

## DOWN SYNDROME ADULT SUMMIT



### Inside this issue:

Did You Know?	2
Caring for the Caregiver	2
Sharing a Life Story	3
The National Task Group	4
NTG Family Support	4
Books & Documents on Our Radar	4
Resources	4

The NTG has joined in partnership with the National Down Syndrome Society (NDSS) and the National Alliance for Caregiving (NAC) to host a summit for families of adults with Down syndrome. We have been working for several months to create a program that promises to be informative, educational and, most importantly, timely.

### Our Partners

According to the **NDSS** Chairman and retired USN Capt. Robert Taishoff, the NDSS is “working to create a world in which all people with Down syndrome deserve the same opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.” The NDSS provides state-of-the-art, comprehensive and critical programs and services to the Down syndrome community that include their National Advocacy & Policy Center, the National Buddy Walk® Program, Community Outreach and Resources, and Public Awareness.

Established in 1996, the **NAC** is a non-profit coalition of national organizations focused on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance is dedicated to improving quality of life for families and their care recipients through research, innovation, and advocacy.

We believe this is a strong partnership that will benefit the families we all serve.

### The Program

Growing up with Down syndrome opens doors to a whole new world. It can feel like the best part of life is over as school years draw to an end! However, there is an exciting world ahead for adults with Down syndrome, filled with opportunities and rewards. Folks with Down syndrome now have the chance to create full and productive lives, look forward to retirement and to age with dignity in a place they choose. Join us as we explore life as an adult with Down syndrome. Sessions will be based on the five pillars of the NDSS (*Health and Research, Inclusive Education, Community Integration, Economic Self-sufficiency and Employment*) and we’ll be talking about planning a life, exploring jobs and meaningful activities, connecting with communities, staying healthy and aging.

We’ll also have sessions specifically for families loving and supporting someone with Down syndrome and Alzheimer’s. No matter what the age or stage of your loved one with Down syndrome, you’ll want to be part of this discussion.

### Save the Date

We’ll be meeting in **Arlington, VA** on **April 9 & 10, 2018**. Watch this newsletter for more exciting information about the program, speakers and the fun we have planned for you.

*Please address all questions regarding the Summit to **Jadene Ransdell, Down Syndrome Adult Summit Chairperson**, at [ntgfamilyadvocate@gmail.com](mailto:ntgfamilyadvocate@gmail.com)*

### Down Syndrome Adult Summit

- Health & Research
- Inclusive Education
- Community Integration
- Economic Self-sufficiency
- Employment
- Older Age & Alzheimer’s Disease

**April 9-10, 2018**  
**Arlington, VA**

## OH MY GOODNESS... DID YOU KNOW?



There is truth in the old saying, “Use it or lose it.” We have learned that exercise helps keep our muscles toned and working. We know that our body is strengthened when we walk, run or do other forms of physical activity. Our hearts are made healthier through physical exercise, as well. *Did you know we can do exercises to strengthen our brains?*

One of the contributing factors to memory loss in dementia, and Alzheimer’s particularly, is the build up of Amyloid plaque that creates tangles. Those tangles ultimately create barriers between the synapses in our brain, resulting in loss of skills and memories.

Studies have shown that doing activities that exercise the brain stimulate the release of electrical chemicals that strengthen and create more permanent synapse connections. One activity has been shown to be exceptionally beneficial to brain health is simple repetitive finger movement.

Nearly twenty years ago Professor Thomas Elbert of the University of Konstanz in Germany discovered that our brains have the ability to adapt to change and acquire new ways of learning. In his studies, Elbert found a superhighway from the fingertips to the brain. Our fingertips are some

of the most touch-sensitive parts of the body with more than 3,000 touch receptors. Using Braille like textures that create pressure on the fingertips create this superhighway to the sensory cortex of the brain. Through sensory stimulation with repetitive finger movement, researchers are finding that memory can be increased, cognitive abilities improved and anxiety, depression and stress may be reduced. Those doing research in this area believe that even people with Alzheimer’s may be capable of creating new neurons that may result in opening connections to old memories and even acquiring new memories.

To learn more about this interesting topic check out the following information:

*Handy Guide to Touch*, John Hopkins Magazine,  
<https://brainpaths.com/active-brain-healthy-brain/>

*Brainpaths Brochure*, Brainpaths,  
[https://cdn.websites.hibu.com/d0d319938f014c2492e8db25df4fe6b3/files/uploaded/brainpaths\\_medical\\_device\\_brochure\\_information\\_2016.pdf](https://cdn.websites.hibu.com/d0d319938f014c2492e8db25df4fe6b3/files/uploaded/brainpaths_medical_device_brochure_information_2016.pdf)

*Brainpaths Rewire Your Brain*, (Video), Brainpaths,  
[https://www.youtube.com/watch?v=BHDLpLF3\\_08](https://www.youtube.com/watch?v=BHDLpLF3_08)



## CARING FOR THE CAREGIVER

How many of these have you heard:

- “You need to take care of yourself.”
- “You can’t take care of someone else if you don’t take care of yourself.”
- “You look exhausted!”

As a caregiver, you have probably heard all of those and more. People who are concerned about you know that giving care to others can be a very demanding job. Even if you don’t provide day-to-day care, your responsibilities can be stressful.

Studies have shown that caregivers suffer from prolonged stress, physical demands and a sense of loss which lead to an increased risk for depression, chronic illness and possible de-

cline in quality of life. Because caregivers generally put others before themselves, they tend to ignore their own health and well-being.

There are things you can do to manage the stress of caregiving. Following is a list of suggestions. Because every situation is different, find something you can do and build from there.

- Learn and use stress-reduction techniques
- Focus on your healthcare needs—including rest, exercise and healthy nutrition
- Take time to “chill”
- Spend time with friends
- Get back to a hobby you’ve neglected—gardening, sewing, woodworking, etc.

- Learn positive self-talk
- Start a gratitude journal—keep track of the things in your life that bring joy and make your heart happy

There are many ways to care for yourself. Only you can do it. If you need to, schedule some “me-time” in your calendar. Just realize that you aren’t being selfish if you take time for yourself.



# SHARING A LIFE STORY

Many caregivers have expressed concern that as their loved one with dementia progresses in the disease, the person they once were gets lost. Life stories can decrease that sense of loss.

Sharing the life story of a person with an intellectual disability and dementia can have many benefits. A life story can keep families connected through the exploration of shared memories. Life stories can help people with dementia feel better about themselves; in addition, healthcare and other service providers will have an opportunity to know your loved one as you do. Planning for services and supports can remain person-centered, based on your loved one's likes and interests.

People with early to mid-stage dementia often have difficulty remembering recent events, however they can recall experiences of their more distant past. Creating a life story with the assistance of the person with dementia provides a stimulating activity that can bring joy into his or her life.

If you would like to create a life story for your loved one, know there are many ways you can accomplish this.

With technological advances, many folks will have years of digital photos and videos that could be used to create an animated life story. However, to keep things simple the focus of this article will be low-tech.

First, think about how you want to share your loved one's story. A scrapbook or unlined journal will work...so will a three-ring binder. The book doesn't need to be fancy, but it should be visually pleasing. You can use copies of old photos, certificates or postcards to prompt memories of life before dementia. If those items aren't available, you can creatively illustrate a life memory with things such as a map that shows the town where your loved one was born or has lived.

Establish a time-line that includes major life events that can help you focus on the most important

## A Life Story

can become a legacy of family relationships and personal history that will support the individual with dementia by purposefully sharing information that is needed to give individualized, person-centered care.

*A Guide to Creating a Life Story for Care Giving*  
Kootenay Boundary Dementia Core Working Group  
Interior Health, British Columbia

occasions for your loved one. You can include any of the following information (or other ideas) that your loved one wants:

- ◇ Place of birth
- ◇ Places lived
- ◇ Family members
- ◇ Hobbies or other fun activities
- ◇ Childhood memories
- ◇ School memories
- ◇ Favorite job
- ◇ Holiday memories

Use a photograph or other memento to start a conversation with your loved one. Whenever possible, write what he or she says about the photo. If your loved one doesn't communicate with words, you may need to write your memory of the photos and mementoes. Read what you have written to your loved one and notice their reaction. It may help you to see if your memory matches that of your loved one.

Not only may the quality of life improve for your loved one, but your life may be enriched as well. Your loved one's life story may become a legacy for your family and friends.

### RESOURCES FOR LIFE STORIES

*A Guide to Creating a Life Story for Care-giving* — <https://www.interiorhealth.ca/YourCare/ChronicConditionDisease/Dementia/Documents/GuideLifeStoryTools.pdf>

*How to Use Personal Information in Care-giving: Tips for Health Care Providers* — <https://www.interiorhealth.ca/YourCare/ChronicConditionDisease/Dementia/Documents/UsingPersonalInformationCare.pdf>

*Fill in the Blanks Life Story* — <http://www.legacyproject.org/activities/lifestory.html>

*How to Make a Scrapbook for Someone with Dementia* — <https://www.unforgettable.org/blog/its-a-wonderful-life-how-to-create-a-life-story/>

*Personal Life History Booklet* — <https://nsw.fightdementia.org.au/sites/default/files/20110303-NSW-LifeHistoryBook.pdf>

*Improving Care for People with Dementia : development and initial feasibility study for evaluation of life story work in dementia care* — [http://eprints.whiterose.ac.uk/104193/2/FullReport\\_hsr04230.pdf](http://eprints.whiterose.ac.uk/104193/2/FullReport_hsr04230.pdf)



We're on the web!  
[AADMD.org/NTG](http://AADMD.org/NTG)

## NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA

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 Gerontol-

ogy 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.

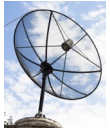
For more information about the NTG, please visit the website.

## NTG FAMILY SUPPORT

The NTG recognizes the valuable role family members play in support of loved ones with intellectual disabilities.

In May, 2016, the NTG began hosting monthly online support group meetings for family caregivers. Participants have shared their gratitude to connect with others who are having comparable experiences. We know that there are many more families who are seeking answers or someone to just listen to them, yet to be effective, we know the group must remain small.

We have learned a lot this past year, and we continue to learn every month. There has been tremendous interest in online support and we have been asked to assist others with starting similar groups in their communities. *If you would like more information about the online support group contact Jadene Ransdell at the email address listed in the resource section below.*



## BOOKS & DOCUMENTS ON OUR RADAR

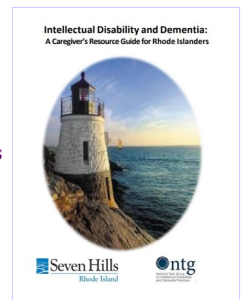
In each issue we want to bring you information that we have found useful to other family caregivers, as well as links to materials that are current and timely.

***Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders***, Seven Hills Rhode Island and the National Task Group on Intellectual Disabilities and Dementia Practices, 2017

This resource guide, while written for Rhode Island families of adults with intellectual disability, is a useful tool for anyone who provides care. The guide was designed to give caregivers of individuals with an intellectual disability an overview of dementia, as well as offer information about caregiving and support options available in Rhode Island. For adaptation and adoption by other states, contact the National Task Group at [mjanicki@uic.edu](mailto:mjanicki@uic.edu).

Print copies of this document may be available from Seven Hills Rhode Island (30 Cumberland Street, Woonsocket, RI 02895 ). You can download a copy through this link:

<https://aadmd.org/sites/default/files/8.5.17%20SHRI%20Resource%20Guide.pdf>.



## RESOURCES

### NTG Contacts:

For general information about the *NTG*:

Seth Keller, Co-Chair: [sethkeller@aol.com](mailto:sethkeller@aol.com) or Matt Janicki, Co-Chair: [mjanicki@uic.edu](mailto:mjanicki@uic.edu)

For information about *Family Advocacy*:

Mary Hogan, Chairperson—Family Advocacy Workgroup: [maryhogan@comcast.net](mailto:maryhogan@comcast.net)

For information about *Family Caregiver Online Support Groups*:

Jadene Ransdell, Online Support Groups Facilitator: [jadeneransdellaz@gmail.com](mailto:jadeneransdellaz@gmail.com)

For information about *NTG Training*:

Kathie Bishop, Co-Chair—Education and Training Workgroup: [bisbur1@earthlink.net](mailto:bisbur1@earthlink.net)

## GOT IDEAS?

If you have an idea for a newsletter article, would like to share information, or have questions about the newsletter, contact the editor of the NTG Caregiver News at [ntgfamiladvocate@gmail.com](mailto:ntgfamiladvocate@gmail.com).

