify topics we would like more information about, we invite specific professionals to lead our conversation. Upcoming issues of this newsletter will include some of the highlights of those conversations. In addition, watch for links to helpful resources.

This issue includes some general information on intellectual and developmental disabilities and dementias, as well as an introduction to the National Task Group (NTG) on Intellectual Disabilities

and Dementia Practices. We encourage you to visit the NTG website for more information on their activities and to become a member. (See page 4.)

We have learned through interactions with families in the online support group that there are lots of questions, many uncertainties, multiple feelings of loss, limited resources in local communities, and *great recognition that love is most important for all of us.*



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Online Group Topics

- Creating Dementia Capable Settings
- Alzheimer's Disease Progression in Down syndrome
- Creating a Baseline of Functional Skills
- Maintenance of Self-Care Skills
- Life-long Health and Wellness Medical Advocacy
- Aging in Place
- Creating and Telling a Life Story

THE ALZHEIMER'S JOURNEY

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 be.

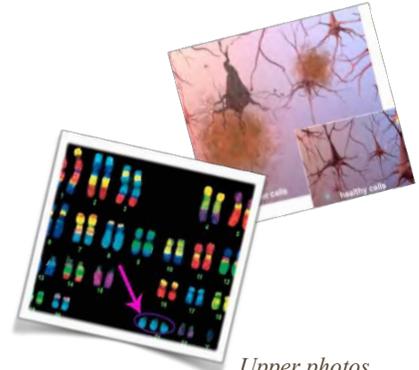
Join other family caregivers in regularly scheduled online meetings to discuss your concerns, to share your fears and to learn. We'll discuss a variety of topics in upcoming meetings, as well as have meetings focused solely on support. We meet the first Thursday night each month at 8:00 p.m. Eastern Time. For more information, see page 4.



DOWN SYNDROME & ALZHEIMER'S FACTS

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.



Upper photos show amyloid plaques and tangles on cells in a brain with Alzheimer's disease and cells in a healthy brain.

Lower photo shows the triple copies of chromosome 21.

CHALLENGE 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.

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.

risk

OF DIAGNOSTIC OVERSHADOWING

Many medical professionals have little training and experience working with people with Down syndrome, therefore there may be 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.

DEMENTIA, INTELLECTUAL & DEVELOPMENTAL DISABILITY, DOWN SYNDROME: THE CONNECTION

The NTG is totally focused on supporting people who have intellectual and developmental disabilities and some type of dementia. Because dementia is non-discriminatory, it may affect people of all nationalities, genders, and intellectual abilities. Much of the information we share is related to people with Down syndrome because they are at a high risk of developing Alzheimer’s at some time in their life. Professionals who work with people who have Down syndrome and Alzheimer’s, as well as those who have some other type of intellectual or developmental disability and another type of dementia have shared that there is great similarity in the support they provide.

If you are a family member or caregiver of a person with an intellectual or developmental disability, other than Down syndrome, please know that you are important to us. And



be aware that much of what we know about providing dementia-capable care is useful for all persons with any type of intellectual or developmental disability and any type of dementia.

So, what is the difference between dementia and an intellectual disability (ID)?

Dementia is an age-associated condition that affects and diminishes quality of life.

- It causes a loss of cognitive function (such as memory, thinking, and reasoning) severe enough to interfere with daily functioning.
- Dementia is not a disease.
- Dementia is NOT part of normal aging.
- The term describes clinical/ behavioral symptoms associated with certain diseases or conditions.
- Dementia robs an individual of his or her mind, capability to be independent, and often his or her dignity.

Most adults with ID are typically at no more risk than the general population. However, adults with Down syndrome are at increased risk, some even are affected in their 40s by ‘early-onset dementia’ shortening their lives and diminishing their quality of life in old age

In the USA, an estimated 9000+ adults with ID may be affected, and this number is expected to triple in the next 20 years.

Dementia: ID vs. Down syndrome

Intellectual disabilities

- Older adults with ID have dementia at same rate a general population.
- All other causes of age-associated decline should be ruled out before dementia is assumed to be present.
- Useful to know of signs and keep track of capabilities after age 50.
- Dementia etiology varies.

Down syndrome

- Older adults with Down are at high risk of Alzheimer’s disease, but not every adult will show clinical signs of dementia as he or she ages.
- All other causes should be ruled out before assuming change is due to dementia.
- Useful to know signs and keep track of capabilities after age 40.
- Dementia etiology mostly Alzheimer’s type.

“Behavioral presentation may be similar, but it’s the loss from previous level of function that differentiates Dementia from Intellectual Disabilities.”

Information on this page is adapted from “*The NTG Education and Training Curriculum on Dementia and Intellectual & Developmental Disabilities*” Module 4: *Introduction to ID and Dementia.*

**NATIONAL TASK GROUP
ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES**

We're on the
web!
AADMD.org/NTG

NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES

The NTG is a coalition charged with ensuring that the interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and related dementias, as well as their families and friends, are taken

into account as part of the *National Plan to Address Alzheimer's Disease*.

The NTG is affiliated with the American Academy of Developmental Medicine and Dentistry and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago and other partners, such as the Center on Excellence in Aging at the University at Albany and the Gerontology Division of the AAIDD (American Association on Intellectual and Developmental Disabilities).

The NTG is a member of *LEAD*- 'Leaders Engaged on Alzheimer's Disease', a Washington-based coalition working to focus attention on Alzheimer's disease and related disorders.

The NTG produces materials related to dementia, including practice guidelines, screening tools, education and training curricula and workshops, agency and family-based information, and other technical materials, as well as provides technical assistance.

The chairs of the NTG are Matthew P. Janicki, Ph.D. and Seth M. Keller, MD.

NTG ONLINE SUPPORT

another support and guidance. The structure of the meeting varies from support to educational topics, depending on the needs of the participants. The online group provides a mechanism for families to share their experiences and learn from each other.

If interested, there is also an active Facebook group called *Down syndrome & Alzheimer's Dementia Capable Care*. It is a closed group for family members, caregivers and professionals who provide support to them.

To join the group, or get additional information about it or the Facebook group, contact Jadene Ransdell, facilitator of the online group, at jadeneransdellal@gmail.com with the subject line stating "NTG Family Caregiver Online Support Group." Jadene is a Down syndrome & Alzheimer's Family Advocate who lives in Florida. She is the mother of an adult son with Down syndrome who is suspected of having Alzheimer's Disease.

NTG FAMILY ADVOCACY GROUP

The NTG provides a connection for families (parents,

siblings, other kin) challenged by providing primary care for adults affected by dementia. It also is involved in advocacy for the rights of people with dementia and their caregivers. NTG's family advocates provide consultation and counseling to family members and others involved in primary caregiving or seeking information about dementia and caregiving challenges. NTG's family advocates also attend and provide comments at the quarterly meetings of the national Advisory Council on Alzheimer's Research, Care and Services. The Advisory Council makes recommendations to the Department of Health and Human Services (DHHS) for priority actions to expand, coordinate, and condense programs in order to improve the health outcomes of people with Alzheimer's Disease and Related Dementias (ADRD) and reduce the financial burden of these conditions on those with the diseases, their families, and society.

Ms. Mary Hogan is the chair of the Family Advocacy Group. A resident of Southern Maine, Ms. Hogan is the sister of a man with Down syndrome who passed away recently after being diagnosed with Alzheimer's disease.

Currently, the NTG Family Advocacy Group is working with the National Down Syndrome Society and the Alzheimer's Association to produce a family-oriented informational booklet on dementia and Down syndrome.

For more information, contact Mary Hogan, Family Advocate at maryhogan@comcast.net.

