Caring for a loved one with Alzheimer’s disease can be difficult. For some parents and siblings, staying connected with a loved one who is no longer able to communicate as effectively as before can be challenging.

Recognize that people can recall emotions long after they can remember the facts of an event. Think back to an occasion in your childhood. You probably have a much clearer memory of how you felt than the particular details of the event. This quote from Dr. Maya Angelou sums it up quite well.

Family caregivers who have been through the Alzheimer’s journey have shared some thoughts that may be helpful to those who travel the path now.

♥ Be comfortable with silence—Have no expectation that your loved one will respond, but remember, he knows you are there.

♥ Stay in close proximity—be physically present and make connections—hold hands, brush her hair, give him a back rub.

♥ Play music that she used to enjoy. Music is one of the last memories lost to Alzheimer’s. She may not communicate, but she will remember it.

These recommendations closely parallel the ideas written about in a book co-authored by Debbie Barr, MCHES, Gary Chapman, Ph.D., and Edward Shaw, M.D. titled *Keeping Love Alive as Memories Fade: The 5 Love Languages and the Alzheimer’s Journey*. Ms. Barr writes that everyone has at least one emotional language or communication channel that makes him or her feel especially loved. The 5 love languages communicate in ways that make an emotional impact when the memory fails. Those love languages include:

1. **Physical Touch** — such as holding hands or stroking the hair.
2. **Quality Moments** — giving someone undivided attention because as memory fades life is experienced only in moments.
3. **Gifts** — tangible tokens of love, whether bought, found or handmade.
4. **Words of Affirmation** — compliments, kind words or words of encouragement.
5. **Acts of Kindness** — anything that can preserve a person’s dignity or make them feel useful, such as including the person in a conversation (even if he can’t speak) or asking her to help fold towels (even if they have to be refolded later).

Always remember that no matter how far the disease has progressed your loved one is still with you.
“There’s an app for that?” It seems there is an app for almost everything these days and here is one and a web site you might find useful.

Late onset seizures in Down syndrome is often associated with Alzheimer’s disease (approximately 84% of people with Down syndrome and Alzheimer’s develop seizures). Many of the families with whom we interact have reported that their loved ones have seizures. One of our family members shared this resource with us in a recent online support group meeting.

SeizureTracker.com, an online resource created by parents of a son who had daily seizures, was developed to help people understand the relationship between seizure activity and seizure medications.

The website and tool was launched in 2007. Seizure Tracker is accessible from any internet-enabled computer or cell phone. You can log and track seizure activity, appointments, and medication schedules in a simple calendar interface. You can also download printable seizure logs that correspond to the website. The tools provide a place to create personalized reports of logged seizure activity and medication history that can be shared with the medical team. Reports can be customized to include graphs comparing seizure activity (counts, time of day, & types) and medication dosages.

The Seizure Tracker APP is available for iPhone, iTouch or iPad through iTunes.

1 https://www.ncbi.nlm.nih.gov/pubmed/15862185

PubMed comprises more than 27 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher web sites.

https://www.seizuretracker.com/index.php

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**To our loved ones with Down syndrome:**

“If I know what love is, it is because of you.”

Herman Hesse

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**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.

Congress has passed a bipartisan bill titled the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act, which is now awaiting the President’s signature. The Secretary of Health and Human Services is to develop, maintain and update an integrated national strategy to support family caregivers with recommendations from an advisory council consisting of federal agencies and representatives from private and public sectors (family caregivers, health care providers, employers and state and local officials). Suggested actions of the council will recognize and support family caregivers in a manner that reflects their diverse needs, including the following:

- Promoting greater adoption of person-centered and family-centered care in all health and long-term services and supports settings, with the person receiving services and supports and the family caregiver (as appropriate) at the center of care teams.
- Assessment and service planning (including care transitions and coordination) involving family caregivers and care recipients.
- Information, education and training supports, referral, and care coordination, including hospice care, palliative care, and advance planning services.
- Respite options.
- Financial security and workplace issues.
- Delivering services based on the performance, mission, and purpose of a program while eliminating redundancies.

The full text of the bill can be found at: https://www.govtrack.us/congress/bills/115/hr3759/text
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/bww2018
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:

| • Healthy Aging | • Common Medical Conditions in Adults with Down syndrome |
| • Creating and Sharing Life Stories | • Caring for the Caregiver |
| • DS Connect: Research Opportunities for Adults with Down syndrome | • Screening, Diagnosis and Stages of Alzheimer’s Disease |
| • The Role of Siblings in the Life of a Person with Down syndrome | • Tips for Caregiving |
| • Pain and Cognitive Disabilities | |

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 HEALTHY AGING

How a person with Down syndrome ages, even with a diagnosis of Alzheimer’s, can be affected by many factors. We all want to be as healthy as possible as we grow older and this is also true for our loved ones with Down syndrome. Our loved ones are living longer (life expectancy is now at 60 years or more) and they can have healthy lives by following some simple guidelines.

Good health is a state of physical, mental and social well-being. Sometimes we forget that good health encompasses more than the physical parts of our bodies. We can do some simple things to encourage our loved ones with Down syndrome to stay healthy and active as they age.

Eat a balanced diet that includes vegetables, fruits and whole grains. Did you know that blueberries are one of the best foods we can eat? They are a good source of many nutrients and antioxidants. Some nutritionists believe that if you make only one change to your diet, it should be to add blueberries—less than a cup per day is all it takes.

Remember that as people age, metabolism slows so it’s also important to pay close attention to portion sizes.

Help your loved one get plenty of sleep. Changes to sleep patterns are part of the normal aging process and as a result, your loved one may have more trouble falling asleep or staying asleep. Research shows that, contrary to what some think, our need for sleep does not decrease with age. Sleep disturbances may be attributed to physical problems, mental health issues or medications. If your loved one snores, it may be an indication of sleep apnea. Untreated sleep apnea puts a person at risk for cardiovascular disease, headaches, memory loss and depression.

Get medical care for your loved one. Encourage him to keep his regular appointments with his primary care provider, dentist and other medical professionals. The topic on aging in the November/December issue of this newsletter focused on common medical conditions that should be monitored by or for people with Down syndrome.

Practice safety habits to avoid accidents and prevent falls. You may be able to get a home-safety evaluation through your state’s Home and Community Based Services (HCBS) Developmental Disabilities Waiver. Or, your loved one’s primary healthcare provider may be able to order one. Some things to consider might include:

- Install secure locks on all outside doors and windows; use audible alarms that go off if a door or window is opened;
- Avoid clutter that may create confusion and danger;
- Make sure rooms are well lighted in the evening; consider adding sheer curtains for the windows to cut down on glare during the daytime;
- Remove scatter rugs and clear electrical cords from places your loved one may walk.

Keep mind and body active by finding activities that your loved one enjoys. Think about quiet activities like arts and crafts, putting together puzzles, and music.

Getting exercise helps people feel better and keeps muscles, joints and hearts in good shape. Taking walks, dancing or even chair exercises are a good option, as well. The National Institute on Aging has an exercise and physical activity campaign, Go 4 Life, with sample exercises and free resources.

It is important, though sometimes overlooked, that our loved ones participate in activities that are meaningful to them and contribute to their sense of self-worth. This may be a paid or volunteer job, or other activities that foster social connections and friendships. There have been many studies showing that people who have successful relationships with their family, friends and community are healthier, happier and live longer. Isn’t that what each of us hopes to achieve in our lifetime?

For more information about:

Healthy Eating—https://www.niddk.nih.gov/health-information/weight-management/health-tips-adults
Sleep—https://www.nia.nih.gov/health/good-nights-sleep
Common Medical Conditions Seen in Adults with Down syndrome—www.aadmd.org/ntg
Active Lifestyle—https://go4life.nia.nih.gov/

This is the second in a series of articles on aging in Down syndrome. The last issue of this newsletter began the series with an article on Common Medical Conditions. Future pieces will address quality of life, the stages of Alzheimer’s, and palliative and hospice care.
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.

LOVING CONNECTIONS RESOURCES


NTG CONTACTS

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.