

# NTG CAREGIVER NEWS

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NTG Caregiver News

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## GOT YOUR OXYGEN MASK?

Many of the readers of this newsletter are caregivers. Some are paid caregivers and many are family members—both parents and siblings of loved ones with intellectual disability and dementia. Many siblings take full responsibility for their brothers or sisters later in their lives when the parents are no longer capable of providing full-time care or have passed away. For parents, caregiving an older adult with intellectual disability is merely an extension of their life as it was when their child was younger.

One common characteristic of caregivers is that they give and give and give—even to the detriment of their own health. Caregivers often share they have no time for exercise, or even time to be sick. Sleep issues are common, along with poor eating habits. Sometimes it just easier to grab fast food (or eat brownies for lunch) than to plan and prepare a nutritious meal.

And because caregivers often have trouble putting themselves first, they may believe they are selfish if they do. While giving comes easy for

them, asking for help is difficult. All of this creates even more stress.

*Brain & Life Magazine* had a recent article focused on self-care for caregivers. We often hear that, in a flight emergency, we should put our oxygen mask on first before helping others. That applies to other parts of our life, as well.

If we don't pay attention to our needs—for nourishment, for rest, for exercise, and for down time—we can't be effective caregivers. When we have trouble making time for ourselves, we need to think about the person we care for.

Reframe thoughts about self-care. For example, "When I take time to write in my journal, I recharge my battery and have more energy to give good care to my son."

By putting our oxygen mask on first—we'll feel better and as a result, will have more to give our loved ones.



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### SELF-CARE

- Take a slow, deep breath
- Read a book (or just a page or two)
- Listen to music & dance like nobody's watching
- Put clean sheets on your bed
- Call a friend
- Write in your journal

# LET'S TALK PALLIATIVE & HOSPICE CARE

In the last edition of this newsletter, we discussed dementia with a focus on Alzheimer's disease. The sad fact of Alzheimer's is that it is a terminal illness.

This article will explore the use of palliative and hospice care as the people we care about journey to the end of their lives. The editor wishes to thank Mary Hogan for her contribution to this article.

## Aging with Dignity

As our family members age, we are confronted with the enormous challenge of ensuring that they have the opportunity to live life as fully as possible until the end of life, despite their serious diagnoses. Families have shared concerns that their member with Alzheimer's be given dignity and respect right through their final days. Palliative and hospice care is a compassionate way to help improve quality of life through the full course of the disease.

## Palliative Care

Palliative care is intended to positively impact the people involved with a person who has a life-limiting disease. It refers to specialized medical care that can be provided in the patient's home, a hospital, nursing home or other specialized clinics. Palliative care *may* be covered by Medicare, Medicaid and private insurance companies.

Palliative care, like dementia care, is both person-centered and relationship focused. It can be provided at any time during the course of a serious illness. Palliative care providers work in partnership with the patient's doctor to offer extra symptom management and extra time to communicate regarding options and goals.

## Hospice Care

At the time a patient's illness no longer responds to medical attempts to cure or slow it, hospice care can be accessed. Just as in palliative care, hospice care provides comfort and support for the patient and family, but active treatment is no longer provided. Typically, it has been determined that the patient has 6 months or less to live if the illness runs its natural course.

Hospice care can be provided wherever the patient lives. Although a hospice caregiver is not usually available overnight, a member of the hospice team does visit regularly, and someone is always available by phone—24 hours a day, 7 days a week.

Insurance coverage for hospice service is available through Medicare, Medicaid and private insurances. Check with your provider to determine eligibility for coverage. It is important to know that hospice benefits will

cover care for treatment of the terminal diagnosis and related conditions. The patient's regular insurance will be billed for all other medical care—for example if the person needs medical care for an acute illness, or injury.

## The Caregiving Team

Unfortunately, because of well-documented health care disparities, attitudinal barriers, and other factors, palliative care may be overlooked for those with intellectual disability and dementia.

One possible answer to help avoid this oversight is an informed caregiving team that believes that people with intellectual disabilities have a right to palliative and hospice care.

The caregiving team needs access to a team of providers who has, or is willing to develop an in-depth knowledge of co-occurring conditions, is dedicated to coordinated care, and committed to optimal outcome for the individual with intellectual disability and Alzheimer's disease or other dementias.

With the knowledge of best care practices, we as families can be empowered to begin to bring this about and ensure that those we care about are *not forgotten*.

"You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die."

Dame Cicely Saunders,  
Founder of Hospice

*This is the sixth and final article in a series on aging in Down syndrome. Previous issues of this newsletter contained articles on Common Medical Conditions, Healthy Aging, Quality of Life, Decline and Assessment, and Dementia. Those newsletters can be found at [aadmd.org/ntg](http://aadmd.org/ntg).*

### Palliative & Hospice Care—A Comparison

Component	Palliative Care	Hospice Care
<b>Where care is received:</b>		
• Patient’s Home	✓	✓
• Nursing Home (including Skilled Nursing)	✓	✓
• Assisted Living Facility	✓	✓
• Hospital	✓	✓
• Other Setting	✓	✓
<b>When care is received:</b>		
• Patient continues active treatment of condition	✓	
• Patient does not receive active treatment of condition		✓
• Through all phases of a life-ending condition	✓	
• Patient is no longer curative—last 6 months of life if disease takes its normal course	✓	✓
<b>What care is received:</b> Note: this list is an example of services and should not be considered exhaustive.		
• Psychological counseling	✓	✓
• Spiritual counseling	✓	✓
• Treatment of symptoms (pain, constipation, nausea, sleep issues, loss of appetite, etc.)	✓	✓
• Treatment to cure condition	✓	
• Doctor service	✓	✓
• Nursing care	✓	✓
• Medical Equipment		✓
• Medical Supplies		✓
• Home health aide & home maker services		✓
• Social Work services	✓	✓
• Short-term in-patient hospital care (respite care)		✓
• Other services as determined necessary for patient comfort		✓
• Support to all people involved in the patient’s care	✓	✓

*\* NOTE: This is not an all-inclusive list of available services.*



## ON OUR RADAR

*Brain & Life Magazine*™ is published by the American Academy of Neurology (AAN). The AAN is the world's largest association of neurologists and neuroscience professionals, with 34,000 members and is dedicated to promoting the highest quality patient-centered neurologic care. *Brain*

*& Life*™ is the only magazine focused on the intersection of neurologic disease and brain health.



Visit <https://www.brainandlife.org/the-magazine/> to subscribe to digital or print copies of the magazine.

## TIPS TO PREVENT BED SORES

Several members of the NTG are part of a closed Facebook group focused on caregiving, Alzheimer's and Regression. Recently there was a post on the group page that is worth sharing more widely. Please note that no identifying information has been disclosed and permission to share the comments was given by members who had contributed.

When the person you care for is confined to a bed, it is important to make sure they are turned "every couple of hours to prevent 'bed sores,' which can be very painful and hard to treat once they take hold. And if your loved one spends hours in a recliner," like the writer's loved one did, "fold over a hand towel (or something) and put it under her/his upper thigh & hip for a few hours then under the other side. This takes off the pressure and helps the blood flow. And for small/beginning sores, Desitin works wonders! Just apply and cover with smooth gauze, (advice from a wound care nurse)...Even the smallest of

bed sores can be very painful and our loved one can't always verbalize it to us."

Another member wrote, "Sometimes I lay in bed and wonder what it would be like if I couldn't move myself to get comfortable. I would be miserable. No one should sit in the same chair for more than an hour during the daytime without having their weight shifted. A nurse can show you how to do that. At night, it's harder because everyone needs to get their sleep but I personally would try to get away with rotating every 4 hours because I don't have any help. Ideal circumstances would be every 2 hours. Air alternating mattresses help."



Down syndrome,  
Alzheimer's, &  
Down syndrome  
Regression  
Support

The original post concluded with this profound statement of truth, "You are all in my heart and my prayers. It isn't easy and tears at the heart-strings but our #1 concern is for the comfort of our loved one."

If you "do Facebook" and might be interested in the group, you can find it here:

<https://www.facebook.com/groups/DSALZ/>

## WEB RESOURCES ABOUT PALLIATIVE & HOSPICE CARE

*What are Palliative Care and Hospice Care?* <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>

*Clinical Practice Guidelines for Quality Palliative Care* [https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf)

*Hospice Foundation of America* <https://hospicefoundation.org/>

## NDSS ADULT SUMMIT: PLOTTING THE ROUTE

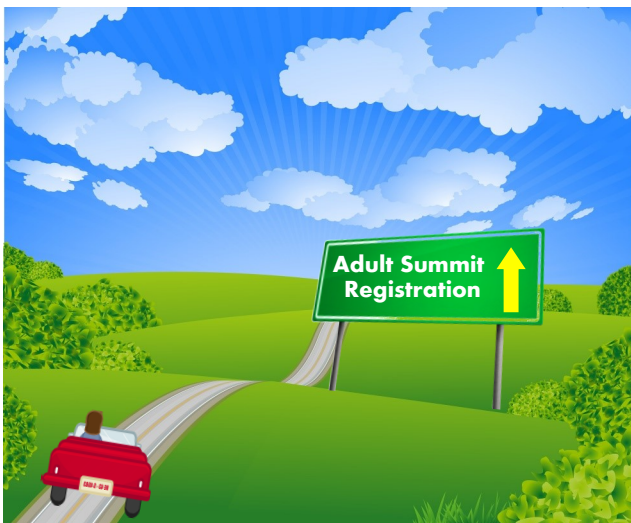
NDSS staff and the host affiliate, the *Down Syndrome Guild of Southeast Michigan* have been working hard to ensure we have a memorable experience when we get together in Detroit, **April 4-6, 2019**. The hotel venue, the **Detroit Marriott**, sounds incredible and has lots of space for exhibitors, vendors and attendees. **We are hoping you will be among the 600 people we expect to attend.**

The NTG is proud to be one of the partners who have joined with NDSS to bring a diverse program that has something for everyone. The planning committee, that consists of self-advocates, family members, Down syndrome affiliate groups, professionals, and NDSS staff are finishing their review of the proposals, in the subject areas identified below, and the final decision for the program will be set by the end of October.



- *ABLE*
- *Adult Sibling Resources/ Supports*
- *Aging & Alzheimer's Disease*
- *Behavior*
- *Employment*
- *Financial Planning*
- *Guardianships*
- *Health & Fitness/Nutrition*
- *Medical Issues*
- *Post-Secondary Education*
- *Residential Options*
- *Self-Determination*
- *Sexuality*
- *Technology*
- *Volunteering*

If you know of an individual, company or organization that might want to be an **exhibitor, vendor or sponsor**, please share this information with them and have them contact Colleen Hatcher at [chatcher@ndss.org](mailto:chatcher@ndss.org).



### Down Syndrome Awareness Month

Adult Summit **individual registrations** will be **reduced 21%** from **October 1-31, 2018**. Use the discount code **DSAM** to receive the discount.

Click here to go to the registration page on the NDSS website: <https://www.classy.org/event/2019-ndss-adult-summit/e181498>

For information on **group pricing**, or **questions** about the Adult Summit, please contact NDSS' Community Outreach & Engagement Manager, Colleen Hatcher at [chatcher@ndss.org](mailto:chatcher@ndss.org) or 202.751.6013.

## 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 other 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 as 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. *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 other dementia.*

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

## NTG FAMILY SUPPORT

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.

## NAPA ADVISORY COUNCIL TO FOCUS ON DOWN SYNDROME

The NTG's very own Mary Hogan has long lobbied the National Alzheimer's Project Act Advisory Council to include a focused presentation on Down syndrome and its connection to Alzheimer's disease. Her dedication has resulted in an invitation to participate on a panel of representatives of special populations at the October 19, 2018 meeting. The meeting will be livestreamed and we hope that many of you will want to view her panel comments. In addition, if you have anything you would like to have her share, please email her at the address listed below. As always, you can send a written comment that will be read at the meeting. Thanks Mary, for always advocating for those we support with Down syndrome and Alzheimer's disease. The live feed will be at <http://www.hhs.gov/live>; when it is available the meeting material will be at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings>.

## NTG CONTACTS

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