As this issue of the NTG Caregiver News is finalized, we are just four short weeks to the opening of the First Annual Down Syndrome Adult Summit. We are partnering with the National Alliance for Caregiving and the National Down Syndrome Society. (See the September–October, 2017 issue of this newsletter for more information about our partners.)

The Summit program will provide hours of opportunities for self-advocates, family members and caregivers to learn about various important issues related to life as an adult with Down syndrome. There are more than 25 breakout and plenary keynote sessions scheduled throughout the one and one-half days of the Summit.

Several NTG members have agreed to present on topics focused on the aging adult with Down syndrome and those experiencing a decline in skills or with Alzheimer’s disease. In addition, there will be sessions on residential and vocational options, person-centered planning, financial planning, healthy relationships, siblings, and grass-roots advocacy.

Featured speakers include Dr. George Capone, from the Kennedy-Krieger Institute in Baltimore, Maryland, who will talk about common medical conditions seen in adults with Down syndrome.

Dr. Harold “Hackie” Reitman, President and Founder of Different Brains in Fort Lauderdale, Florida will share his insights on neurodiversity—basic variations in the human brain and how this can help us celebrate the differences in people with Down syndrome to improve their lives and maximize their potential.

Dr. William Sears, a well-known pediatrician and father to Stephen, 26, who has Down syndrome, will share actions he and his wife took to help Stephen live his best life, and reassure everyone that it’s never too late to get healthy.

Joe Shapiro, a NPR news investigations correspondent will speak with Mary Clayton, a parent advocate and mother of a young woman whose story was shared in Mr. Shapiro’s series on sexual assault of people with intellectual disabilities.

Rob Snow, parent of a son with Down syndrome and motivational speaker will provide attendees with a humorous and powerful experience about managing through life’s biggest challenges.

In addition, Dr. Matthew Janicki, NTG, Sandra Fournier, Seven Hills Rhode Island and Jennifer Sladen, the Arc US, will lead a discussion about explaining dementia to people with intellectual disabilities. Self-advocates, family members and caregivers are invited to provide their perspective on the development of a new section in a guide created for caregivers.

Visit the NDSS website to learn more about the Summit and to register. https://www.ndss.org/2018-ndss-adult-summit/

Plan to stay another day to visit with members of Congress to discuss issues important to people with Down syndrome.
Flexibility can be an important tool in our bag of tricks, as we journey through Alzheimer’s with someone for whom we provide care and support. Over the years, you have probably noticed that sometimes it’s necessary to switch to Plan B...or C...or even Plan Y. Life can be challenging, and it may flow better if we change our approach sometimes.

As Alzheimer’s progresses, people may feel lost in a world that used to be quite familiar to them. Being flexible and making adaptations may help them feel more comfortable and safer.

Has your family member ever stood in the closet and stared at all the shirts or blouses hung there? Does she empty the dresser drawers of all the contents? She may have been very capable, in the past, of picking an outfit to wear; where now she is unable to focus and decide. Saying to her, “Stop that,” or “Hurry up and get dressed,” probably doesn’t help and may cause more frustration. So what can you do?

You might remove the t-shirts in the drawer and leave only 2 or 3, limiting the confusion. If you hang only one or two outfits in the closet, there is less to distract her.

Explain what you want her to do. Let her know why she needs to get dressed—in a positive way. For example, instead of saying, “If you don’t hurry up and get dressed you can’t go to program today!”, you could say, “You can wear your green blouse or the blue one to program today.” It may help reduce the anxiety she feels and she will know why she should get dressed.

Going out to eat may have been a preferred activity in the past. If now your loved one gets very loud and upset when eating out, perhaps you can go out at a time when there are fewer people and it is quieter.

Adapting the environment or the routine may feel like you are taking things away from the person you care about. If you reframe that thought it may help you understand that making adaptations and being flexible is one more way you can create an environment that is comfortable and safe for your family member and shows you still care about them.

**ON OUR RADAR**

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

_Jenny’s Diary_ A resource to support conversations about dementia with people who have a learning disability, Karen Watchman, Irene Tuffrey-Wijne, Sam Quinn, Pavilion Publishing and Media Ltd. Hove, UK, 2015

Several of the NTG members had the opportunity to work with Karen Watchman when she hosted the International Summit on Intellectual Disability (ID) and Dementia in October 2016. Karen has done a great deal of writing and research on issues related to this topic. _Jenny’s Diary_ focuses on delivering the news of a diagnosis of dementia to a person with ID. It comes with photos, discussion prompts, and a booklet about how to frame the conversations for use. It is a rich resource that might be helpful for many family members and caregivers. If you happen to use _Jenny’s Diary_, Karen would like feedback on how it was used, and if it was helpful. The link to the book is provided. _Note:_ the website contains two versions; the one labeled “ID” is for US families and caregivers, as in the UK they use the term “LD” for people with an intellectual disability. [www.learningdisabilityanddementia.org/jennys-diary.html](http://www.learningdisabilityanddementia.org/jennys-diary.html)

Note: The NTG, Seven Hill Rhode Island and the Arc of the United States are collaborating on material to help family members and caregivers explain dementia to a person with an intellectual disability. This work will be a new module for the publication, _Intellectual Disability and Dementia: A Caregiver’s Resource Guide for Rhode Islanders_, which was highlighted in the September/October, 2017 issue of this newsletter. There will be a review of the module at the Down Syndrome Adult Summit; watch this newsletter for more information when it becomes available.
FIRST ANNUAL DOWN SYNDROME ADULT SUMMIT

Educate, Advocate, and Celebrate Adults with Down Syndrome

April 9th & 10th, 2018
Westin Gateway Hotel, Arlington, VA
give.classy.org/bw 2018
DOWN SYNDROME ADULT SUMMIT INFORMATION

The Program

The 2018 NDSS Down Syndrome Adult Summit is a conference hosted by the National Down Syndrome Society (NDSS) and its Self-Advocate Advisory Board (SAAB) in collaboration with the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and the National Alliance for Caregiving (NAC) to discuss important and critical topics for all adults with Down syndrome. Speakers and topics will align with NDSS’ robust and comprehensive programs and pillars, including healthcare and research, inclusive education, community integration, economic self-sufficiency as well as employment and our NDSS #DSWORKS® Campaign. Aging-related changes and health issues, including Alzheimer’s disease, will also be covered. Join us for a day and a half and meet other families who share your journey. For more information visit the NDSS website at: http://www.ndss.org/2018-ndss-adult-summit/.

Topics of interest include the following:

<table>
<thead>
<tr>
<th>Topic</th>
<th>Speaker(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy Aging—Leone Murphy, MSN</td>
<td>Tips for Caregiving—Adel Herve, OTD, OTR/L, FAOTA</td>
</tr>
<tr>
<td>Creating and Sharing Life Stories—Elizabeth Bodien, Jane Boyle</td>
<td>Common Medical Conditions in Adults with Down syndrome—George Capone, MD</td>
</tr>
<tr>
<td>DS Connect: Research Opportunities for Adults with Down syndrome—Sujata Bardhan, PhD</td>
<td>Caring for the Caregiver—Maja Pasovic, MA, MEd, Joe Caldwell, PhD</td>
</tr>
<tr>
<td>The Role of Siblings in the Life of a Person with Down syndrome—Mary Hogan, MAT, Kathy Srsic-Stoehr, MSN, MS, RN, NEA-BC, Margie Douglas, PhD, Embry Burrus, MCD, Kenya Jones</td>
<td>Decline in Adults with Down Syndrome: Assessment and Care Considerations—Seth Keller, MD, Kathy Service, RN, PhD [c], FNP-BC, CDDN</td>
</tr>
<tr>
<td>Explaining Dementia as a Family Member and Understanding Dementia as an Adult with Down syndrome — Helping the NTG Create a Guide for Families—Matt Janicki, PhD, Sandra Fournier, MS, RN, CDDN, Jennifer Sladen</td>
<td></td>
</tr>
</tbody>
</table>

The Location

The 2018 Adult Summit will be held at the Westin Arlington Gateway Hotel, 801 North Glebe Road, Arlington, Virginia 22203. To confirm a space in the NDSS room block at $239 per night at the Westin Arlington Gateway, please call 888-627-7076 and mention “NDSS.”

The Cost

The cost for the 2018 Down Syndrome Adult Summit on April 9-10 is $50 per person. Adults ages 18 and up are welcome to attend. Register today.

The NDSS 2018 Buddy Walk on Washington

Annually, the NDSS hosts a two-day advocacy conference that brings the Down syndrome community together to advocate for legislative priorities that directly impact the lives of people with Down syndrome and their families. During the first day of the conference, advocates receive training. They head to Capitol Hill on the second day to meet with Members of Congress and their staff to discuss legislative issues that would advance education, research and healthcare opportunities for people with Down syndrome. This year, the Buddy Walk on Washington will follow immediately after the Down Syndrome Adult Summit. We encourage you to stay over to meet with Federal Legislators with other Down syndrome advocates.

The cost for the 2018 Annual Buddy Walk® on Washington Advocacy Conference on April 10-11 is $50 per person. All are welcome to attend. Children age 5 and under are free. Register today.

2018 Annual Buddy Walk® on Washington: Pre-purchase your bus ticket to Capitol Hill from the Westin Arlington Hotel on April 11. Cost is $10 per person. (This is a one-way ticket.)

Register for both the 2018 Annual Buddy Walk® on Washington and 2018 Adult Summit and receive a $20 discount upon checkout!
LET'S TALK QUALITY OF LIFE

Quality of life...those three words are talked about a lot. But just what is quality of life? There has been vast research into this term and one thing is very clear—quality of life is subjective and multidimensional.

Some believe that one’s quality of life is tied to happiness; Meriam-Webster defines it as how good or bad a person’s life is. Communities use a quality of life index to look at social, health, economic and environmental conditions that affect people, and use that information to focus community action.

You may be wondering just why this is important to you. Caregiving responsibilities may be so great that you don’t have time to consider your quality of life, or that of the person for whom you provide care. Some share that they have a poor quality of life, and that may be true because it is influenced by life events.

Humans have needs to belong, to contribute, to feel secure—all elements of what gives our life meaning. Let’s try a little exercise. Think about your life—in a time where you felt content and happy. Make a list of things that were in place when you felt that life was good. Did you have a close family, belong to a group, religious organization or a social club? Did you have a job or work that you enjoyed? Did you have activities that made you feel good about yourself? What is on your list are the things that bring quality to your life.

We want the people we care for to have a good quality of life, just as others do. We can provide opportunities for our family members to live their best life by focusing on things that they enjoy or make them feel good about themselves.

Various authors have identified the domains of being, belonging and becoming as important aspects of quality of life.

Being and belonging relate to the physical, psychological and spiritual self.

Being is supported through nutritious meals, exercise, a calm environment and hope for the future.

Belonging deals with the environment, which could be our home, neighborhood or community. Maintaining a clean and safe home is important, as is spending time with family, close friends and others in our community. Accessing professional services such as medical care and other community resources is part of the belonging domain.

Becoming is about practical, leisure and growth attributes. In this domain are our personal goals, our careers or other activities that give our life meaning. Becoming also includes activities that are enjoyable and relaxing, activities that help us cope with change and improve our health.

Cultural values also play a part in the expectations we have for our lives and ultimately our quality of life.

It is difficult to determine quality of life for someone else. Knowing what brings contentment to them will help.

To maintain a good quality of life for our family member with Alzheimer’s or other dementia we can do several things. Pay attention to routines and the environment, especially as the disease progresses. People with dementia find comfort in keeping a schedule they are used to. When normal daily activities are changed, perhaps for a doctor appointment or because of the weather, it can be unsettling for them. In addition to the basics, such as meals, bathing or grooming, be sure the routine includes activities that are stimulating like games or exercise.

You can sort old photographs and put them in an empty photo album or use them to reminisce. Let the photos spark conversation of old memories. Remember, long-term memories may be recalled even when short-term memories fail.

Take walks around the yard, the neighborhood or in a local park. If your loved one can no longer walk, use a transport wheelchair, if possible. Exercise is essential, so helping your family member move his arms and legs is important. Toss a balloon and help him swat at it. A little movement is better than none.

Play music, sing songs. One mom recently shared that she was able to calm her son by singing the same songs she had sung when he was a baby. Music is a powerful connector, even when all other forms of communication have stopped.

The most important thing you can do is to maintain life as normally as possible. Adapt activities so that your family member can continue to participate. If your family member used to help make supper, find another task she can do in the kitchen to help during meal preparation—putting the napkins on the table, perhaps. She needs to know that she can still contribute, that she is still needed.

Quality of life, after all, is important to all of us. No matter how it is defined!
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.

We produce 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 provide technical assistance.

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 various university centers and the Gerontology Division of the AAIDD. Read more about us.

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.

In May 2016, the NTG began hosting a monthly online support group meeting for family caregivers. We have long recognized the valuable role family members play in supporting one another and are all constantly learning as we share our family stories. Support group participants and those who join us via email have expressed their gratitude for the opportunity to connect with others who are having comparable experiences. Over the past 1.5 years NTG members from a variety of disciplines have joined us for selected meetings and have shared their knowledge and expertise. Family caregivers have also noted the benefit of hearing from NTG members who specialize in Medicine, Occupational Therapy, Gerontology and Psychology.

There has been significant interest in the online support group. We know that there are likely many more families who are seeking answers or someone to just listen to them. We also recognize that to be effective, the online group must remain small.

Over the course of the next few months the NTG will assemble a small workgroup to develop a process to set up regional online support groups, organized by knowledgeable facilitators. In the meantime, the Alzheimer’s Association has a 24-hour Call Center that families can access. A growing number of local Alzheimer’s Association offices are becoming more informed about ID and Alzheimer’s disease and may be able to provide family support more locally.

If you would like more information about the online support group contact, Jadene Ransdell at the email address listed in the resource section below.

Some Great Reads … Books by Family Members

These two books, although not related to dementia, are enjoyable reads as they share a glimpse into the lives of families living with and loving someone with Down syndrome in different parts of the world.

Just Call Me Alex, Lynda Johnson Vitali, Leggere Per Cambiare, Italy, October, 2017. Lynda writes of her advocacy efforts for her son, Alex, who is now in his 30s, successfully living and working in Italy. http://www.leggerepercambiare.it/Down%20Syndrome

The Life We Choose A Sibling’s Story, A. Embry Burrus, Solomon & George Publishers, 2017. Embry shares delightful stories of life with her sister with Down syndrome, as they grew up in the south. https://www.solomonandgeorge.org/books

For general information about the NTG:

Seth Keller, Co-Chair: sethkeller@aol.com or Matt Janicki, Co-Chair: mjanicki@uic.edu

For information about Family Advocacy:

Mary Hogan, Chairperson—Family Advocacy Workgroup: maryhogan@comcast.net

For information about Family Caregiver Online Support Groups:

Jadene Ransdell, Online Support Groups Facilitator: jadeneransdellalz@gmail.com

For information about NTG Training:

Kathie Bishop, Co-Chair—Education and Training Workgroup: 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 ntgfamilyadvocate@gmail.com.