



# NTG NDSS

## CAREGIVER NEWS

### ARTS AND DEMENTIA

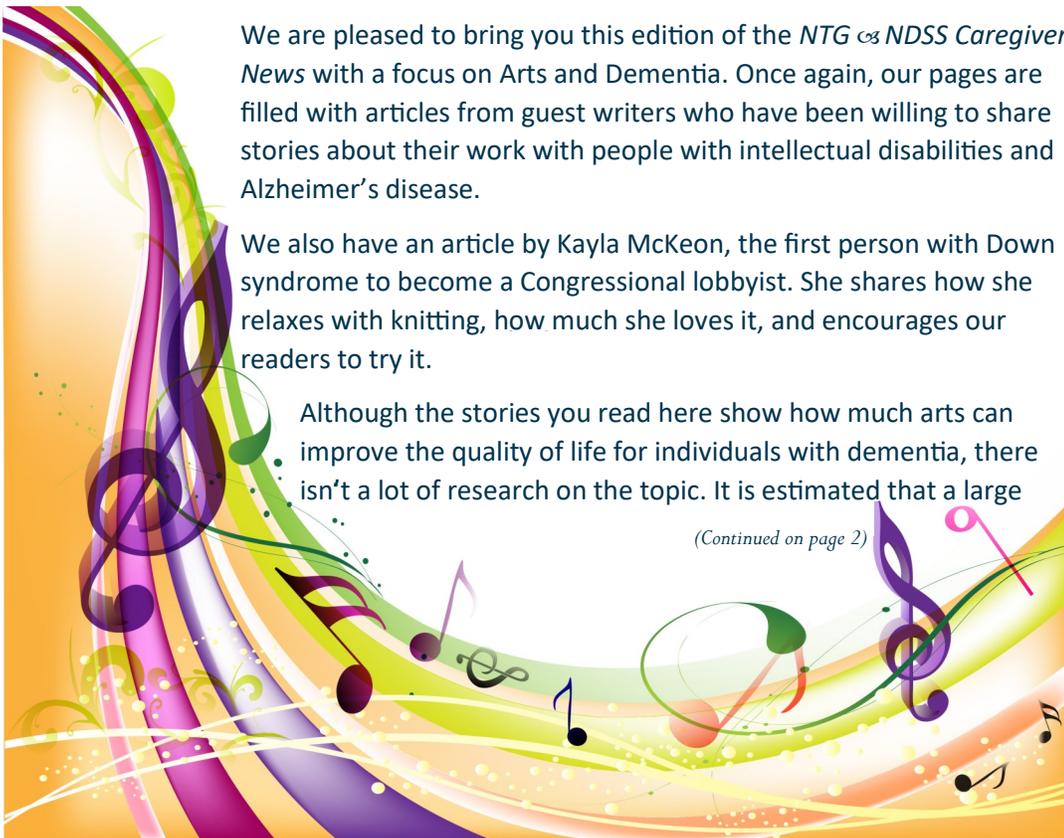
Jadene S. Ransdell, B.S., Co-Editor, Caregiver News

We are pleased to bring you this edition of the *NTG & NDSS Caregiver News* with a focus on Arts and Dementia. Once again, our pages are filled with articles from guest writers who have been willing to share stories about their work with people with intellectual disabilities and Alzheimer’s disease.

We also have an article by Kayla McKeon, the first person with Down syndrome to become a Congressional lobbyist. She shares how she relaxes with knitting, how much she loves it, and encourages our readers to try it.

Although the stories you read here show how much arts can improve the quality of life for individuals with dementia, there isn’t a lot of research on the topic. It is estimated that a large

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“There are an estimated 5,500 art therapists, nationwide. They use art materials to help people express their feelings through painting, sculpture and other media.”  
*Fischer Center for Alzheimer’s Research Foundation*  
<https://www.alzinfo.org/articles/prevention/how-art-can-aid-people-with-alzheimers/>

“Participating in arts opens up a non-verbal form of communication, allows the person who is affected to let go of negative emotions and express his or her thoughts and feelings.”  
*Dementia and Art Therapy—The Beauty of the Mind*  
<https://artanddesjoninspiration.com/dementia-and-art-therapy-the-beauty-of-the-mind/>

“To love a person is to learn the song in their heart, and sing it to them when they have forgotten.”  
*Arne Garborg*  
*Norwegian Writer, 1851-1924*

## ARTS AND DEMENTIA

**Jadene S. Ransdell**

*(Continued from page 1)*

number of people with dementia will experience symptoms that increase caregiver burden, result in more facility placement and a greater cost of care.

The limited studies appear to show that art therapy has the potential to improve the psychological well-being and quality of life (especially verbal skills and slowing cognitive decline) of individuals with dementia.

For more information from articles and some of the research, check out these resources:

- *Art Therapy in Dementia Care: Toward Neurologically Informed, Evidence-Based Practice*, Elena Guseva, *Art Therapy: Journal of the American Art Therapy Association*, pp 1-4, 2019  
<https://doi.org/10.1080/07421656.2019.1564613>
- *Co-creativity, Well-being and Agency: A Case Study Analysis of a Co-creative Arts Group for People with Dementia*, Hannah Zeilig, Victoria Tischler, Millie van der Byl Williams, Julian West, Sarah Strohmaier, *Journal of Aging Studies*, pp 16-24, 2019  
<https://www.sciencedirect.com/science/article/pii/S0890406519300040>
- *Opening Hearts, Minds and Doors with Creative Arts Therapy*, Danielle Leheny, September 1, 2018  
<https://livingbranches.org/blog/opening-hearts-minds-and-doors-with-creative-arts-therapy/>
- *This is How the Creative Arts can Help People with Dementia*, Joanna Jaaniste, May 17, 2019  
<https://www.weforum.org/agenda/2019/05/creative-arts-therapies-can-help-people-with-dementia-socialise-and-express-their-grief/>

## SPACE FOR THE ARTS

**DARLENE KELLY**, BSN, QDDP, Service Coordinator, and NTG Affiliated Regional Trainer

Reserving space in your life for the arts is an important part of self-care. This could take the form of listening to your favorite music, reading poetry, or painting. In my practice over the years I have found music and dance to be especially important to people with intellectual disability. And as many have observed music has the potential to unlock memories, and improve function in those individuals with an intellectual disability and Alzheimer's dementia.

During the time of person-centered planning and conversation, it is important to find out about the individual's interest and love of music or other art forms. This can be translated into actionable strategies to support the person. An example of this follows:

*Mary has a love of music, especially Whitney Houston and Michael Jackson. In our team plan we decided to put this music on the radio when we pick Mary up for the day. Mary was not always able to find her words and take part in conversation. However, after listening to these favorite artists and songs she lit up and could find her words more easily to take part in her day. When we reached a point in the*



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## SPACE FOR THE ARTS

**Darlene Kelly**

*(Continued from page 2)*

*day when she was starting to have frustration about not being able to speak we added music and the dance routine that went with it. This movement of her body coupled with the lyrics of the song never failed to brighten her spirits and it seemed to help her connect better. And the best part is that it was fun!*

Knowing about a person's music preferences is important. We also found that being mindful about how it was delivered was also very important. An example of this follows:

*John is a man with an intellectual disability and Alzheimer's Dementia. He lives in a nursing facility. He loves John Denver music. But, because of his hearing loss and the inability to tune out background noise, playing the radio did not suffice. John's team supported him to get an iPad and head phones. Now his favorite music was not only being played for him but it was also accessible to him. In addition, he was able to couple the music with videos which he loved as well. We eventually observed that this was John's favorite way to watch movies. Finally, his iPad gave him greater access to friends through Facetime. His friends even sent videos of Christmas greetings to him through his iPad that he could enjoy again and again.*



If, in the person-centered process, you discover that the person liked to paint give them the opportunity to continue this love. Here is an observation in practice:

*Lisa always loved painting. However, with the progression of Alzheimer's Dementia, Lisa does not show an interest. After trying again we found that Lisa just needed support to get started. The motor planning of picking up the paint brush needed support. Once she got started with that*

*support she appeared to enjoy painting again. Taking the "Let me get you started" approach has proven successful in activities that require motor activity and planning.*

Incorporating the arts into the daily life of someone with an intellectual disability and Dementia is an essential part of a person's care. Making supports personalized respects the dignity of that person and the life they have lived.

*Darlene Kelly, is an NTG Affiliated Regional Trainer, a Qualified Developmental Disabilities Professional (QDDP) and has a BSN degree. She works for the Rutland Mental Health Services Community Care Network in Vermont. Their Community Access Program services promote the health and safety of individuals and families, and help individuals become valued and respected members of the community, build meaningful and mutually supportive relationships and social connections, and make choices and decisions that affect her or his life. Trained staff and contracted workers empower individuals to live as independently as possible, to obtain employment or engage in other meaningful activities, to participate in community life, and to engage in life-long learning. You can contact Darlene at [dkelly@rmhscn.org](mailto:dkelly@rmhscn.org).*



## BENEFITS OF DANCING FOR PEOPLE WITH DEMENTIA

*Cara Bulson Arcuri, MA, BC-DMT, NCC, LCAT*

As a dance/movement therapist working with individuals with intellectual disabilities and dementia for over 25 years, I have seen firsthand the benefits of moving with another person. Assisting individuals in moving and maintaining a positive connection to their bodies is so important. Dance/movement therapy is based on the mind-body connection, specifically the idea that it is through our bodies that our minds experience reality.

Typically, when people develop dementia, they are provided with less opportunities to move and physically engage with their world. There are very real concerns about wandering and potential falls. As a result, their ability for cognitive, social, and emotional engagement becomes limited. Human beings are constantly moving, it is our natural state. Breath and speech are movement; the beating of our heart is movement; the flow of blood through our veins is movement. Movement is how we stay alive. Yet for many individuals with dementia a lot of movement is discouraged because of how it manifests.

Rather than discourage movement, caregivers can focus on finding positive outlets for that energy. One such outlet is dance. When physically assisting an individual with movement always remember to stay within their natural range of motion. Try playing some music and going through movements similar to those needed when providing care, this is a great way of practicing the movements needed for everyday life, such as lifting your arms up to take off a shirt or reaching your arm to the side to put on a coat sleeve. Pick everyday movements and set them to music to make them more fun to practice. Use familiar verbal cues for movements that have meaning to the person, such as bouncing a ball or wiping down a table. Dance to familiar songs as they can trigger memories of the past and may be a conversation starter. Holding someone's hands to dance, provides a positive physical connection, especially for those who experience limited independent movement. This action may bring back memories of social dances.

Not only is movement our natural state, but people are programmed to move with each other. Thanks to specific cells called mirror neurons, when we see someone move we internally respond to that movement. This is why moving *with* someone, not *for* someone is so important. We intuitively want to mirror the movements we see. Turn on some music, position yourself where your loved one can see you clearly, and just dance. Try using simple repetitive movements, making sure you have the individual's attention, and they may spontaneously mirror you movements.

Movement helps us be aware of our body boundaries and where we are in space. It provides needed proprioceptive feedback (the body's ability to sense its movements, actions, and location in space). Gentle tapping of body parts while dancing can aid this further, you can even name the parts when you suggest movements, i.e., tap your head, clap your hands, pat your legs, stomp your feet. Proprioception is one of the senses that is negatively impacted for some people with dementia.



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## BENEFITS OF DANCING FOR PEOPLE WITH DEMENTIA

**Cara Bulson Arcuri**

*(Continued from page 4)*

Try using props such as scarves, balloons, pool noodles cut in half, or even a tablecloth to encourage movement. For example you can use a pool noodle to pretend to conduct music. You can work together with your loved one



to shake out a table cloth, a familiar activity for many, varying the rhythm based on the music, shaking it fast or slow, or raise it up and down reminiscent of a parachute in gym class.

Make sure not to make dancing with your loved one work, dancing is fun, joyful, and expressive. It is a chance to communicate without words. It is a chance to love being in your body, where there is no right or wrong way to move. Dance allows you to explore movement in a playful way, which often results in

greater movement than is seen at other times. There are so many fun ways to move together. Be creative. Try to create a little time each day to play some music and dance.

*Cara Bulson Arcuri is a NTG Affiliated Regional Trainer, Behavior Specialist – Gan Kavod, Licensed Creative Arts Therapist, Board Certified Dance/Movement Therapist, Certified Montessori Dementia Care Professional, Certified Resilience Chair and Chair-Assisted Yoga Teacher (RChYT). You can contact Cara, who lives in New York, at [cb.arcuri@gmail.com](mailto:cb.arcuri@gmail.com)*



## ART CAN BE SIMPLE

**Sabrina Moore, DSP**

No disability will stop this individual with whom I work. I colored white snowflakes on white paper and told her to paint until she finds all of them. She really loves the process and keeps laughing when a new one appears. ❤️



*Editor's note: I found this wonderful project through a Facebook group in which I belong. I wanted to share it with our readers because it can be an easy way to engage people with intellectual disabilities and dementia in an art project. As Sabrina mentioned in a communication with me, the woman she works with had a blast searching for the snowflakes. The result is a colorful piece of art that could be displayed for her and those around her. Sabrina is a Direct Support Professional who lives in New York.*

# SELF-EXPRESSION DURING A PANDEMIC

*Michelle McCaffrey, MS, Art Therapist, Alexander Trotty, Director of Community Outreach and Engagement*

So much around us has changed during the past year. Covid-19 began as a disease that seemed very far away and over time it slowly made its way to us here at Divine Providence Village in Springfield, Pennsylvania. When Covid-19 reached us, we all worked together to protect every individual and keep them safe in the place they call home. In March, Day Programs closed and individuals were quarantined in their homes. Usual visits with family and friends were no longer possible. Familiar faces and warm smiles, once visible, began to be covered with masks and face shields. We were faced with illness and losses that are still hard to process. Our new reality is challenging for everyone but especially for those with dementia.

In response to the pandemic, our Art Therapist, Michelle McCaffrey, implemented a creative process that provided our individuals the opportunity for self-expression. When asked, she describes how this creative process works especially for our individuals with dementia. "Engaging in a creative process, whether dancing, singing or painting has a multitude of benefits for the average person. These benefits may actually increase as we age. The creative process and art making can create beneficial changes in the brain and has the potential to produce life-changing effects. Particularly, when working with individuals with dementia, art therapy can facilitate non-verbal expression, teach new skills leading to a sense of mastery, increase social opportunities, and overall help to keep aging adults healthier."



There are often misconceptions surrounding the field of Art Therapy. According to the American Art Therapy Association, Art Therapy is "an integrative mental health and human services profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship. Art Therapy is used to improve cognitive and sensory-motor functions, foster self-esteem and self-awareness, cultivate emotional resilience, promote insight, enhance social skills, reduce and resolve conflicts and distress, and advance societal and ecological change."

Whether it is an individual or a group session, art therapy allows participants with dementia to express themselves in ways that go beyond their limitations. As individuals experience a reduction in their ability to express themselves in traditional ways, including verbal language, engaging in the creative process offers an additional outlet for expression.

Researchers studying creativity and aging (Cohen, 2006) found that individuals with dementia who participate in creative arts interventions



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## SELF-EXPRESSION DURING A PANDEMIC

**Michelle McCaffrey, MS, Art Therapist, Alexander Trotty, Director of Community Outreach and Engagement**

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have better overall health, fewer doctors' visits, less medication use, fewer instances of falls, and fewer health problems overall. Additionally individuals engaging in a creative arts group experienced increased morale, less loneliness, and an increase in overall activity engagement. This finding is particularly relevant and essential right now as we journey through the Covid-19 pandemic. As these researchers proved, engaging in a creative process can truly be life-changing.

While the health and wellness benefits of making art are already immense, with the impact of Covid-19, art making and the creative arts are even more important. With day-to-day life unrecognizable and isolation rampant, particularly in programs serving individuals with intellectual and developmental disabilities and other long term care settings, engaging in creative arts can offer the opportunity for participants to learn a new skill, feel a sense of control in a

disorderly time. We are also able to put safety measures in place to offer a socially distanced group setting within cohorts to provide crucial social opportunities to fight isolation. Recently, our groups have had an emphasis on grief support in order to help residents process the multitude of losses we have experienced during the pandemic.

Researcher Judith Glaser stated, "Neuroscience is teaching us that self-expression might be one, if not the most important ways for people to connect, navigate, and grow with each other." Engaging in a creative process, alongside others if possible, is an important form of self-expression for individuals with dementia. The connections made, both in the brain and body as well as with others, have the potential to produce life-changing effects.

We have found the therapeutic use of art making and the creative process are important opportunities that should be offered to individuals living with dementia in order to experience these positive effects. This has become even more crucial during our unprecedented journey through Covid-19.



*The Communities of Don Guanella and Divine Providence, a part of the Intellectual Disabilities Division of Catholic Social Services within the Archdiocese of Philadelphia, is an organization dedicated to transforming the lives of individuals with intellectual and physical disabilities. Michelle McCaffrey has an MS degree and is an art therapist. Alexander Trotty is the Director of Community Outreach and Engagement. They can be reached at [mmccaffrey@chs-adphila.org](mailto:mmccaffrey@chs-adphila.org) or [atrotty@chs-adphila.org](mailto:atrotty@chs-adphila.org)*

## KNITTING KEEPS YOUR BRAIN SHARP

**Kayla McKeon**, NDSS Manager of Grassroots Advocacy

Knitting is good for the mind, body and soul. It keeps your brain sharp. Knitting can be challenging. It can reduce the chance of mild cognitive impairment by 30 to 50 percent for seniors. I also found an added benefit—it's good for us to keep our hands busy to prevent snacking.

My friend tried to teach me how to crochet, but, having Down syndrome I have low muscle tone in my fingertips. I can't clasp bracelets or necklaces. I can't hold crochet needles to have the tension correct. My friend taught me how to loom knit which is much easier for me.

I started loom knitting over a year and half ago. I first made a scarf for myself; I graduated to making hats, baby hats, other scarves, blankets, shawls and many other projects. I love knitting because it is creative and when I finish a project I am always proud of my end results. Once in a great awhile I will make a project for others. Sometimes people order a hat for someone else and I make a little profit from it. I also make them for gifts for Christmas. I feel good when I donate some of my hats to a good cause.

Sometimes other projects are difficult to make, due to counting rows. This is where a lot of concentration comes in; with those kind of projects you don't want distractions. Working on easier crafts, sometimes distractions are less of a problem. When working on a loom you do need to remember to work your row entirely. If you're going to set aside the loom do something else try to remember to finish the row you are starting, it will make the project easier when you end up going back to your knitting so accidents don't happen.

I have made plenty of mistakes in knitting, to the point of having to take rows out of my project and basically redo what I just did. Sometimes I have even dropped stitches or just have tangled mess of yarn. I often need help untangling myself and straightening me back out. My friend also helps me to end my project but I am working on learning that as well. Don't be afraid of making a mistake, my friend always said it's something we all do and easy to figure out.



Another thing you can do is look at videos on YouTube, they are very helpful for learning, and there are patterns for different projects, as well. Knitting makes me relax which is a great thing during this pandemic. Don't be afraid to try your hand at it.

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For more information about knitting and cognitive decline, see, *"Engaging in Cognitive Activities, Aging, and Mild Cognitive Impairment: A Population-Based Study"*, Geda, Topazian, Lewis, Roberts, Knopman, Pankratz, Christianson, Boeve, Tangalos, Ivnik, Petersen, *The Journal of Neuropsychiatry and Clinical Neurosciences*, April, 2011

<https://neuro.psychiatryonline.org/doi/full/10.1176/jnp.23.2.jnp149>

*Kayla is the Manager of Grassroots Advocacy at the National Down Syndrome Society. She is the first registered federal lobbyist in the United States*

*Congress. To contact Kayla, email her at [kmckeon@ndss.org](mailto:kmckeon@ndss.org).*

# Our COVID-19 Stories

**Seth Keller, MD**

*Editor's note: We thank the AADMD and Our Covid-19 Stories for permission to use the artwork from the website.*

Life during the COVID-19 pandemic has been a rollercoaster – but without the excitement and thrills. We've endured the ups, downs, curves and have been thrown around a few. Unlike a coaster, however, we can't predict what happens next. We don't know the long-term impact this year will have on us, our family, our friends or the groups and organizations we support or who support us. Our sense of security and plans for the future were tossed out the window. And getting back to what we thought was "normal", is now our "new normal."

If you – or someone in your life – got really sick, hospitalized or perhaps your loved one tragically died from COVID-19, then this terrible pandemic is an even heavier burden on you, as it is for my family. My mother, Mitzi, died last April from the virus. My family's very personal story is shared by nearly 400,000 Americans and counting. It's horrible. It's tragic. It's unbelievable. This outrageous number does not include those who had been sick and have dealt with, and even may still be dealing with, the aftereffects of the virus. My family's tragedy happened early in the pandemic and even though our mother was quarantined in her long-term care facility it didn't matter as she and other residents, all very vulnerable seniors, had no chance once the virus got inside the facility.

Moments before my mom passed away, my siblings and I had a FaceTime call with her to say goodbye. A FaceTime call. No soft touch, no kiss goodbye, no moment holding her hand as she slipped away. None of that. We still don't have the closure our mother and family deserve – and I'm not sure we ever will. As the virus surges across the country we face a scary and uneasy daily life. We hope getting back to "normal" or a "new normal" is not far off. The news of the vaccination distribution and the high hope of a huge reduction in the risk of further spread of the infection may help us bring this to an end. We can sort of see it, believe it to be true, hope for its safety and wish that we all can get it really quickly – but who can really be sure judging from our rollercoaster of a year? When and where do we get off this ride?



My personal life is intertwined with my professional life. I am a neurologist specializing in the care of adults with intellectual and developmental disabilities. My practice in southern New Jersey has been greatly affected by the pandemic. We closed the office early in the pandemic and started video chats with our patients. Aside from the

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## OUR COVID-19 STORIES

**Seth Keller**

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person's specific neurologic difficulty, much of the conversation with them, including with their families and supports, was about the pandemic and how they were impacted one way or another. Speaking to people sitting in their kitchens, their living rooms and even from their beds was so very personal. I got to see pictures on their walls, books on the table, the various awards that they may have won from Special Olympics. We often spoke about some of these personal items. And as we spoke about life during the pandemic, we had a deeper appreciation of the pre-pandemic life. The conversations covered what (and who) was missed, how they have adapted and tried to adjust.

*The unique experiences of people with intellectual and developmental disabilities often unites us as a community. We relate deeply to families caring for a loved one with a lifelong disability, the importance of family and community supports, working with experts and specialists along the way, and also feeling the need sometimes to fight the fight and advocate for the rights as a deserving citizen who has meaning and value and to be inclusive.*

It was very clear that everyone had a story to tell – and sharing them was important.

As a leader in national intellectual and developmental disability healthcare efforts, I have been involved in education, training, and policy initiatives. This work led me to meet and work with amazing leaders in the field of intellectual and developmental disability in the United States as well as from across the world. I know I am not alone and when challenges arise, it is best to reach out to my friends and colleagues to learn from each other, share ideas, collaborate across disciplines of care and advocate together. COVID-19 is no doubt a burden we must all bare together, as a community.

This is how Our COVID-19 Stories was born. In frequent – and sometimes frantic – conversations with colleagues, patients and friends it was evident that persons with intellectual and developmental disabilities experienced hardships that most outside the intellectual and developmental disability world did not. How would families and



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## OUR COVID-19 STORIES

**Seth Keller**

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Direct Support Professionals be impacted by the pandemic? What would happen when programs closed down, mask wearing is mandated, social distancing and quarantining are implemented, and the concerns of a dreaded “silent enemy” remain out there and are getting worse before we get back to a new normal? What happens to the maintenance of both physical and mental health? Who is more at risk than others? Who do we look forward to and give us guidance and hope for the future?

We are best when we work together. We must take note of what is happening to those with intellectual and developmental disabilities, their supports and families during these difficult and uncertain times. Story telling is one of the best ways to learn, share and to understand what others are going through. All of us in the disability field either directly or indirectly have had a COVID-19 experience. Not all situations are tragic nor are they totally disrupting. Resilience of the human spirit and the will to get by, survive and make the best of a difficult situation are aspirations that we all hope to reach and achieve.

The American Academy of Developmental Medicine and Dentistry (AADMD), in partnership with Positive Exposure, created an online platform – [www.OurCovid19Stories.org](http://www.OurCovid19Stories.org) – to be able to share these stories. We interviewed people with intellectual and developmental disabilities, their families, caregivers, healthcare providers and Direct Service Professionals. I conducted a number of these personal chats myself and have been impressed by the eagerness to share. People’s COVID-19 experiences are so different, and each person has had a variety of personal and social situations related to COVID at some point during the pandemic. The ups and downs are exhausting and the desire to get to the “end” of this and to a back to normal life is an ongoing growing hope and desire we all want, sooner rather than later.

**We want to get the word out to encourage more people to share their stories through this project. We’re documenting the past for a healthier future. This is an opportunity to network, learn and support each other in the IDD community. Your story might impact someone else profoundly or give others the comfort they need to tell their own story.**



“Surviving” the pandemic requires us to lean on each other.

All of us appreciate that the disability world is made up of a community that includes those with intellectual and developmental disabilities, their families, friends, direct service provider community support organizations, state and national leaders as well as those healthcare providers involved in their care. We are all interconnected, and our stories need to be told together to form the whole picture.

My family’s personal tragedy is part of the fabric that has been woven into this unbelievable historic period of time. Many others will also be left with memories and stories that they will never soon forget.

Please go to our website and join this important personal campaign. Spread the word and encourage others to tell their important stories as well. [Our Covid-19 Stories](http://www.OurCovid19Stories.org)

*Seth Keller, MD, is a practicing neurologist in southern New Jersey. In addition to his professional work, he is the co-president of The National Task Group on Intellectual Disability and Dementia Practices (NTG) ([the-ntg.org](http://the-ntg.org)), and a past president of the American Academy of Developmental Medicine and Dentistry (AADMD) ([aadmd.org](http://aadmd.org)). He can be reached at [sethkeller@aol.com](mailto:sethkeller@aol.com)*

# Down Syndrome and Dementia

*Kelly April Tyrell, Senior Science Writer, University of Wisconsin-Madison*

*Editor's note: we recently received an email containing information on this study conducted by researchers at the University of Wisconsin-Madison.*

**N**ot so many years ago, people with Down syndrome rarely survived to middle age. Many died young due to heart problems associated with the congenital condition. Today, advances in treatment have allowed them to live longer, healthier lives. But these advances have also revealed a previously unknown characteristic of the condition: increased risk for dementia and Alzheimer's disease, and at younger ages than people without Down syndrome. In fact, evidence from autopsies shows that, by age 40, the brains of nearly all adults with Down syndrome harbor signs of dementia.

A new study of 3,000 people in Wisconsin aged 21 and older with Down syndrome, published in *JAMA Neurology* by researchers at the University of Wisconsin-Madison, shows that *by age 55, three in five will be diagnosed with Alzheimer's disease or a similar neurodegenerative condition*. Meanwhile, people without Down syndrome are rarely diagnosed with dementia before age 65.



"I am a Special Olympics coach and, in the community, people are not aware of this (dementia risk). While there is a lot of support and attention for the physical health of people with Down syndrome, right now we're not doing much for memory and cognitive function as people age," says study lead author Eric Rubenstein, a postdoctoral researcher at the UW-Madison Waisman Center. "We hope these population-level estimates raise awareness in the population with Down syndrome. As researchers and public health professionals, the prevalence and incidence data show us areas where we need to invest resources in services, treatment and research."

"Research into Alzheimer's disease among people with Down syndrome also provides insights into dementia among the broader population," explains senior author Lauren Bishop, Waisman Center researcher and professor in the School of Social Work. People with Down syndrome possess an extra copy of chromosome 21, which is also where the amyloid precursor protein gene can be found. The protein has been implicated in the changes to the brain associated with Alzheimer's disease.

"Prior to this study, researchers had recorded higher rates of Alzheimer's disease in Down syndrome patients who participate in clinical studies," explains Bishop. She, Rubenstein, and UW-Madison co-author Sigal Hartley sought to better understand whether people with Down syndrome who don't participate in clinical studies have similar rates of dementia as those who do.



Since virtually all people born with Down syndrome are enrolled in Medicaid, the researchers turned to claims data provided by the Wisconsin Department of Health Services, spanning from January 1, 2008 to December 31, 2018. This allowed them to capture all people in the state and look for diagnoses with dementia in people younger than 40, between ages 40 and 54, and 55 and older.

"People on Medicaid represent a more diverse population than those in studies conducted in research clinics, since only certain people can come into a research clinic," Bishop explains. Based on previous studies, including from UW-Madison nursing professors Amy Kind and Andrea Gilmore-Bykovskyi, she says, "we have reason to believe dementia might work differently in people from lower socioeconomic status and among racially diverse

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populations. Disparities lead to higher rates of dementia."

## DOWN SYNDROME AND DEMENTIA

*Kelly April Tyrell*

And, Rubenstein adds, people experiencing memory challenges are also more likely to visit a clinic than those who are not. However, the study showed that clinical populations of people with Down syndrome and the broader population represented in the Medicaid data do indeed experience similar incidence and prevalence of dementia. The researchers expect data from other states might yield similar results.

"We found (among claims data) that if you started without dementia, as time goes on, your likelihood of diagnosis increases every year," Bishop says. "Your probability of having any dementia is 61 percent at age 55."

Rubenstein adds: "Having a number is so important when conveying the importance to policymakers. We can tell them that by age 55, three in five people with Down syndrome have dementia. It's clear and actionable."

The information could also help families better plan for their loved ones by, for instance, enrolling them early in memory care centers, and it could help communities better support people with Down syndrome.

"Whether it's through case managers or group homes or some living assistance or job coaches," says Bishop, "as

## COVID-19 and People with Down Syndrome

The CDC has made changes to their list of conditions that put people at higher risk for COVID-19. From the CDC website:

Revisions were made by the CDC on December 23, 2020 to reflect recent data supporting increased risk of severe illness among persons with **Down syndrome** from the virus that causes COVID-19. Revisions also include addition of sickle cell disease and chronic kidney disease to the conditions that might increase the risk of severe illness among children.

We are learning more about COVID-19 every day. **The below list of underlying medical conditions is not exhaustive and only includes conditions with sufficient evidence to draw conclusions;** it is a living document that may be updated at any time, subject to potentially rapid change as the science evolves. This list is meant to inform clinicians to help them provide the best care possible for patients, and to inform individuals about their level of risk so they can make individual decisions about illness prevention. Notably, the list may not include every condition that might increase one's risk for developing severe illness from COVID-19, such as those for which evidence may be limited (e.g., rare conditions). Individuals with any underlying medical condition (including those conditions that are NOT on the current list) should consult with their healthcare providers about personal risk factors and circumstances to determine whether extra precautions are warranted.

Adults of any age with **certain underlying medical conditions** are at increased risk for severe illness from the virus that causes COVID-19. Severe illness from COVID-19 is defined as hospitalization, admission to the ICU, intubation or mechanical ventilation, or death.

**Cancer, Chronic kidney disease, COPD (chronic obstructive pulmonary disease), Down syndrome, Heart conditions, such as heart failure, coronary artery disease, or cardiomyopathies, Immunocompromised state (weakened immune system) from solid organ transplant, Obesity (body mass index [BMI] of 30 kg/m<sup>2</sup> or higher but < 40 kg/m<sup>2</sup>), Severe Obesity (BMI ≥ 40 kg/m<sup>2</sup>), Pregnancy, Sickle cell disease, Smoking, Type 2 diabetes mellitus**

## Share Your Story

We are now accepting stories for future issues of the *NTG & NDSS Caregiver News*. Feel free to contact us with your story idea. We will provide information on how to get your story to us and we are always happy to work with you to write the story you would like to share.

Write to us at [ntgfamilyadvocate@gmail.com](mailto:ntgfamilyadvocate@gmail.com) or [rgrimm@ndss.org](mailto:rgrimm@ndss.org). Include “*NTG & NDSS Caregiver News Submission*” in the subject line of your email. Below are the topics which will be the focus of upcoming newsletters. Although we welcome pieces on other subjects, primary consideration is given to articles related to these topics.



### NTG NDSS CAREGIVER NEWS FOCUSED TOPICS

| ISSUE       | SUBJECT                            | SUBMISSION DEADLINE / DISSEMINATION DATE |
|-------------|------------------------------------|------------------------------------------|
| Spring 2021 | Working with Health Care Providers | February 15, 2021 / March 21, 2021       |
| Summer 2021 | Living Healthy with Dementia       | May 1, 2021 / June 21, 2021              |
| Fall 2021   | TBD                                | August 1, 2021 / September 21, 2021      |
| Winter 2021 | TBD                                | November 1, 2021/December 21, 2021       |

## NTG & NDSS News

The **NTG** has become a formally incorporated not-for-profit organization under the laws of the State of Maine. The new status enables the NTG to expand its scope and activities as well as link more effectively to other national organizations. More information can be found on the NTG's website ([www.the-ntg.org](http://www.the-ntg.org)). Families and caregivers can affiliate with the NTG via its new “associate” membership—a form to join is located on the NTG's website.

Check the NTG website for up-to-date information on COVID-19 and people with intellectual and developmental disabilities, including a link to the **COVID-19 Vaccine Allocation Principles** developed by the Consortium for Citizens with Disabilities and signed on by many national disability organizations.

**NDSS** is pleased to announce that Colleen Hatcher has been promoted to Senior Manager of Community Relations. On January 1st, 2021, Rachel Grimm began her role as Health Program Manager – Aging & Caregiving. She will be working on priorities surrounding aging and caregiving, the virtual 2021 Adult Summit, and health related program needs.



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