Volume 4 Issue 2
Summer 2020

NTG & NDSS CAREGIVER NEWS

Behavior Challenges in Dementia

A Message from your Co-Editors

Rachel Grimm, B.S., & Jadene S. Ransdell, B.S.

We hear from more and more families who are supporting loved ones with Down syndrome and Alzheimer's. They have lots of questions, and are sometimes overwhelmed dealing with all the changes they see. Behavior changes related to Alzheimer's can be some of the first signs that something is going on and often leave caregivers with many questions.

Behavior management during the progression of Alzheimer's is an area of concern for many caregivers. In this issue we will share information on some of the most frequent behavior challenges that families have noticed—such as Sundowning, angry outbursts, pacing and wandering, repetitive comments and questions, and hiding objects. These certainly are not all the behavior changes we might observe in someone who is living with Alzheimer's or other dementia and we encourage our readers to learn as much as they can so they are able to offer the best support for whom they provide care.

Inside this issue:

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COVID-19 Q & A
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https://www.the-ntg.org/covid-19-qanda

https://www.ndss.org/covid-19-fact-sheet/

"Seeing people change isn't what hurts. What hurts is remembering who they used to be"

Author Unknown

Dementia-Related Behavior Challenges

Jadene S. Ransdell, B.S., Co-Editor, NTG & NDSS Caregiver News

The word dementia often makes people think primarily of memory loss. And while memory is a big factor in the progression of dementia, for people with Down syndrome, changes in function, personality and behavior may be more common early signs.

Some of the more frequent changes in personality and behavior may include:

- Reduced socialization, conversation
- Loss of interest in usual activities
- Reduced ability to pay attention
- Increased sadness, fear, anxiety
- Increased irritability, aggression
- Reduced cooperation
- Increased restlessness or sleep disturbances
- Increased excitability or noisiness

> *First and foremost, when behaviors change suddenly, do not assume that Alzheimer's is the reason for those changes. It is important to consult with the doctor when behaviors are unusual as they may be caused by something physical or a medical condition that could be treated.*

Different terms have been used for dementia-related behaviors— "challenging behaviors," "behaviors of concern," "needs-driven behavior," or "problem behavior" are some of them. The term used is not as important as understanding the *why* of the behavior. Knowledge of challenging behaviors can lead to more effective support of the person with the possible outcomes of reductions in stress and injury for both the individual and the caregiver.

Caregiver frustration may grow as a result of more challenging behaviors and changes. Sometimes, it can feel like the person is just trying to be difficult. Recognizing that dementia causes damage to the brain that increases as the disease progresses can help the caregiver to view the behavior as another symptom of the disease.

Because changes are inevitable, it is helpful for caregivers to learn ways to cope with them and to be more effective in the way support is provided. These tips may help.

- ◊ Keep things simple—give single-step requests.
- ◊ Develop a schedule—routines are comforting.
- ◊ Focus on the feelings behind the words—they may be an expression of fear, sadness, or worry.
- ◊ Do not argue—what is said is reality at that moment in time.
- ◊ Use humor when possible—lighten the moment with laughter.
- ◊ Use music, singing, or dancing to distract—it's especially helpful with repetitive statements and questions.
- ◊ Involve the individual—ask for help with daily tasks such as setting the table or making the bed.

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Dementia-Related Behavior Challenges

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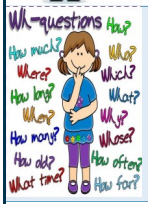
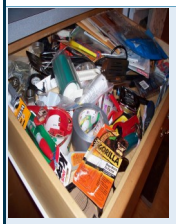
All behavior is communication. It is important to remember that statement, especially as caregivers see new behaviors or changes in the frequency of other behaviors. As dementia advances behavior becomes more and more a way to communicate. Challenging behaviors may be caused by the person's reactions to brain changes or they may be caused by external factors. As visual perception changes, a person may not be able to find something in a room that is cluttered. The lighting in a room can affect the person, as well. In addition, people with dementia may react to what others around them may be doing. The tone and volume of someone's voice or their facial expressions may also trigger a behavior challenge. Even what is playing on the television may become a source of agitation or anxiety for someone.

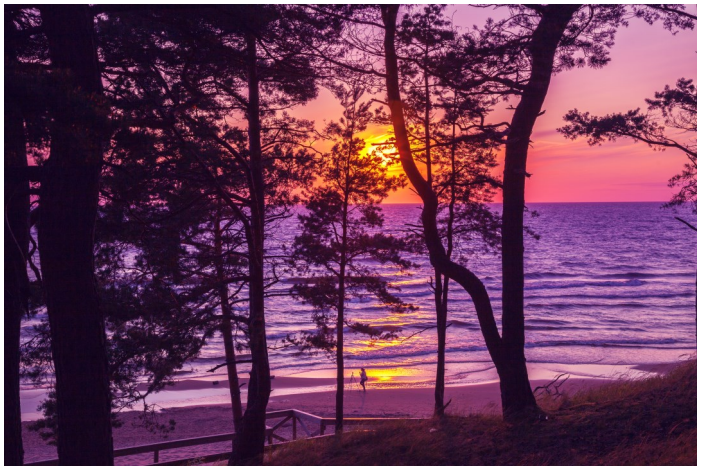
Below is a chart of some of the common dementia-related behavior challenges people may exhibit and tips to remember about each of them.

Dementia-Related Behavior	*Tip*
 **Angry Outbursts & Physical Aggression**	Check for an immediate cause for the behavior, such as pain or over stimulation.
 **Hand-Wringing, Pacing, & Rocking**	These behaviors are often triggered by anxiety and may be related to the environment. Divert attention with a short walk, listening to music or singing a song.
 **Accusing Others of Wrongdoing, and Hallucinations**	These may be behaviors not grounded in reality. If not serious, simple diversions such as mentioned above may help. If serious, consult with the doctor.
 **Repetitious Stories & Questions, Disorientation, Confusion about Time Passage**	Remain calm and be patient. Do not argue or tell them they are repeating themselves. Smile and nod. Sometimes "fiblets" may necessary to keep the person safe. Use memory aids such as photos and picture-sequenced calendars so the individual knows what is coming up next.
 **Sleep problems & Sundowning**	Nighttime restlessness is not uncommon. Keep naps to a minimum and provide structured activities during the day. Sometimes naps happen because of boredom. Provide various activities to keep the person engaged. Close the curtains or window shades just before dusk and turn on as many lights as possible.
 **Rummaging & Hiding Items**	The person may be looking for something specific and is unable to communicate what it is. Learn where the person often hides things and check those places often (out of sight of the person). Check trash containers before they are emptied. Lock up dangerous or toxic products; put important and valuable items in a safe place. Provide a special place for the person the rummage through things.
 **Startling Easily, and Trouble Eating or Drinking**	Loss of peripheral vision early on and further loss of the visual field later makes it difficult to tell when someone is approaching and may also make it difficult to see their utensils, plate or beverage. Approach the person from the front and announce that you are coming near them. Use brightly colored plates, cups or glasses to help the person see their meal.

Sundowning and What it Means for Your Loved One with Alzheimer's Disease or Dementia

By Rachel Grimm, B.S., Co-Editor, NTG & NDSS Caregiver News

With the diagnosis of Alzheimer's and other dementias will come many new realities and your loved one will begin showing behaviors that you may have never seen before. Among these may be a symptom called *Sundowning Syndrome*. Although this symptom to dementia is largely a mystery to doctors, there are a few items to consider when caring for someone with Down syndrome or an intellectual disability and Sundowning syndrome.



What is Sundowning?

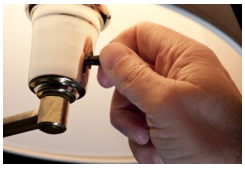
Sundowning, sometimes called Sundowners, is a symptom of Alzheimer's disease and other related dementias. It is identified with behaviors such as confusion, anxiousness, aggression, and restlessness, consistently showing up in the late afternoon or early evening. This symptom can occur at any stage of the disease but may show up in the middle stages.

How will it affect my loved one with Down syndrome?

Although the research on sundowning as it relates to those with Down syndrome is inconclusive, it can be helpful to monitor your loved one's changes in behaviors to find patterns of change. There can be many causes to sundowning and behavior change including exhaustion, inability to cope with stress, disruption in sleep, and less activity later in the day compared to the morning (leading to restlessness).

How can I help care for my loved one going through this?

* Keep a daily routine. Setting a regular sleep schedule, activities and mealtimes will help your loved one recognize their surroundings.
* Schedule unfamiliar appointments and outings earlier in the day when they're feeling their best.
* Limit or avoid things that affect sleep.
* Keep things calm in the evening.
* See if behavior is caused by discomfort, i.e. hunger, pain.
* Prevent overstimulation by electronics and loud noises.
* Provide adequate lighting to lessen shadows when it begins to get dark.



When should I get a medical professional involved?

Keep track of your loved one's behavior, especially as it begins to become out of the ordinary. By keeping a log of when things happen and what happened, as well as the situation (was anything our of the norm at that time?), the doctor can better assess your loved one to ensure medications are up to date and the dosages are correct, explore other medical reasons, or identify patterns that seem to set off reactive behaviors. Consult with your loved one's doctor if behaviors are consistent with the above symptoms.

Intellectual Disabilities, Dementia, and Applied Behavior Analysis: An Emerging Trio of Need

Risley "Ley" Linder, MA, M. Ed., BCBA

The discussion of intellectual and related disabilities and dementia is an increasingly necessary, although stressful, topic amongst caregivers within the intellectual and related disabilities population. The application of principles related to applied behavior analysis (ABA) to provide a framework of care to those with intellectual and related disabilities and dementia is an emerging area of specialty.

Pop Quiz

Before delving into depths of the relatively unknown, let us start where we are all confident! Can you correctly match the terms in the first column with the definitions in the second column?

Term	Definition
Dementia	A. Characterized by significant limitations in both intellectual functioning and in adaptive behavior**,** which covers many everyday social and practical skills.
Intellectual Disabilities	B. Characterized by changes in cognitive, language, problem solving, and other thinking abilities that are severe enough to interfere with daily life.

How was the trip down memory lane to second guess yourself during an unexpected pop quiz? In general, dementia can be described as *changes* in cognition, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life (option B above). A similarly general characterization of intellectual disabilities can be described as significant limitations in both intellectual functioning and in adaptive behavior**,** which covers many everyday social and practical skills (option A above). The similarities and overlaps in definitions of intellectual disabilities and dementia highlight the difficulties faced when caring for individuals living with both diagnoses. Applied behavior analysis offers an evidence-based method of helping develop strategies for assisting with the reduction and management of symptoms of dementia, particularly as related to problem behavior.

The intersection of intellectual and related disabilities , dementia, and ABA is an emerging area of practice. From a research vantage point, the combination of these three areas remains in its conception stage. Information is sparse, but is seeing growth, as evidenced by a recommended article "Behavior-Analytic Approaches to Working with People with Intellectual and Developmental Disabilities who Develop Dementia: A Review of the Literature." *Behavior Analysis in Practice*, *12*(1), 255-264. Two primary, but separate, literature bases have to be pulled from when working with individuals with intellectual disability and dementia: behavior analytic & intellectual disability, and behavior analytic & dementia. Additionally, behavior analysis in long-term care settings could be useful when looking to find research related to congregate/residential service provision.

Applied behavior analysis provides a systematic method for understanding all behavior, not just dementia behaviors. This systematic approach provides a guided framework, but to be effective ABA assessments,

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Intellectual Disabilities, Dementia, and Applied Behavior Analysis: An Emerging Trio of Need

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programs, and approaches to care must be fluid and adaptable. The fundamental components of behavior are the antecedent, behavior, and consequence, which are often referred to as the "ABCs of behavior." This is what is most commonly associated with ABA, as it's easy and catchy, but it is incomplete and we need more!

Through assessment, ABA identifies four functions of any behavior - the behavior of your spouse, child, annoying coworker, *any* behavior! These functions are access to attention, access to items/activities, escape or avoidance, and internal sensory reinforcement. Using the fundamentals of ABA, we can "dissect" behavior and determine why the behavior happened. The assessment of problem behaviors is done to break down all the components contributing to the problem behavior and develop preventative and management strategies to address each of these concerns.

Behavior assessments rely heavily on information from the person's past, not just their current symptomology and behavioral presentations. This becomes even more important with individuals with dementia, as primary caregivers are often the most knowledgeable and reliable respondents during assessments. The information caregivers can provide is invaluable to identify personal characteristics of the person, components of problem behavior, and symptoms of medical concerns (e.g. dementia). One assessment tool that is commonly used to assist with this delineation is the "*National Task Group – Early Detection Screen for Dementia*", which is designed for caregivers to be a respondent in a user-friendly manner that provides immediate feedback.

In practice, it is recommended to use a dementia screening tool to have a baseline for aging individuals, in addition to those who may be at a higher risk of having cognitive declines at an earlier age (e.g. Alzheimer's and Down syndrome). Once a person is thought to be showing signs of cognitive decline it is recommended to complete the screen periodically (e.g. annually, every 6 months) as indicated. These screens can be valuable tools to provide information to primary care physicians or medical specialists and to monitor global status. As caregivers, it is also important to take notes on the personal characteristics of the person before the onset of cognitive, physical, or global declines. These notes can include but are not limited to, social history, preferences/dislikes, fine/gross motor skill abilities, idiosyncratic behaviors, and communication/ comprehension skills.

As people with intellectual and related disabilities age their needs will continue to change. Those providing care to these individuals will continue to have a multitude of tasks, such as daily care, global decision making, and the management of difficulties that arise. An interdisciplinary team approach, including applied behavior analysis, can assist with guiding the care of individuals with intellectual disabilities and dementia. To find a listing of Board-Certified Behavior Analysts (BCBA) in your area please visit https://www.bacb.com/

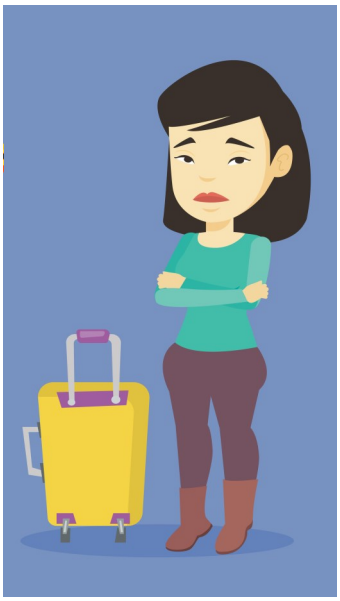
About the Author: Ley is a Board-Certified Behavior Analyst, a South Carolina DDSN approved provider of Intensive Behavior Intervention Services, and an NTG Regional Trainer. He has a Masters of Arts in Gerontology, as well as a Masters of Education, with an emphasis in Applied Behavior Analysis. In addition to behavior analytic work, his experience includes direct service professional in long-term care settings, previously licensed long-term care administrator in North Carolina, outpatient rehabilitation therapy clinic management, and CRCF management. If you would like to communicate directly with Ley you can reach him at ley@crescentbehavioralhealth.com

Applied Behavior Analysis & Dementia in Action: Ms. C. Wants to Go Home

Risley "Ley" Linder, MA, M. Ed., BCBA

One of the most common discussions related to persons with intellectual disabilities and dementia is the management of challenging behaviors. Challenging behaviors associated with dementia can be exacerbations of previous concerns but are frequently new issues that create difficulties in a person's daily life. The following is a real-life example of the management of dementia-related behaviors for a person with intellectual disabilities using applied behavior analysis (ABA).

Background Information



Ms. C. is a 47-year old woman who lives in a group home setting, has worked the same community-based job for many years, and spends every Sunday with her family. She is diagnosed with Down syndrome, mild intellectual disability, dementia, and hypothyroidism. Ms. C. was referred for behavior assessment based on the staff report of increased instances of yelling, screaming, physical aggression, and confusion in the evening. During observation periods on weeknights, Ms. C. would pack a bag, place it by the door, and state ,"My mom is coming to pick me up to go home." Staff members would provide verbal prompts for her to take her bag back to her room, along with telling her that her mother was "not coming this evening." This led to yelling, screaming, and increased the likelihood of physical aggression.

Behavioral Considerations

The first step that was taken was to explore the actions of Ms. C. The following questions were asked:

- What are the various behavioral concerns for Ms. C.?
- What are the possible reasons for these behaviors?
- What interventions would you use and why?
- Are your interventions preventative and not exclusively reactive?

The Approach (See Figure 1)

As part of the behavioral assessment, the various components of the challenging behavior were identified, which included setting events and antecedents. These two components formed the basis for preventative strategies for challenging behaviors. *A priority of the assessment process was identifying the functions of identified challenging behaviors*.

For Ms. C., these functions were identified as:

- access to attention,
- access to items/activities, and
- sensory factors related to confusion.

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Applied Behavior Analysis & Dementia in Action: Ms. C. Wants to Go Home

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By examining the setting events, antecedents, and functions of behavior, various strategies for the prevention and management of the challenging behaviors were developed. An important dynamic to effective behavioral programming is to develop strategies for each of these identified components and functions. It is also important to remember that many behaviors serve multiple functions, thus necessitating multifunctional interventions. For example, when Ms. C. stated her mother was coming to pick her up to go home, it was believed she was wanting to gain:

- ◊ *access to attention* (seeing her mother), and
- ◊ *access to an activity* (going home or for a ride).

It was also believed the behaviors were in the *context of being confused about time and schedules*.

The Strategies (See Figure 1)

Setting Events – **Discussion of new-onset symptoms of confusion with physicians monitoring dementia and hypothyroidism.** It is always recommended to present any change in behavioral presentations to medical professionals (e.g. primary care physicians, medical specialists) to ensure that all medical issues are known and addressed. In the example of Ms. C., hypothyroidism can have symptoms such as depression, fatigue, difficulty concentrating, and/or memory issues. These symptoms could impact her current behavior presentations, which could be viewed as dementia progression.

Antecedents – **Discover what is happening (or not happening) before the behavior occurs.** Structured programming, even for leisure activities, was needed (group, 1:1, and individual). The decrease in structured activities after dinner led to an increase in leisure time, but Ms. C. needed assistance with starting and continuing independent leisure activities.

When Ms. C. was showing signs of confusion, it was necessary to "go to her reality." It is recommended to address this type of confusion or delusional thoughts by going to their reality through affirmative statements and providing direction towards reality-based social interaction and activity engagement. For example, "Ms. C, you like visiting with your mother, don't you? I could use your help folding the towels while you wait."

Functions – **To be effective, the purpose of the behavior must be known.** The program included planned ignoring of her suitcase being put by the door. However, it necessitated additional interventions to address access to attention and activities. Telling Mrs. C. to take her suitcase back to her room, that her mother was not coming, or only ignoring the suitcase and comment created behaviors, so we didn't do any of these!

We did provide access to her highly preferred activities (eating ice cream, doing word searches, watching television) while "she waits to go." Example: "Ms. C., would you like to do a word search at your table, while watching TV with the other ladies, and have some ice cream with me while we wait?"

These activities allowed for Ms. C. to have highly preferred activities, that were done with high amounts of attention (from her peers and staff), which also promoted reality-based thinking and activities.

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Applied Behavior Analysis & Dementia in Action:

Ms. C. Wants to Go Home

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Setting Event (Foundational causes of challenging behavior, occur hours or days before)	**Antecedent** (Immediately precedes, seconds or minutes, before challenging behavior)	**Challenging Behavior(s)** (What is observed and described as challenging)	**Function/ Consequence** (Why is the person doing this?)
• *Medical Concerns?* ♦ Dementia, ♦ Hypothyroidism • *Psychiatric Concerns?* ♦ Confusion	• A decrease in a structured environment • Confusion of time/ schedule • Assistance starting/ continuing independent leisure activities	• Screaming, Yelling • Physical Aggression • Confusion	• Access to person, attention (looking for her Mom) • Access to activity (looking to go home, possibly ride?) • Sensory – Confusion (Believes her Mom is coming to get her)

Figure 1: Summary Statement (e.g. ABC Pattern) for Ms. C.

Outcomes – **Interventions should serve to decrease challenging behaviors and increase a supportive structure and environment.** By the second day, staff members became adept at creating a supportive structure after dinner. The availability of highly preferred leisure activities (with assistance) and increased social attention were successful in decreasing the occurrence of the challenging behaviors.

The interventions were also effective at decreasing the intensity and duration of challenging behaviors when they occurred. The interdisciplinary team agreed that social attention and preferred activities assisted in increasing reality-based thoughts, as 20-30 minutes after the interventions were implemented staff was able to take Ms. C.'s suitcase back to her room without incident.

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Although applied behavior analysis is a discipline practiced by highly trained Board-Certified Behavior Analysts, the principles of behavior analysis can be used by anyone. ABA promotes looking at all components of challenging behavior, not just the behavior itself. Additionally, if the answer to "why is this behavior occurring?" is similar to "this is just what they do" or "this is just dementia", keep looking at the concern, as you have not arrived at your solution (yet!). Lastly, continue to familiarize yourself with ABA and subspecialties, such as Behavioral Gerontology, at https://www.bacb.com/about-behavior-analysis/

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 or 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**
Autumn 2020	Siblings	August 15, 2020 / September 21, 2020
Winter 2020	Arts & Dementia	November 1, 2020 / December 21,2020
Spring 2021	Working with Health Care Providers	February 1, 2021 / March 21, 2021
Summer 2021	Living Healthy with Dementia	May 1, 2021 / June 21, 2021

Resources

Articles in this newsletter used information from, or referenced content linked below. Additionally, we have links to other resources that you may find helpful, including the NDSS publication, *Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers.*

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6411549/

https://dementiacarenotes.in/dementia/dementia-behaviour/

https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome

https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome

https://www.aarp.org/caregiving/health/info-2017/ways-to-manage-sundown-syndrome.html

https://www.ndss.org/about-down-syndrome/publications/caregiver-guide-order-form/

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