PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
SEPTEMBER 2023
$14.95

INSIDE:

DEMENTIA *and* INTELLECTUAL DISABILITIES

PLUS:

CAREGIVING: A LIFESPAN ISSUE

AND:

AUTISM DIAGNOSIS *in* ADULTHOOD

ALSO:

OVERCOMING SPEECH AND COMMUNICATION CHALLENGES *for* AGING PATIENTS

EP'S ANNUAL ISSUE:

ELDERLY CARE

PLUS • A LIFETIME OF EXPERIENCE:

THANKS *for* LETTING ME FAIL

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ELDERLY CARE

AN EP SPECIAL SECTION
BE PREPARED

FEATURES

ON OUR COVER

For the first time, EP Magazine makes makes Elderly Care its central focus as a monthly editorial theme. Getting older may be difficult for most everyone, but people with special needs and their professional and family caregivers face many additional challenges as they age. *Coverage begins on page 12.*

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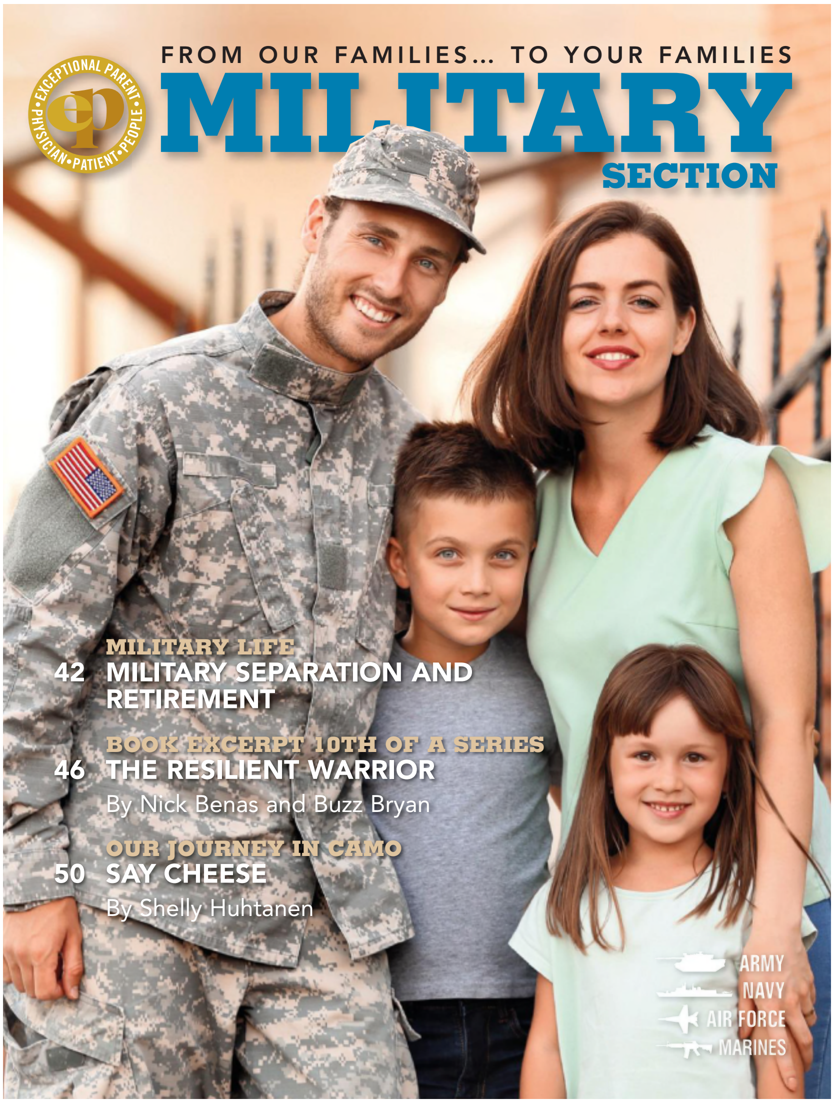
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MILITARY SECTION

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A New Age

EP has featured many articles on aging in the past, but we decided that the topic deserved an issue all its own.

This September, for the first time in its history, EP has made Elderly Care and Senior Issues its main focus as a monthly editorial theme. In the past, we have featured many articles on aging and its effect on people with disabilities, but we decided that the topic deserved an issue all its own.

As the French actor and vaudevillian of the last century, Maurice Chevalier, once said, “Old age isn’t so bad when you consider the alternative.” That may be true, but getting older poses many challenges for people with special needs and their professional and family caregivers. Particularly daunting are problems with communication. “While people have come to expect physical challenges that accompany the aging process – such as eyesight or hearing changes – they may be surprised by changes that diminish a person’s ability to speak and express oneself,” writes Avivit Ben-Aharon, M.S.Ed., M.A. CCC SLP in her article “Overcoming Speech and Communication Challenges for Patients with Alzheimer’s, Parkinson’s and Dementia.”

> “Getting older poses many challenges for people with special needs and their professional and family caregivers.”

In her article addressing the concerns of caregivers who help both young and older members of their family, Loren Agoratus, M.A. stresses that “the single most important thing for caregivers is respite, or a break from caregiving. No one can help anyone else if they are depleted themselves.” She follows up by offering real solutions and proven resources.

This issue also features Be Prepared: An EP Special Section. Ellen Smith reports on what she does to get ready for a scheduled – or emergency – hospital stay as a person who is medically complex. In “Effectively Preparing for Emergencies and Disasters,” we present a thorough checklist from **Ready.gov** that will help get our readers safely through weather-related or other emergencies.

In our Features section. you’ll find toilet training tips for children with Autism Spectrum Disorder, as well as an article from the American Academy of Audiology that gauges whether or not your child’s academic decline might be due to hearing loss.

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Faye Simon

Editor In Chief

THE EDITOR IN CHIEF’S DESK

Faye Simon is a certified pre-K–8 teacher with a wide range of educational experience. She has worked in deaf/blind and infant stimulation programs, taught K–2 in public schools, and was a Head Teacher and Parent Coordinator for Head Start. She is Founder and President of the volunteer-run IES Brain Research Foundation. As EP’s Editor In Chief, Faye sources and edits articles, creates partnerships with businesses and not-for-profit organizations, and develops relationships with EP’s writers, corporate partners, readers and staff.

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

LABOR DEPARTMENT OFFERS NEW GRANT OPPORTUNITY TO BOOST DISABILITY EMPLOYMENT

HIRE PURPOSE: The initiative seeks to address historical barriers that have impeded the transition from school to work for marginalized youth and young adults with disabilities.

Federal officials are pouring millions of dollars into a new effort to improve the transition from school to work for young people with disabilities.

The U.S. Department of Labor announced the availability of more than $69 million in funding over a five-year budget period to support the development of innovative strategies that will help youth and young adults with disabilities transition to the workforce successfully.

Administered by the department's Office of Disability Employment Policy, the funding will be awarded in cooperative agreements with four recipients, subject to federal fund availability, at about $17 million per organization. Initial funding is expected to total $12.9 million or $3.2 million per agreement.

"When it comes to finding and exploring opportunities for employment, youth and young adults with disabilities have historically faced systemic barriers related to their disabilities," said Assistant Secretary for Disability Employment Policy Taryn M. Williams. "The funding opportunity announced today will help us identify policies and practices that enable these young people to transition to employment successfully and move us toward a more equitable and inclusive workforce."

Aligned with the Biden-Harris administration's efforts to foster a more inclusive workforce, the grants will identify evidence-based solutions to help recipients to better address employment needs of youth and young adults with disabilities.

Eligibility for the grant is extended to state agencies focused on labor, employment, education, health and human services, vocational rehabilitation services, or workforce development. The U.S. Department of Labor has emphasized that the funding should be utilized to develop "scalable strategies" aimed at enhancing employment outcomes for individuals with disabilities who belong to marginalized groups. The target demographic for this initiative includes individuals between the ages of 14 and 24.

Over the course of five years, up to four grants will be awarded, signifying a sustained commitment to fostering positive change in the employment landscape for young people with disabilities. The application window for states to submit their proposals is open until October 31.

WHAT'S HAPPENING

NAVIGATING AGING: A NEW MEDICARE PROPOSAL WOULD COVER TRAINING FOR FAMILY CAREGIVERS

BY JUDITH GRAHAM

Even with extensive caregiving experience, Patti LaFleur was unprepared for the crisis that hit in April 2021, when her mother, Linda LaTurner, fell out of a chair and broke her hip.

LaTurner, 71, had been diagnosed with early-onset dementia seven years before. For two years, she'd been living with LaFleur, who managed insulin injections for her mother's Type 1 diabetes, helped her shower and dress, dealt with her incontinence, and made sure she was eating well.

In the hospital after her mother's hip replacement, LaFleur was told her mother would never walk again. When LaTurner came home, two emergency medical technicians brought her on a stretcher into the living room, put her on the bed LaFleur had set up, and wished LaFleur well.

That was the extent of help LaFleur received upon her mother's discharge.

She didn't know how to change her mother's diapers or dress her since at that point LaTurner could barely move. She didn't know how to turn her mother, who was spending all day in bed, to avoid bedsores. Even after an occupational therapist visited several days later, LaFleur continued to face caretaking tasks she wasn't sure how to handle.

"It's already extremely challenging to be a caregiver for someone living with dementia. The lack of training in how to care for my mother just made an impossible job even more impossible," said LaFleur, who lives in Auburn, Washington, a Seattle suburb. Her mother passed away in March 2022.

HELPING HANDS: Patti LaFleur's mother, Linda LaTurner, moved into her home after her dementia progressed and care became complicated. "My mom had always been a very happy easygoing person. But she withdrew from social situations and cried a lot," LaFleur says.

PHOTO COURTESY PATTI LAFLEUR

A new proposal from the Centers for Medicare & Medicaid Services addresses this often-lamented failure to support family, friends, and neighbors who care for frail, ill, and disabled older adults. For the first time, it would authorize Medicare payments to health care professionals to train informal caregivers who manage medications, assist loved ones with activities such as toileting and dressing, and oversee the use of medical equipment.

The proposal, which covers both individual and group training, is a long-overdue recognition of the role informal caregivers – also known as family caregivers – play in protecting the health and well-being of older adults. About 42 million Americans provided unpaid care to people 50 and older in 2020, according to a much-cited report.

"We know from our research that nearly 6 in 10 family caregivers assist with medical and nursing tasks such as injections, tube feedings, and changing catheters," said Jason Resendez, president and CEO of the National Alliance for Caregiving. But fewer than 30% of caregivers have conversations with health professionals about how to help loved ones, he said.

Even fewer caregivers for older adults – only 7% – report receiving training related to tasks they perform, according to a June 2019 report in JAMA Internal Medicine.

Nancy LeaMond, chief advocacy and engagement officer for AARP, experienced this gap firsthand when she spent six years at home caring for her husband, who had amyotrophic lateral sclerosis, a neurological condition also known as Lou Gehrig's disease. Although she hired health aides, they weren't certified to operate the feeding tube her husband needed at the end of his life and couldn't show LeaMond how to use it. Instead, she and her sons turned to the internet and trained themselves by watching videos.

"Until very recently, there's been very little attention to the role of family caregivers and the need to support caregivers so they can be an effective part of the health delivery system," she told me.

Several details of CMS' proposal have yet to be finalized. Notably, CMS has asked for public comments on who should be considered a family caregiver for the purposes of training and how often training should be delivered.

Advocates said they favor a broad definition of caregiver. Since often several people perform these tasks, training should be available to more than one person, Resendez suggested. And since people are sometimes reimbursed by family members for their assistance, being unpaid shouldn't be a requirement, suggested Anne Tumlinson, founder and chief executive officer of ATI Advisory, a consulting firm in aging and disability policy.

As for the frequency of training, a one-size-fits-all approach isn't appropriate given the varied needs of older adults and the varied skills of people who assist them, said Sharmila Sandhu, vice president of regulatory affairs at the American Occupational Therapy Association. Some caregivers may need a single session when a loved one is discharged from a hospital or a rehabilitation facility. Others may need ongoing training as conditions such as heart failure or dementia progress and new complications occur, said Kim Karr, who manages payment policy for AOTA.

CONSTANT CARE: Cheryl Brown's husband, Hardy, was diagnosed with amyotrophic lateral sclerosis, also known as Lou Gehrig's disease, in 2002. He can't walk but he can use his arms and hands. Brown says she "never gets a break" from caregiving responsibilities.

When possible, training should be delivered in a person's home rather than at a health care institution, suggested Donna Benton, director of the University of Southern California's Family Caregiver Support Center and the Los Angeles Caregiver Resource Center. All too often, recommendations that caregivers get from health professionals aren't easy to implement at home and need to be adjusted, she noted.

Nancy Gross, 72, of Mendham, New Jersey, experienced this when her husband, Jim Kotcho, 77, received a stem cell transplant for leukemia in May 2015. Once Kotcho came home, Gross was responsible for flushing the port that had been implanted in his chest, administering medications through that site, and making sure all the equipment she was using was sterile.

Although a visiting nurse came out and offered education, it wasn't adequate for the challenges Gross confronted. "I'm not prone to crying, but when you think your loved one's life is in your hands and you don't know what to do, that's unbelievably stressful," she told me.

For her part, Cheryl Brown, 79, of San Bernardino, California – a caregiver for her husband, Hardy Brown Sr., 80, since he was diagnosed with ALS in 2002 – is skeptical about paying professionals for training. At the time of his diagnosis, doctors gave Hardy five years, at most, to live. But he didn't accept that prognosis and ended up defying expectations.

Today, Hardy's mind is fully intact, and he can move his hands and his arms but not the rest of his body. Looking after him is a full-time job for Cheryl, who is also chair of the executive committee of California's Commission on Aging and a former member of the California State Assembly. She said hiring paid help isn't an option, given the expense.

And that's what irritates Cheryl about Medicare's training proposal. "What I need is someone who can come into my home and help me," she told me. "I don't see how someone like me, who's been doing this a very long time, would benefit from this. We caregivers do all the work, and the professionals get the money? That makes no sense to me."

ABOUT THE AUTHOR:

Judith Graham, a contributing columnist, writes the "Navigating Aging" column for KFF Health News. She has covered health care for more than 30 years. She's been an investigative reporter, national correspondent and senior health reporter at the Chicago Tribune and a regular contributor to The New York Times' New Old Age blog. Judith was the first topic leader on aging for the Association of Health Care Journalists. Her work has appeared in publications including Stat News, The Washington Post, and the Journal of the American Medical Association. She is a graduate of Harvard College and has a master's in journalism from Columbia University.

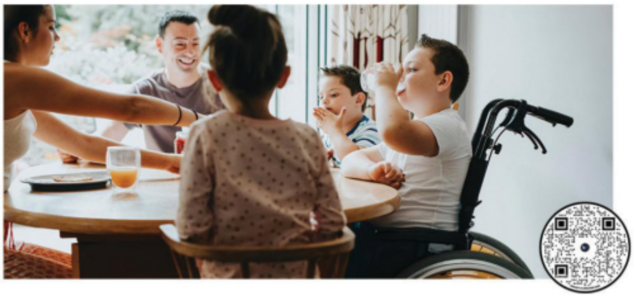


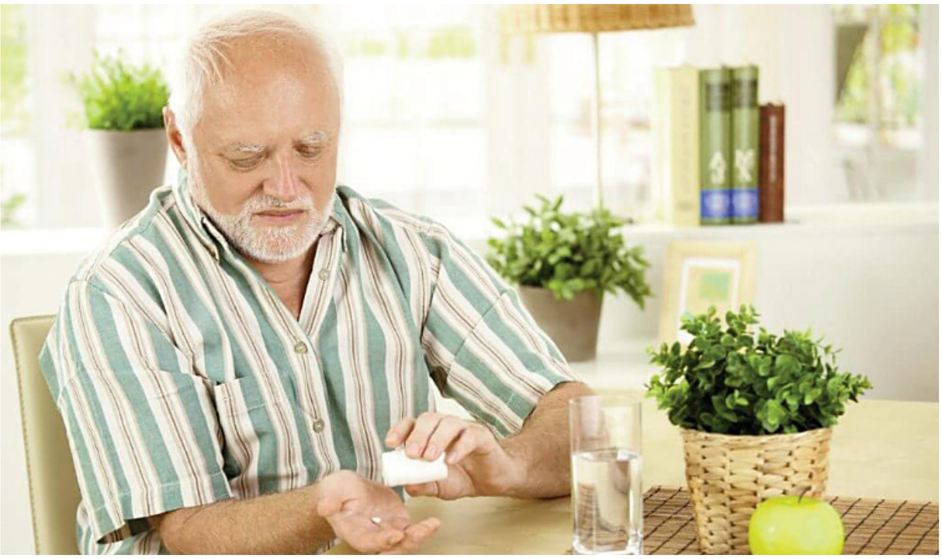
PHOTO BY VAN HOWARD/IMAGE ARTS

WHAT'S HAPPENING

DAILY MULTIVITAMIN MAY ENHANCE MEMORY IN OLDER ADULTS: COGNITIVE HEALTH STUDY

BY JUDITH GRAHAM

Memory and thinking skills tend to decline as we get older. Certain lifestyle factors – such as a healthy diet, physical activity, and social interactions – might help to protect cognitive health as we age.



DAILY DOSE: A large clinical trial found that daily multivitamins led to modest improvements in memory over a three-year period in older adults.

Some studies have suggested that taking multivitamins or other dietary supplements may help protect thinking and memory. But few large-scale studies have directly examined how dietary supplements affect cognitive health in older adults. Clinical trials to date have shown mixed results.

A research team led by Dr. Adam M. Brickman of Columbia University set out to test the idea. Their study included more than 3,500 volunteers, ages 60 and older. Most were white (94%), and more than half had a college degree (56%). Participants were randomly assigned to receive either a daily multivitamin or a placebo pill. Neither they nor the researchers knew which type of pills they were given.

When the study began, the participants took a series of web-based online tests to assess their cognitive abilities. The tests were then repeated annually for three years. Results appeared in the *American Journal of Clinical Nutrition* on May 24, 2023.

At the end of the first year, people taking the daily multivitamin had significantly higher scores on a test of immediate recall compared to the placebo group. The test involved viewing a series of 20 words, one at a time, for three seconds each. Immediately afterward, people were asked to key in as many words as they could remember.

In the multivitamin group, scores improved from an average of about 7.1 recalled words to 7.8 words after the first year. For comparison, scores changed from about 7.2 words to about 7.6 words in the placebo group. The improved scores in the multivitamin group continued but did not significantly increase over that of the placebo group into the second and third years of the study. Other types of cognitive tests showed no significant differences between the groups.

Notably, participants with a history of cardiovascular disease had lower immediate-recall scores at the start of the study compared to those without such history. But after one year of taking multivitamins, the scores of those with cardiovascular disease improved significantly, becoming comparable to those without the disease.

These results refine the findings of a related NIH-supported study published last year. That study of more than 2,200 people ages 65 and older found that a daily multivitamin improved a broad measure of cognitive function. Improvements were likewise more prominent in those with a history of cardiovascular disease.

"There is evidence that people with cardiovascular disease may have lower micronutrient levels that multivitamins may correct, but we don't really know right now why the effect is stronger in this group," explains Brickman.

"Cognitive aging is a top health concern for older adults, and this study suggests that there may be a simple, inexpensive way to help older adults slow down memory decline," he adds.

Further research is needed to study more diverse populations and pinpoint which nutrients might play a role in protecting memory. •

ABOUT THE AUTHOR:

Vicki Contie is a Science Communication & Digital Outreach Specialist at the National Institutes of Health

Reference

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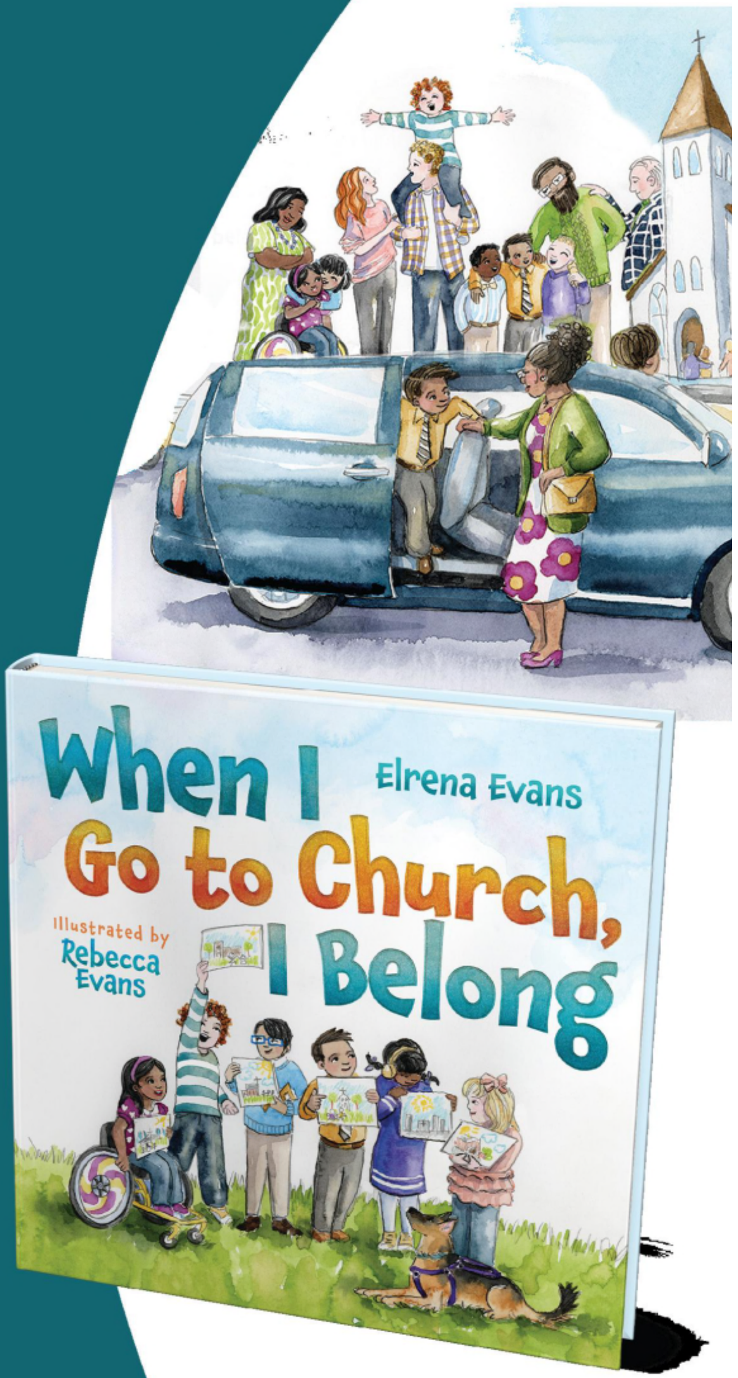
When I Go to Church, I Belong
Elrena Evans
Illustrated by Rebecca Evans

AUTISM DIAGNOSIS IN ADULTHOOD

SOME ADULTS WHO ARE NOT FORMALLY DIAGNOSED ACHIEVE MAJOR MILESTONES LIKE BEING IN RELATIONSHIPS OR BUILDING SUCCESSFUL CAREERS. OTHERS SPEND THEIR LIVES FEELING OUT OF PLACE, STRUGGLING TO SUCCEED IN CERTAIN AREAS, OR MASKING THEIR AUTISM TO FIT IN.

BY MARTA CHMIELOWICZ

Dr. Elisheva Levin was 45 when she received her autism diagnosis. After a lifetime of struggling to fit in, the pieces finally clicked when her son was diagnosed with autism, and she realized that they shared many similarities. Her diagnosis gave her a deeper understanding of herself and a new perspective on the challenges she faced throughout her life.

LEADING BY EXAMPLE:: Dr. Elisheva Levin; “Growing awareness of autism spectrum disorder has led to a rise in diagnoses among children, but for adults, getting a diagnosis remains a challenge.”

“I spent a lot of my time as a young girl daydreaming,” she says.[1] “I spent my young teenagerhood imagining that I was in fantasy worlds and not in the world that I was in, because the world I was in was so painful. When I got my diagnosis, I was actually relieved. All of a sudden, I could understand my life and my problems in a very different way, because I understood that my brain works differently.”

Now, Dr. Levin, Ph.D., devotes her career to disability policy. In her work as a senior research scientist, at the Center for Development and Disability in the University of New Mexico School of Medicine, she is bringing autistic representation to the field and using public health data to provide research that benefits people with autism and other developmental disabilities.

THE WEIGHT OF NOT KNOWING

Like Dr. Levin, many autistic people live much or all of their whole lives, without a formal diagnosis. Growing awareness of autism spectrum disorder (ASD) has led to a rise in diagnoses among children,[2] but for adults, getting a diagnosis remains a challenge. Autism Speaks’ Adult Autism Diagnosis Tool Kit,[3] written by a team of autistic adults, can help people who suspect they may have autism, identify the signs and learn about next steps.

“There are approximately 5.4 million autistic adults in the U.S., yet the autism field’s understanding of aging across the lifespan is exceedingly low,” says Andy Shih, chief science officer at Autism Speaks. “It is increasingly clear that there is a large population of autistic adults who were not diagnosed in childhood and who were frequently misdiagnosed with other conditions. Our recent Thought Leadership Summit on Autism and Aging[4] revealed that this has resulted in a critical absence of research and healthcare professionals capable of providing the specialized care needed for this unique population.”

Many adults who are not formally diagnosed, do not realize that some of the things that make them unique are related to undiagnosed ASD. Some learn to navigate their differences very well, achieving major milestones like being in relationships or building successful careers. Others spend their lives feeling out of place, struggling to succeed in certain areas, or masking their autism to fit in.

According to a Drexel report,[5] autistic adults experience higher rates of co-occurring mental health conditions than their peers, including anxiety (28%), bipolar disorder (25%), ADHD (23%) and depression (22%).

“From talking to lots of adults diagnosed in adulthood, there’s good reason to believe that co-occurring anxiety and depression, in particular, could be a result of spending many decades of life feeling stigmatized, and not understanding the difficulties that they had in certain areas,” says Dr. Vanessa Bal, M.Sc., Ph.D., Karmazin & Lillard chair in adult autism and associate professor at the Graduate School of Applied & Professional Psychology at Rutgers University. [6] “The uncertainty of not having an autism diagnosis as a way to understand their experience could contribute to higher rates of these conditions.”

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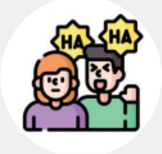
SIGNS OF AUTISM IN ADULTS

You may have spent your entire life not recognizing the signs of autism, or not realizing that some of the issues and feelings you have dealt with were related to autism. Here are what the three hallmark symptoms of ASD might look like:

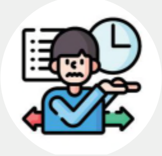


SOCIAL INTERACTIONS

- Feeling left out of social circles or not fitting in
- Difficulty interpreting what others are thinking and feeling
- Inability to pick up on or misunderstanding nonverbal cues, including eye rolls, shoulder shrugs, grimaces and other facial expressions used to convey emotion
- Inability to see things from another person's perspective

COMMUNICATION DIFFERENCES

- Difficulty carrying on a conversation
- Tendency to carry on monologues on a favorite subject
- Needing a high level of directness and honesty in conversation
- Preference to communicate via text or email



REPETITIVE BEHAVIORS

- Needing to keep household or other objects in a fixed order or place, and becoming upset if someone or something disrupts the order
- Needing strict consistency in your environment or daily routine
- Having an extreme interest in a certain topic

Read more in our Autism Speaks Adult Autism Diagnosis Tool Kit:

www.autismspeaks.org/AdultToolkit

A study from *Autism Research*[7] shows that age of diagnosis can have a major impact on mental health. People who were diagnosed over age 21 were 2.7 times more likely to have co-occurring mood, anxiety, personality or eating disorders than people who were diagnosed in childhood. These conditions greatly impact quality of life and can increase the complexity and cost of healthcare.

"Experts have claimed for a long time that autistic people are more prone to anxiety and depression, and that it's somehow caused by their brains. But the fact is, that the world looks a lot different from the perspective of people with autism. If you don't fit in, it makes sense that you're going to be more anxious and depressed, because being social takes so much of your energy that you don't get to live your life," says Dr. Levin.

THE PATH TO A DIAGNOSIS

Screening for autism in adults can be challenging. Currently, there are few clinicians who specialize in adult autism, so it can be difficult to find someone who is comfortable with (and skilled in) diagnosing and treating autism in adults.

Dr. Cathy Lord, Ph.D., George Tarjan distinguished professor of psychiatry in the David Geffen School of Medicine at UCLA, recommends that adults seeking a diagnosis start by going to a general therapist, psychologist or psychiatrist.[8] While these specialists will take self-referrals, a referral from a primary care physician could help speed up the process.

Another approach is contacting a clinician who specializes in autism in children. A developmental pediatrician, child psychiatrist or pediatric neurologist may be open to seeing older patients.

Though there are established diagnostic tests for ASD in adults, autism looks different for everyone, and many older adults learn how to mask their symptoms, making an autism diagnosis based on observation challenging. Over the course of multiple appointments, adults are typically asked to speak with the clinician about their childhood and present life, do various activities, and fill out questionnaires.

At Dr. Lord's clinic, the process begins with a conversation about what the adult is seeking from the assessment. Then, clinicians speak with someone who knew the patient as a child. "That is very useful, because autism is a developmental disorder, so we are looking for something that has always been there but may not have caused difficulty until later in life," she explains.

After the initial interviews, patients are asked to do a full assessment to test their cognition, executive functioning, and ability to make judgments. Lastly, clinicians do a social-emotional functioning interview to measure people's ability to hold a job, make friends, and other social activities, as well as an adaptive behavior scale to measure independent living skills. They also screen for depression, anxiety and ADHD – common co-occurring conditions that accompany autism.

A formal diagnosis will come with a written evaluation that explains which autism criteria was met, the level of diagnosis, as defined in the DSM-5, and other diagnoses and suggested supports. This document could open the door to benefits or services from state, federal and other public agencies.

THE WORK AHEAD

While the medical profession has made huge strides in early diagnosis, much work remains in the field of autism and aging. There is a shortage of research into issues that affect autistic individuals across the lifespan, and a shortage of mental health professionals who are trained to provide support to autistic adults.

"We've made huge strides in early diagnosis, but we also need to do a much better job of training our general practitioners in the mental health field, to be prepared to see autistic adults," says Dr. Bal. "We simply do not have the capacity as a specialty field, to assess and diagnose all the people who need to be seen. So we need to find other ways. Some people will continue to benefit from specialty care, but there ought to be a subset of people who can go and get a diagnosis from a more general mental health professional, who has enough training to help them map out their path forward."•

ABOUT THE AUTHOR:

Marta Chmielowicz is the Content Manager of Mission Delivery at Autism Speaks, where she leads science communications to advance the mission of Autism Speaks to create an inclusive world for all individuals with autism throughout their lifespan.

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7. Jadav, N., & Bal, V. H. (2022). Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research. Autism Research, 15(11), 2112–2125. https://doi.org/10.1002/aur.2808
8. Autism Speaks. Expert Q&A: What to expect when getting an autism diagnosis as an adult. 2023. https://www.autismspeaks.org/blog/expert-qa-what-expect-when-getting-autism-diagnosis-adult

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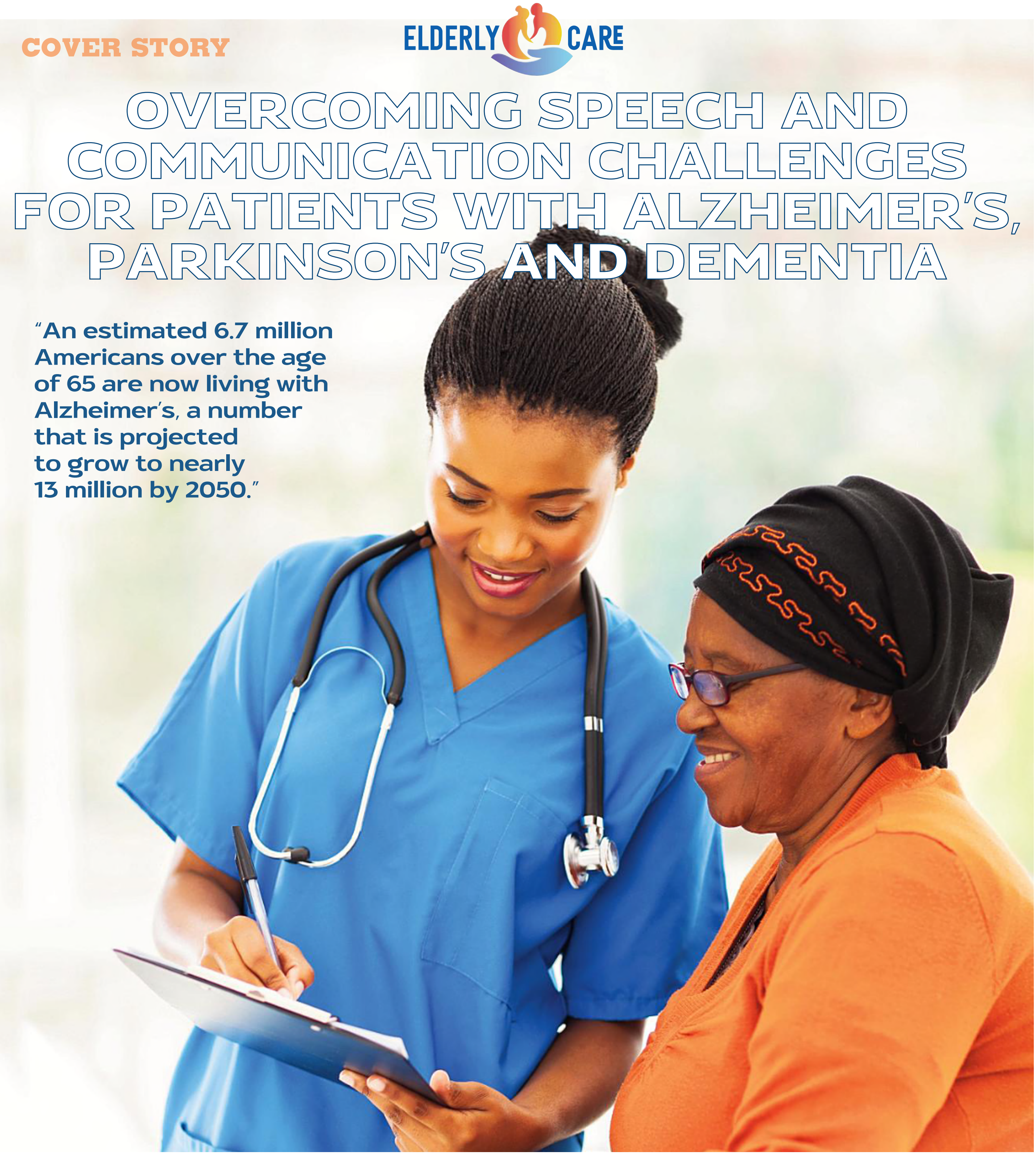
OVERCOMING SPEECH AND COMMUNICATION CHALLENGES FOR PATIENTS WITH ALZHEIMER'S, PARKINSON'S AND DEMENTIA

> "An estimated 6.7 million Americans over the age of 65 are now living with Alzheimer's, a number that is projected to grow to nearly 13 million by 2050."



BY AVIVIT BEN-AHARON, M.S.ED., M.A. CCC SLP

As we age, our bodies change in a wide variety of ways, some of which are unexpected. While people have come to expect physical challenges that accompany the aging process – such as eyesight or hearing changes – they may be surprised by changes that diminish a person's ability to speak and express oneself. When speech and language skills decline, especially with the onset of Alzheimer's Disease (AD), Parkinson's and dementia, one's independence and quality of life often dissipates.

Early diagnosis, and intervention with speech therapy, and the opportunity for people to access care "online" or "virtually" from licensed Speech-Language Pathologists (SLPs) may help to delay the onset or progression of issues which impact self-expression. With speech therapists available nationwide, virtual speech therapy offers increased access to personalized care and a specialized therapy plan that is tailored to each individual for more focused therapy sessions, and possibly faster results in a shorter time frame.

A key goal of an intervention plan is to maintain current cognitive function, as much as possible. This involves developing coping skills that enable individuals to manage their decline, as effectively as possible, and address memory loss or other cognitive deficits.

Speech and language therapy means not only working on speech-related issues, but also stimulating the brain so that language skills, including memory, also improve. This enhances a person's quality of life, interpersonal and familial relationships, and the impact of worsening symptoms.

ASSESSING SPEECH AND LANGUAGE SKILLS : A CLOSER LOOK AT COMMUNICATIONS CHALLENGES

ALZHEIMER'S DISEASE (AD)

For the 55+ million people worldwide who are living with AD or another form of dementia, communication is challenging because the individuals have trouble remembering.[1] According to the National Institute on Aging, AD causes some people to get confused about language, struggle to find words or forget what they want to say.[2] For example, the person might forget or no longer understand English, if it was learned as a second language, and prefer to use only the first language learned, such as Spanish. Other issues include:

- *Finding the right word or losing his or her train of thought when speaking*
- *Understanding what words mean*
- *Paying attention during long conversations*
- *Remembering the steps in common activities – cooking,[3] paying bills, or getting dressed*
- *Dealing with background noises from the radio, TV, or conversations*
- *Becoming very sensitive to touch and to the tone and loudness of voices*

These individuals may show signs[4] of memory loss, challenges in planning or solving problems, confusion with time or place and trouble understanding visual images and spatial relations. All of these symptoms can lead to social isolation and diminished quality of life.

To help make communication easier, experts offer these tips:

- *Make eye contact and call the person by name.*
- *Be aware of your tone, how loud your voice is, how you look at the person, and your body language.*
- *Encourage a two-way conversation, for as long as possible.*
- *Use other methods besides speaking, such as gentle touching.*
- *Try distracting the person if communication creates problems.*

1. www.who.int/health-topics/dementia#tab=tab_1.
2. www.nia.nih.gov/health/alzheimers-caregiving-changes-communication-skills
3. www.nia.nih.gov/health/adapting-activities-people-alzheimers-disease
4. www.cdc.gov/aging/healthybrain/ten-warning-signs.html

PARKINSON'S

The Parkinson's Foundation advises that most people with the disease experience a soft voice volume, that may be difficult to hear. Loss of automatic facial expression can be misinterpreted as boredom, anger or sadness.[5]

Mood changes in Parkinson's, such as: apathy, depression or anxiety can also affect communication, as speech may become fast or slow, rushed, mumbled or slurred. Some people notice a stutter, or difficulty starting to speak, and their voices can become quieter, breathy, hoarse, or change in pitch.

The following tips can ease communications:

- *Try to have conversations one-on-one or in small groups.*
- *Reduce or remove distractions, like TV, radio or music, when conversing.*
- *Be close to each other when you talk, so it is easier to hear. Avoid yelling from another room in the house! Encourage the individual to take a deep breath before beginning to speak, to enhance his or her vocal loudness.*
- *Give him/her time to respond or participate in conversation.*
- *Do not make assumptions about how your loved one is feeling based on facial expressions.*

5. www.parkinson.org/sites/default/files/documents/addressing-communication-challenges.pdf.

ADOPTING THE USE OF TECHNOLOGY

According to Pew Research Center, the adoption of technology by Americans in the oldest age group has grown "markedly" over the past decade: 61% of those 65+ own a smartphone and 45% reported using social media.[6] As the elderly become more comfortable with using new technology, it becomes easier for them to receive virtual care.

Dementia and gait impairments often coexist in older adults and patients with neurodegenerative diseases, such as AD and Parkinson's.[7] Since mobility issues often restrict someone's ability to travel to clinics or treatment facilities, the availability of online speech therapy is key to accessing timely, ongoing care.

This option can relieve some of the burdens and stress for family members and caregivers. It improves quality of life for those who prefer the familiar surroundings of home, instead of traveling to brick and mortar offices. There is the benefit of scheduling flexibil-

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6 www.pewresearch.org/fact-tank/2022/01/13/share-of-those-65-and-older-who-are-tech-users-has-grown-in-the-past-decade/

7. www.ncbi.nlm.nih.gov/pmc/articles/PMC4119872/

ity, since often, SLPs working virtually offer wide availability, including evenings and weekends. Convenient access to care accommodates busy schedules, that may be strained by ongoing appointments with doctors or other treatment regimens.

ADDRESSING ISSUES OF ISOLATION AND LONELINESS

Virtual speech therapy also helps to address challenges of isolation and loneliness, key Social Determinants of Health (SDoH) that accompany these conditions.

- **Help Recovering Lost Memories:** SLPs can work with patients to retrieve memories, helping people learn ways to recall daily tasks or more deep-seated memories. When patients can remember specifics, it helps them process thoughts and communicate better.
- **Increase Social Interaction:** It's not uncommon to see these individuals withdraw from friends, family, and regular social activities, when they develop communication issues. The onset of depression and loneliness can lead to more rapid deterioration. As people rebuild their ability to recall information and communicate clearly, they feel more confident, and are more likely to interact with others, and reconnect with friends and loved ones.
- **Changes in Behavior:** When it's tough to communicate, anyone might act out. When people with Parkinson's, Alzheimer's and dementia struggle to form thoughts and communicate, it can lead to poor behavior. Speech therapy helps patients feel heard, communicate more effectively, and abandon poor behavior that they may have used to get attention.

> "A key goal of an intervention plan is to maintain current cognitive function, as much as possible. This involves developing coping skills that enable individuals to manage their decline, as effectively as possible, and address memory loss or other cognitive deficits."

Research from the Alzheimer's Association shows the number of people being diagnosed continues to go up, as the baby boomer population ages.[8,9] It's estimated that 6.7 million Americans over the age of 65 are now living with Alzheimer's, a number that is projected to grow to nearly 13 million by 2050. The U.S. will face an unprecedented wave of dementia and cognitive decline, and it is more important than ever that individuals have access to virtual care nationwide.•

ABOUT THE AUTHOR:

Avivit Ben-Aharon, MS ED., MA CCC SLP is the Founder and Clinical Director at Great Speech, Inc, a virtual speech therapy company founded in 2014. She is recognized as a trail blazer for nationwide virtual access to speech therapy. It allows anyone to receive expert services to improve their communication, regardless of location or scheduling limitations. Her work has been featured on Forbes, Good Morning America, US News and World Report, Miami Herald and more. She holds an undergraduate and a Master of Arts degree in Speech-Language Pathology from The City University of New York. She earned a Master of Science in Special Education and Teaching from Hunter College. For more information: **www.greatspeech.com**.

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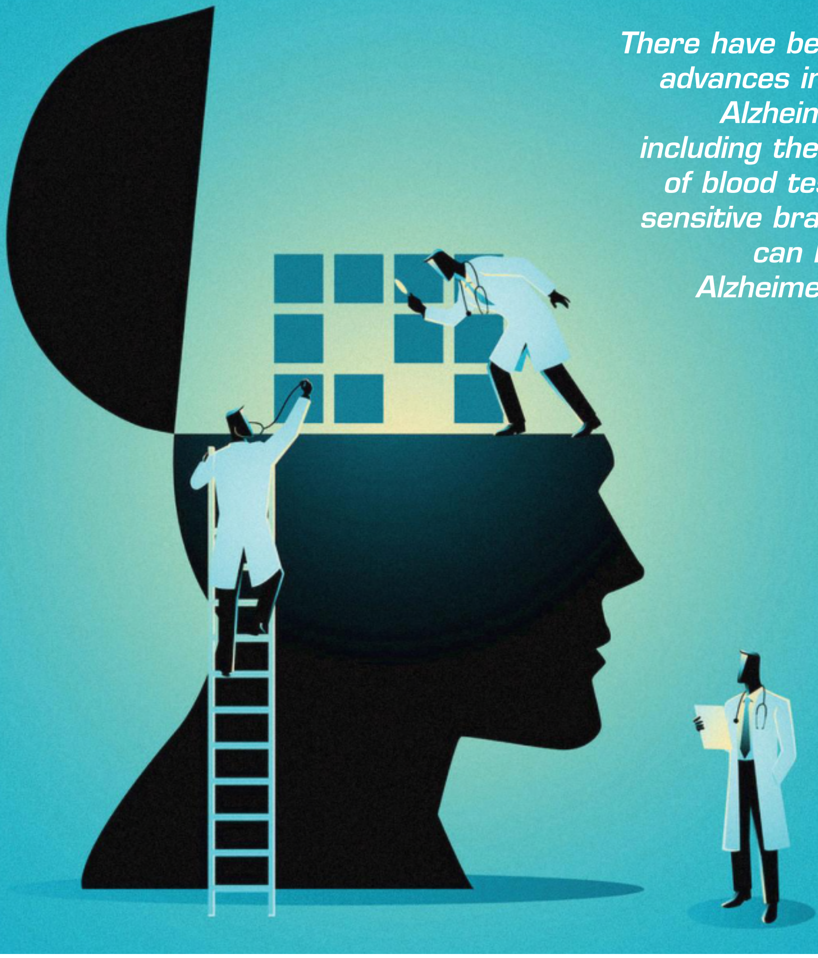
[8] www.cbsnews.com/philadelphia/news/alzheimers-disease-numbers-increasing-as-baby-boomers-age-study

[9] www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf

DEMENTIA AND INTELLECTUAL DISABILITIES

BY CRAIG ESCUDÉ, MD FAAFP, FAADM

There have been significant advances in research on Alzheimer's disease, including the development of blood tests and more sensitive brain scans that can help diagnose Alzheimer's dementia.



Dementia can be a pretty scary thing for anyone. For people with disabilities, changes or a decline in cognitive functioning can be quite challenging to recognize, especially in people who do not use words to communicate.

When we are looking to diagnose dementia, clinicians frequently use tests like a mental status exam where a person is asked to remember lists of items, draw a picture of a clock with numbers on it, and recall current events, like naming the current president and the city and state where they live. For some with disabilities, questions like these may not have ever been able to be successfully answered due to a different baseline of knowledge and comprehension. So how then, can we attempt to accurately diagnose dementia in people with differing levels of cognitive baseline functioning?

One way to do this is to look at changes in functional status over time. There is a tool developed by the National Task Group (NTG) on Intellectual Disabilities and Dementia Practices called the Early Detection and Screen for Dementia (EDSD)[1] (**www.the-ntg.org/ntg-edsd**), which is specifically geared to help assess levels of functional decline over time in people with intellectual and developmental

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[1] www.pewresearch.org/fact-tank/2022/01/13/share-of-those-65-and-older-who-are-tech-users-has-grown-in-the-past-decade/

disabilities. This tool is designed to be used by family members and other supporters. Looking at serial measurements annually or every six months can help determine if a person is having a functional decline, but does this mean that the person definitely has dementia? No, it does not. Ruling out other causes for symptoms consistent with dementia is also very important. Mental health conditions, untreated sleep apnea, metabolic toxicity including alcohol, medication side effects, vitamin deficiencies, brain tumors, and thyroid, kidney, and liver disease can all present with signs resembling dementia. However, having the type of information that the EDSD can provide can be very helpful to a clinician in determining whether or not a person has evidence of dementia. When we see changes in cognition, we should never hastily conclude that it is due to dementia, but instead look for treatable underlying causes, such as, those mentioned above. Working with a clinician knowledgeable about dementia in people with disabilities is advisable.

> ***People who are supporting those with dementia also need support.***
>
> ***The NTG also has a Family Support Committee.***

People with Down Syndrome are at a much higher risk of Alzheimer's type dementia. People with Down Syndrome have an extra copy of chromosome 21, which also carries a gene responsible for producing a protein called amyloid precursor protein. Too much buildup of this protein in the brain leads to beta-amyloid plaques, which are implicated as a significant cause of Alzheimer's disease. It is estimated that 50% or more of people with Down Syndrome will develop Alzheimer's, and they are more likely to develop it earlier than those without Down Syndrome. It's recommended that screening for dementia using a tool like the EDSD be started at age 40.[2]

There have been significant advances in research on Alzheimer's disease, including the development of blood tests and more sensitive brain scans that can help diagnose Alzheimer's dementia. While these tests are currently not available everywhere, soon, we should have widespread availability of blood testing to diagnose the condition. There have also been advances in medication treatment options for dementia, and current trials are promising for the availability of effective treatment options, in the near future. As with any new treatment, caution is warranted before starting medications. One should always weigh the risk and benefits of treatment, and include frank discussions with the clinician, the person for whom treatment is being considered, and the person's support network, to help ensure that the best decision is made for each person.

People who are supporting those with dementia also need support. The NTG also has a Family Support Committee. Activities of the committee include providing written and public comments on federal issues related to dementia, as well as an inclusive, monthly, national online support group for family caregivers, and the option to participate in a Facebook group for caregivers and professionals supporting individuals with Down Syndrome and Alzheimer's disease. You can learn more about the NTG Family Support Committee by visiting **www.the-ntg.org/family-caregivers**.

Realizing that someone we love is showing signs of dementia can spark a wave of fear and anxiety. Ensuring a proper diagnosis, involving compassionate clinicians, and aligning ourselves with others facing similar situations, can help us gain understanding and position ourselves to continue to grow and thrive in a life that, despite challenges, is filled with many joys and blessings.

ABOUT THE AUTHOR:

Dr. Craig Escudé is a board-certified Fellow of the American Academy of Family Physicians and the American Academy of Developmental Medicine and President of IntellectAbility (**https://replacingrisk.com**). He has over 20 years of clinical experience providing medical care for people with IDD and complex medical and mental health conditions. He is the author of *Clinical Pearls in IDD Healthcare* and developer of the *Curriculum in IDD Healthcare*, an eLearning course used to train clinicians on the fundamentals of healthcare for people with IDD. He is also the host of the IDD Health Matters podcast.

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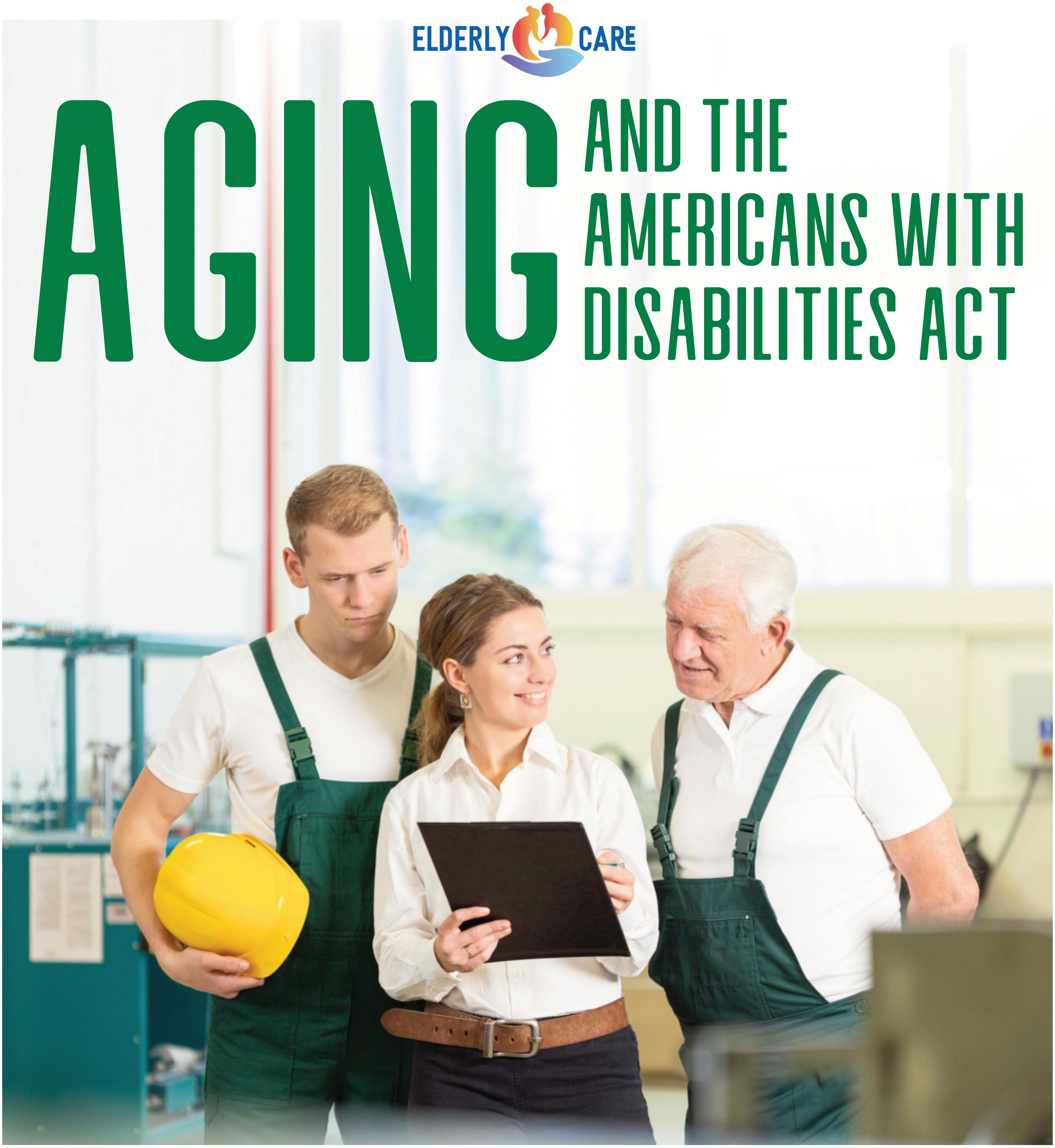
2. National Institute on Aging. 2020. Alzheimer's Disease in People With Down Syndrome: www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome

ELDERLY CARE

AGING AND THE AMERICANS WITH DISABILITIES ACT



COURTESY OF ADA NATIONAL NETWORK

As people get older, many start to develop problems with hearing, seeing, or getting around. Others experience chronic illnesses like hypertension, diabetes, arthritis, or memory loss. People may have disabilities under the definition in the ADA when age-related changes in function make it more difficult to get around at home, participate in their community, or go to work. The ADA is a civil rights law. It was designed to make sure that people with disabilities have equal access to work, education, and their community.

HOW DOES THE ADA RELATE TO OLDER PEOPLE?

Although people who are aging often don't think of themselves as having a disability, according to the ADA, having a "physical or mental impairment that substantially limits a major life activity" means a person has a disability.

More than 30 percent of Americans over age 65 have some kind of disability, and over 50 percent of those over age 75. These may range from difficulties seeing and hearing to walking and thinking. Under the ADA, it isn't the cause of the disability that matters, but what it means in everyday life.

To read the legal definition of "disability," as stated in the ADA, see **https://adata.org/faq/what-definition-disability-under-ada**.

WHAT AREAS OF LIFE ARE INCLUDED UNDER THE ADA?

Work: Employers may not discriminate against you because of your disability if you can do your job "with accommodation." An accommodation may be required to help employees with disabilities succeed in the workplace by making changes to the work environment or schedule, as long as it is not an "undue hardship" for the employer. For example, a person who is experiencing age-related vision loss can request a larger monitor or a screen reader to help them access their computer screen. Changes like this are called "reasonable accommodations."

Many people continue to work past traditional retirement age. If you start having problems doing your job because of health or physical problems, you may be eligible under the ADA for workplace accommodations.

Transportation and Travel: Public transportation, such as light rail, transit and busses, is required to be accessible to people with disabilities.

Taxi companies are required to provide accessible service. This means that transportation companies cannot refuse service if you use a mobility device such as a walker or a wheelchair.

People with disabilities have protections when flying, including the right to bring a service animal. Accessibility of the airport is covered under the ADA, but the accessibility of the airplane itself is covered under the Air Carrier Access Act (**www.transportation.gov/airconsumer/passengers-disabilities**).

Entertainment and Hospitality: "Places of public accommodation" like restaurants, hotels, theaters, arenas, and museums must be physically accessible to individuals with disabilities. They must also provide "reasonable modifications of policies, practices, or procedures" when requested, so long as it is not an undue burden to the business. For example, a person with some age-related vision loss may go to a restaurant and have difficulty reading the menu. If the customer requests assistance, the restaurant should provide a menu in a format that works for that person, such as large print, or should offer to read it aloud.

Health Care: The ADA requires that health care providers, including medical facilities and dentists' offices, provide reasonable modifications to patients. The health care provider must provide assistance with communication if needed. This means that they may help you fill out a form or read small print in documents before you sign them. Health care providers must also ensure that you can access medical equipment. For example, they can provide exam tables that can move up and down to make it easier for patients to sit or lie down for examination.

Public places: Public places and activities owned and controlled by state or local government like streets, sidewalks, parks, and government buildings are required to be accessible and they must provide requested reasonable modifications. For example, if a city is hosting a town hall meeting, they must ensure that there is an accessible entryway so that people who use mobility devices will be able to enter the building and participate.

Housing: Accessibility in housing is covered under the Fair Housing Act, which is enforced by the Department of Housing and Urban Development (HUD). The Fair Housing Act (**www.justice.gov/crt/fair-housing-act-2**) applies to buildings with four or more units. Covered buildings must be physically accessible, according to the building code used by the state. In addition, housing providers must provide reasonable accommodations and modifications to tenants with disabilities. A housing provider might provide a designated parking space near the door of an apartment or modify its policies to allow a tenant to pay rent by mail as an accommodation.•

ABOUT THE ADA NATIONAL NETWORK

The ADA National Network provides information, guidance and training on the ADA, tailored to meet the needs of business, government, and individuals at local, regional, and national levels. You may contact your regional ADA Center by phone or email, or find more ADA resources on the ADA National Network's website. Call 1-800-949-4232, visit **adata.org** or email **https://adata.org/email**

HELPING ELDERS : RESOURCES FOR OLDER ADULTS

U.S. Department of Health and Human Services administers more than 100 programs across its operating divisions. HHS programs protect the health of all Americans and provide essential human services, especially for those who are least able to help themselves.

ADMINISTRATION FOR COMMUNITY LIVING

Services available to the disabled elderly

https://eldercare.acl.gov/Public/Index.aspx

PROGRAMS OF ALL-INCLUSIVE CARE FOR THE ELDERLY (PACE)

Disabled elderly individuals may also be eligible for Medicaid benefits

www.medicaid.gov/medicaid/long-term-services-supports/program-all-inclusive-care-elderly/index.html

BENEFITS.GOV

An interactive benefit eligibility screening tool

www.benefits.gov

Source: www.hhs.gov/answers/programs-for-families-and-children/index.htm

CARAREGIVING: A LIFESPAN ISSUE

BY LAUREN AGORATUS, M.A.

Caregivers can be parents of children who need lifelong care, "well-spouses," or eldercaregivers.

CAREGIVING ISN'T JUST AN ELDERCARE ISSUE!

Families of children with special healthcare needs may not even realize that they are caregivers. They're not just taking care of their children, as would be expected. They are using feeding tubes, special formulas and diets, giving shots, dealing with incontinence past potty-training, and using medical equipment, such as: lifts, wheelchairs, walkers and they need accessible homes and vehicles. These families need to go beyond "parenting" – as they are family caregivers.

This can also be true of "well-spouses," when one person becomes disabled at any age and is cared for by the spouse or partner. Siblings also may help aging parents care for an adult brother or sister with a developmental or intellectual disability. Even youth themselves can be caregivers for siblings, parents, or grandparents. And finally, the most well-known image of a caregiver is one caring for an older adult. But all of these scenarios mean that someone isn't just being a good sibling, son/daughter, spouse/partner etc. They are going above and beyond through caregiving.

ANSWERING THE CALL: The most well-known image of a caregiver is one caring for an older adult; this sibling, son/daughter, spouse/partner is going above and beyond through caregiving.

IMAGE BY PIKISUPERSTAR

INNOVATIVE PROGRAMS

Some newer programs in some states are “consumer-directed care” in which the care recipient can choose who is paid as their caregiver. Some states allow parents to be paid as home health aides. Some parents can get paid as nurses. Many of these initiatives began during the COVID 19 pandemic to address worker shortages, and some have been continued.

Other programs such as Home and Community Based Services under Medicaid, keep individuals in their homes and communities and out of institutions. A bill in New Jersey awaiting the Governor’s signature, at the time of print, is the Hospital at Home bill, again keeping people at home instead of in institutional settings. Many Centers for Independent Living around the country have nursing home diversion initiatives that are part of their state’s Medicaid waiver programs.

CARING FOR THE CAREGIVER

The single most important thing for caregivers is respite, or a break from caregiving. No one can help anyone else if they are depleted themselves. According to the Caregiver Community Action Network (CCAN), “more people enter institutional care due to caregiver burnout rather than deterioration of their condition”. Caregivers need to take care of their own physical/mental health and their spiritual health too, whatever it means to them. Mental and intellectual well-being may be helped by finding out as much as you can about your care recipient’s condition and the choices you have. As Suzanne Mintz who founded CCAN noted, “you may not have all the choices you had before, you may not like some of the choices, but you still have the power to choose”. Informed caregivers don’t feel as helpless or hopeless. Also, emotions can take over if a caregiver can’t do everything as usual, for their care recipient. For example, in the hospital caregivers can’t do their loved one’s personal care (bathing/grooming) if they’re hooked up to medical equipment, but nurses can be helpful in reminding families that they don’t have to be the aide or nurse, just the mom, brother, or daughter etc. *At the Heart of the Matter: A Spiritual Journey for Caregivers* by Dr. Green is helpful for those struggling spiritually. In this book, caregivers have the “opportunity to personalize his or her caregiving journey based on their individual needs.” She reminds us that spirituality doesn’t necessarily mean religion; it’s whatever the personal transformation means to you. The book has inspirational quotes, poems, thinking points, caregiver assessments and short chapters, as time is frequently limited for caregivers.

> *“You may not have all the choices you had before, you may not even like some of the choices, but you still have the power to choose.”*

TAKE CARE : BECOMING A RESILIENT CAREGIVER

CAREGIVER COMMUNITY ACTION NETWORK
Toolbox
www.caregiveraction.org/family-caregiver-toolbox

FAMILY CAREGIVER ALLIANCE
www.caregiver.org

CAREGIVER SUPPORT SERVICES
www.caregiversupportservices.com

MEDICAID
Self-Directed Care
www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html
Home and Community Based Services
www.medicaid.gov/medicaid/home-community-based-services/index.html

ARCH NATIONAL RESPITE NETWORK
https://archrespite.org/caregiver-resources/respitelocator

By taking care of themselves in these areas, families can truly become resilient caregivers. •

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for the Caregiver Community Action Network as a volunteer. Nationally, Lauren has served on the Center for Dignity in Healthcare for People with Disabilities transplant committee (antidiscrimination), Center for Health Care Strategies Medicaid Workgroup on Family Engagement, Family Advisor for Children & Youth with Special Health Care Needs National Research Network, National Quality Forum-Pediatric Measures Steering Committee, and Population Health for Children with Medical Complexity Project-UCLA. She has written blogs and articles nationally, including publications in 2 academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was named a Hero Advocate by Exceptional Parent Magazine (**www.epmagazine.com Archives June 2022**).

EFFECTIVELY PREPARING FOR EMERGENCIES AND DISASTERS

PLAN AHEAD FOR ACCESSIBLE TRANSPORTATION THAT YOU MAY NEED FOR EVACUATION OR GETTING AROUND DURING OR AFTER DISASTER.

CHECK WITH LOCAL TRANSIT PROVIDERS AS WELL AS WITH YOUR EMERGENCY MANAGEMENT AGENCY TO IDENTIFY APPROPRIATE ACCESSIBLE OPTIONS.

COURTESY READY.GOV

AN EP SPECIAL SECTION • BE PREPARED

Disability intersects every demographic group – there are people with disabilities of all ages, races, genders or national origin. And, disabilities can impact a person in a variety of ways – both visible and invisible. For people with disabilities and their families, it is important to consider individual circumstances and needs to effectively prepare for emergencies and disasters.

GET INFORMED

Know what disasters could affect your area, which ones could call for an evacuation and when to shelter in place: **www.ready.gov/be-informed**

Keep a NOAA Weather Radio tuned to your local emergency station and monitor TV and radio. Follow mobile alerts and warnings about severe weather in your area:.

Download the FEMA App and get weather alerts from the National Weather Service for up to five different locations anywhere in the United States: **www.fema.gov/mobile-app**

MAKE A PLAN : CRUCIAL STEPS TO TAKE BEFORE DISASTER STRIKES

In the event of a disaster could you make it on your own for several days? After a disaster you may not have access to a medical facility or even a drugstore. It's crucial to plan for your daily needs and know what you would do if they become limited or unavailable. Additional planning steps include:

Create a support network of people who can help you in a disaster. Keep a contact list in a watertight container in your emergency kit or on your electronic devices.

Inform your support network where you keep your emergency supplies. You may want to consider giving a trusted member a key to your house or apartment.

Plan ahead for accessible transportation that you may need for evacuation or getting around during or after disaster. Check with local transit providers as well as with your emergency management agency to identify appropriate accessible options.

Plan for children and adults who may have difficulty in unfamiliar or chaotic environments. Consider your service or support animal or pets and plan for food, water and supplies. If you need to evacuate, you'll need to know whether your shelter allows pets or not, since some shelters only allow service or support animals.

Many city and county emergency management agencies maintain voluntary registries for people with disabilities to self-identify in order to receive targeted assistance during emergencies and disasters. Contact your local emergency management office to find out more.

If you are on dialysis or other life-sustaining medical treatment know the location and availability of more than one facility that can help you.

If you use medical equipment in your home that requires electricity, talk to your doctor or health care provider about what you may be able to do to keep it running during a power outage. You can also ask your power provider to put you on a list for priority power restoration.

About half of all Americans take a prescription medicine every day. An emergency can make it difficult for them to refill their prescription or to find an open pharmacy. Organize and protect your prescriptions, over-the-counter drugs, and vitamins to prepare for an emergency.

Wear medical alert tags or bracelets. Also add pertinent medical information to your electronic devices.

If you have a communication disability consider carrying printed cards or storing information on your devices to inform first responders and others how to communicate with you. Be sure to udate the information as your conditions or treatments change.

If you use assistive technologies, plan how you will evacuate with the devices or how you will replace equipment if lost or destroyed.

Locate and access your electronic health records from a variety of sources by using the U.S. Department of Health and Human Services' online tool (http://healthit.gov/bluebutton).

Keep a list of the nearest medical facilities, local hospitals and nearest transportation.

GET YOUR BENEFITS ELECTRONICALLY

A disaster can disrupt mail service for days or weeks. If you depend on Social Security or other regular benefits, switching to electronic payments is an easy way to protect yourself financially before disaster strikes. It also eliminates the risk of stolen checks. The U.S. Department of the Treasury recommends two safer ways to get federal benefits:

- Direct deposit to a checking or savings account. If you get federal benefits you can sign up by calling 800-333-1795 or sign up online at https://fiscal.treasury.gov/GoDirect
- The Direct Express® prepaid debit card is designed as a safe and easy alternative to paper checks. Call toll-free at 877-212-9991 or sign up online at https://fiscal.treasury.gov/GoDirect

BUILD A KIT : ITEMS TO MEET YOUR INDIVIDUAL NEEDS IN VARIOUS EMERGENCIES

In addition to having your basic survival supplies, an emergency kit (www.ready.gov/kit) should have items to meet your individual needs in various emergencies. Consider the items you use every day and which ones you may need to add to your kit.

TIPS FOR MEDICATIONS

- Talk to your doctor or pharmacist about how you can create an emergency supply of medicines.
- Keep a list of your prescription medicines. Include information about your diagnosis, dosage, frequency, medical supply needs and allergies.
- Store extra nonprescription drugs, like pain and fever relievers, antihistamines and antidiarrheal medicines.
- Have a cooler and chemical ice packs available to chill medicines that need to be refrigerated.

TIPS FOR PEOPLE WHO ARE DEAF OR HARD OF HEARING

- Weather radio (with text display and a flashing alert)
- Extra hearing-aid batteries
- Pen and paper (in case you have to communicate with someone who does not know sign language)
- Battery operated lantern to enable communication by sign language or lip reading, especially when the electricity is out and it's dark.

TIPS FOR PEOPLE WHO ARE BLIND OR HAVE LOW VISION

- Mark emergency supplies with Braille labels or large print. Keep a list of your emergency supplies and where you bought them on a portable flash drive or make an audio file that is kept in a safe place where you can access it.
- Keep communication devices for your particular needs, such as a Braille or deaf-blind communications device as part of your emergency supply kit.

TIPS FOR PEOPLE WITH SPEECH DISABILITY

- If you use an augmentative communications device or other assistive technologies plan how you will evacuate with the devices or how you will replace equipment if it is lost or destroyed. Keep model information and note where the equipment came from (Medicaid, Medicare, private insurance, etc.).
- Plan how you will communicate with others if your equipment is not working, including laminated cards with phrases and/or pictogram.

TIPS FOR PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES

- Keep handheld electronic devices charged and loaded with videos and activities.
- Purchase spare chargers for electronic devices and keep them charged.
- Include sheets and twine or a small pop-up tent (to decrease visual stimulation in a busy room or to provide instant privacy).
- Consider a pair of noise-canceling headphones to decrease auditory stimuli.
- Have comfort snacks available.

TIPS FOR PEOPLE WITH A MOBILITY DISABILITY

- If you use a power wheelchair have a lightweight manual chair available as a backup if possible.
- Show others how to assemble, disassemble and operate your wheelchair.
- Purchase an extra battery for a power wheelchair or other battery-operated medical or assistive technology devices. If you can't purchase an extra battery, find out what agencies, organizations or local charitable groups can help you buy one. Keep extra batteries charged at all times.
- Consider keeping a patch kit or can of sealant for flat tires and/or extra inner tube if wheelchair or scooter is not puncture proof.
- Keep an extra mobility device such as a cane or walker if you use one.
- Keep a portable air pump for wheelchair tires.
- If you use a seat cushion to protect your skin or maintain your balance and you must evacuate, consider keeping an extra cushion on hand.
- Communicate with neighbors who can assist you if you need to evacuate the building.

TIPS FOR INDIVIDUALS WITH ALZHEIMER'S AND RELATED DEMENTIA

- Do not leave the person alone. Even those who aren't prone to wandering away may do so in unfamiliar situations.
- If evacuating, help manage the change in environment by bringing a pillow and blanket or other comforting items they can hold onto.
- When at a shelter, try to stay away from exits and choose a quiet corner.
- If there is an episode of agitation, respond to the emotions being expressed. For example, say "You're frightened and want to go home. It's ok. I'm right here with you."

ADDITIONAL ITEMS

- Multi-day supply of prescription medicine
- A list of all medications, dosage and any allergies
- Extra eyeglasses, contacts, hearing aids and batteries
- A backup supply of oxygen
- A list of the style and serial number of medical devices (include special instructions for operating your equipment if needed)
- Copies of insurance and Medicare cards
- Contact information for doctors, relatives or friends who should be notified if you are hurt
- Pet food, extra water, collar with ID tag, medical records and other supplies for your service or support animal •

HOW TO BE PREPARED

FOR AN EMERGENCY OR PLANNED HOSPITALIZATION FOR INDIVIDUALS WHO ARE MEDICALLY COMPLEX

BY ELLEN SMITH

Coping with two incurable conditions and being medically complex has led to many experiences in the hospital. I have learned that it is best to prepare for a planned or emergency stay, to be as safe as possible.

AN EP SPECIAL SECTION
BE PREPARED

I highly recommend taking time to get a "just in case" list or even a bag that can be grabbed to bring to the hospital for you. I have had too many experiences of not getting food I can metabolize, correct medications, and being handled in a way that has caused permanent damage to my body.

So, with this in mind, I am sharing tricks that I have developed, to be prepared to the best of my ability.

PREPARATION IS KEY : PLANNING FOR AN EMERGENCY HOSPITAL STAY

ARRIVAL

I arrive with a packet of the following medical information printed out to hand to the staff, that includes:

- Insurance number
- Pharmacy contacts
- Medications presently being taken
- Copy of my DNA drug sensitivity testing results
- A list of medications in the past that have worked, but are not presently being used
- List of medication reactions - not to be administered
- List of past surgeries with dates
- Diagnoses list and dates when established
- My doctors currently caring for me
- My living will

IF YOU ARE FOOD REACTIVE

- Prepare and freeze individual-size meals and snacks to be brought in for you. I always keep some in the freezer "just in case".

DO'S AND DON'TS LIST

(The following is what I need others to respect and actually have taped to the door of my room)

DO'S 👍

- For the needle, use a butterfly for taking blood
- Use child tubes for any intubation
- When in doubt, don't take a chance, Contact one of the doctors that follows these two rare conditions: Ehlers-Danlos and Sarcoidosis
- Insert PICC line instead of IV, so it will hold
- Feel free to use any meds on the page listed MEDICATIONS THAT WORK
- Honor my no CHEST COMPRESSION order in the copy of my Living Will

👎 **DON'TS**

- No chest compressions - it will break my ribs and they will never heal
- No larger gauge needles - they easily blow veins and lines fall out
- No meds are to be given on the MEDICATION REACTION LIST
- Don't use any forms of steroids; it breaks down collagen rapidly with EDS

PHOTOS PROVIDED BY ELLEN SMITH

I hope these suggestions will be of help for your planned hospital stay or for an unexpected visit. Being in the hospital is not an easy assignment, so the more you can prepare, helps the experience will go more smoothly.

ABOUT THE AUTHOR:

Ellen Lenox Smith has emerged as a leading voice for patients living with pain in Rhode Island and the country. She suffers from two rare conditions, Ehlers-Danlos Syndrome and sarcoidosis. She enjoyed a career, predominantly in the field of education, before having to resign due to health. She devotes much of her time to advocacy. Presently, she is a co-director for Cannabis Advocacy for the US Pain Foundation, along with being on their board, runs Rhode Island Patient Advocacy Coalition, and was appointed by the governor to both the Adaptive Telephone Equipment Loan Program and the RI Medical Cannabis Oversight Committee representing patients, and helps run the RI EDS Support group. A proud mother of four sons and five grandchildren, Ellen is also an organic gardener, and prior to her disability, was a master swimmer and high school swim coach. She was a staff writer for National Pain Report and 1000 WATTS Magazine before they shut down, was a former staff writer for Pain News Network, and with her husband speaks out to educate others about her condition and pain management. She has spoken to: the FDA, Brown Medical students, Blue Cross nurses, and physical therapy students in RI and CT, along with speaking at the EDS national conferences. She is also the author of two books: *It Hurts Like Hell!: I Live With Pain - And Have A Good Life Anyway* and *My Life as a Service Dog!*

PREPARATION IS KEY : PLANNING FOR AN EMERGENCY HOSPITAL STAY cont.

IF YOU ARE CONCERNED WITH BEING HANDLED

For me, people don’t seem to understand the danger of handling an Ehlers-Danlos and Sarcoidosis patient inappropriately. Just a simple process of transferring me from the rescue chair to placing me onto their stretcher, actually caused permanent damage to the hip that became dislocated by their rough treatment. That happened despite my son and daughter-in-law advocating for me while I was unresponsive. So, either be sure to have an advocate with you and/or consider handing a list of concerns to the medical team.

IF YOU ARE CONCERNED WITH MEDICATIONS BEING GIVEN TO YOU

Despite having DNA drug sensitivity testing in hand showing medications that I cannot metabolize, I have confronted the situation of being given medications that are not compatible with my condition, and then paying the price with a physical reaction that exacerbates my symptoms. Again, be sure to hand the list that is safe and not safe to the staff, and tape it on the door of your room.

HOSPITAL CONVENIENCE AND COMFORT

Consider adding the following into a bag to grab “just in case”

- Deodorant and comb/brush of choice
- Activities to keep you occupied - like a pen, pencil, sudoku, puzzle, drawing paper, puzzles, wordle, crossword puzzles, etc.
- Pack a change of socks, underwear, sweatpants, robe, and shirt, to keep warm and clean, since many times the room can get chilly
- If you also deal with food sensitivities, pack some healthy snacks
- Think of items you need to use for medical or comfort that would be helpful to have with you. For instance, I have a fused neck, so my specific pillow is something I have to be sure to bring with me. My mouth guard to protect the position of the jaw, any current brace I am using, and my neck collar that is very specifically created for me since the fusion, are all essential to bring.

THANKS FOR LETTING ME FAIL

BY DR. JOSIE BADGER DHCE, CRC

PHOTO COURTESY JOSIE BADGER

Over July 4th weekend, my husband and I hosted a good old American cookout with all of the additional Independence Day festivities that make this holiday so exciting (including a slip and slide, water balloons, and of course, fireworks).

STRENGTH-TESTED: The author enjoys an evening beside the firepit at her home with her dog, Kloey

In the midst of the excitement and cheers of our kids, I took a moment to step away to talk to one of our friends with her nine-month-old baby. He had been diagnosed with Spinal Muscular Atrophy or SMA at only a couple months of age, and had made tremendous progress since receiving treatment. I commented on how well he was doing at holding his head up, which was something he was unable to do a few months ago. When last I saw him, it was nearly impossible for him to lift his head. His dutiful and caring mother would intervene to help him lift his head back to an upright position. This time, he worked even harder to be successful. It was exciting to see his progress. Even more so, it was exciting to watch his mom let him do it. She told me when we had been together the last time, she realized that she had to let him struggle, so that he could grow.

> **I AM SO GRATEFUL FOR THE COUNTLESS TIMES THAT MY PARENTS LET ME FIND MY OWN LIMITS, MAKE BAD CHOICES, AND ULTIMATELY, PAY FOR THEM.**

The ability to struggle and even fail is invaluable for a child's development and ultimate success in adult life. However, for families of children with disabilities, failing is often a right that families struggle to permit. I was born with an extremely rare disability called Congenital Myasthenic Syndrome, where my nerves and muscles do not communicate properly, causing extreme weakness. As a result, I use a power wheelchair, ventilator, and have 24-hour care. With the amount of care surrounding me, I could have practically lived my entire childhood without ever failing, but I'm so grateful I was allowed to.

Childhood and adolescence are tough, and when a disability is added to the equation, life becomes exponentially more difficult. I have found that adulthood can also be tough. Now there are less supports and more negative implications when I do fail. I am so grateful for the countless times that my parents let me find my own limits, make bad choices, and ultimately, pay for them. When I made poor decisions as a child, there were always people there to help me get straightened out and on the right path. I had the right to fail, safely. Those safety nets are not as readily available as a business owner, foster mom, wife, and homeowner. Even though those nets are not as frequently available as they once were, I have a lifetime of experience and wisdom that I have gathered from struggling and failing, which has allowed me to be where I am today.

In spite of my countless experiences with struggling and failure, I still fail regularly. However, I have learned that: failing at one thing does not mean that I am a failure, and the risk of failure does not outweigh the benefit of trying. •

ABOUT THE AUTHOR:

Dr. Josie Badger received her Bachelor's degree from Geneva College in Disability Law and Advocacy, a Master's from the University of Pittsburgh in Rehabilitation Counseling, and a Doctorate from Duquesne University in Healthcare Ethics. In 2012, Dr. Badger was crowned Ms. Wheelchair America. In 2014 Josie founded J Badger Consulting Inc. where she provides youth development and disability consulting services. She is the National Transition Director for SPAN Parent Advocacy Network, working with RAISE and the National Healthcare Transition Center for Youth with ID/DD. She is the Campaign Manager of the United Way of Southwestern PA's #IWantToWork Campaign, to improve the employment of people with disabilities, is the lead Field Organizer for the Family Care Act that supports paid family leave, and is the developer of TRAIL, a statewide advocacy and lobbying training program. She serves as the Secretary of FISA and co-chair of the Grants Committee. Josie recently founded PEACOCK a nonprofit that will further support the needs of the disability community and diversity, equity, inclusion, and access. With this new initiative, she hopes to be able to support the work of a new commission on men's mental health.

ACADEMIC DECLINE COULD BE A SIGN OF HEARING LOSS

SUBMITTED BY THE AMERICAN ACADEMY OF AUDIOLOGY

Children with hearing loss may struggle with their studies and may not be properly diagnosed

As children across the U.S. head back to school, the American Academy of Audiology recommends that parents and teachers pay close attention to children's hearing ability. Education is primarily delivered through auditory input and even a mild hearing loss can impact a child's success in school.

Children with untreated hearing loss use more cognitive energy to understand what is being said or may appear to not be paying attention because they are missing what was said. A drop in academic performance could be a sign of hearing loss. According to the National Institutes of Health's National Institute on Deafness and Other Communication Disorders, about two to three out of every 1,000 children in the United States are born with a detectable level of hearing loss in one or both ears. The total number of children with some type of hearing loss is unknown and many cases may go undiagnosed.

While most infants' hearing is tested within hours of birth, hearing loss can be progressive and start in early childhood. In addition, ear infections and exposure to loud sounds as well as various illness can cause hearing loss. The American Academy of Audiology recommends that any parents concerned with an otherwise unexplained decline in their children's academic performance or any sign of hearing loss should take them to an audiologist to have their hearing tested.

"Because children often don't realize they are missing information and may not communicate hearing difficulties, issues with auditory accessibility may go undetected," cautioned Virginia Ramachandran, Au.D., Ph.D., president of the American Academy of Audiology. "A child with minimal hearing loss may be missing a significant amount of the classroom discussion."

Children identified as having a learning disability may actually have untreated hearing loss. Hearing loss should always be ruled out when there are academic and speech and language issues. "We want to treat the hearing loss first since untreated hearing loss can disrupt all aspects of educational success," Ramachandran added.

In addition, a growing number of young adults are experiencing hearing loss from the use of personal listening devices and exposure to loud entertainment. In a study in the BMJ Global Health Journal in November 2022, researchers reported on hearing loss in young adults 12-34 years of age due to PLD's and loud entertainment venues, and concluded that more than 1 billion young people worldwide may be at risk of hearing loss.

Hearing loss in children and young adults can lead to behavioral issues, lack of focus, even depression. Children with hearing loss often don't recognize that they can't hear and parents may not know the signs.

> **“Children identified as having a learning disability may actually have untreated hearing loss. Hearing loss should always be ruled out when there are academic and speech and language issues.”**

HEARING LOSS : PARENTS AND TEACHERS MAY NOT KNOW THE SIGNS

Here are some of the signs parents and teachers should look for:

- ☐ Child has difficulty following through with assignments and often doesn’t seem to understand the task.
- ☐ Child often doesn’t understand questions and either does not respond or doesn’t respond appropriately.
- ☐ Child’s speech is different from other children the same age. He/she may struggle to pronounce simple words or is unable to repeat a phrase. May have problems articulating or may have language delays.
- ☐ Child often asks you to repeat things or watches your face intently trying to understand what you’re saying.
- ☐ Child has difficulty hearing on the phone.
- ☐ Child speaks loudly when not warranted.
- ☐ Child has chronic ear pain.
- ☐ Child often complains of noises he/she cannot identify.
- ☐ Child cannot keep up academically.
- ☐ Child appears exhausted at the end of the school day (more so than other children.)
- ☐ Child may turn up the volume on the computer, headphones or television so that it is louder than normal.
- ☐ Child appears to not be paying attention or ignoring people speaking to them.
- ☐ Child favors one ear over the other when using the phone, when choosing a seat, or when responding to questions

“Parents and teachers don’t always realize that a child’s behavior may be a sign of hearing loss,” Ramachandram. “If parents suspect an issue, they should have their child evaluated by an audiologist. Audiologists have the tools and training to identify hearing loss, degrees of hearing loss, and can recommend solutions for children of any age.” •

The American Academy of Audiology provides a list of licensed audiologists on its website at **www.audiology.org**

ABOUT THE AMERICAN ACADEMY OF AUDIOLOGY

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The American Academy of Audiology is the world’s largest professional organization of, by and for audiologists. Representing the interests of audiologists and future audiologists nationwide, the Academy is dedicated to providing quality hearing care services through professional development, education, research, and increased public awareness of hearing and balance disorders. For more information, visit **www.audiology.org**

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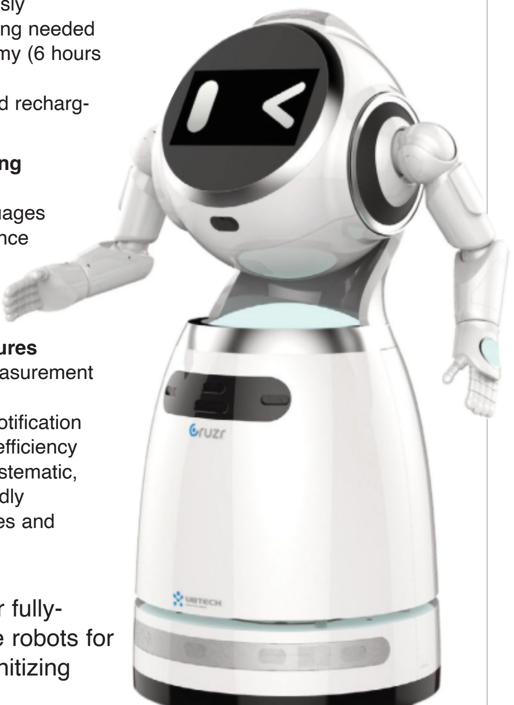

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TOILET TRAINING TIPS FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

BY ALEECE FOSNIGHT, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, HAES

Raising a child with autism spectrum disorder (ASD) is a journey with many unexpected paths. One aspect that some parents raising a child with ASD experience, is prolonged toilet-training along with various difficulties.

Many children with ASD, experience incontinence due to the disconnect between the muscles in the bladder and the brain, leading to common delays in toilet-training. While this experience may not apply to all parents raising a child with ASD, for those who are seeking more nuanced instruction, begin with some of the starting points below.

GETTING THE JOB DONE : TOILET-TRAINING TIPS FOR CHILDREN WITH ASD

SET A CONSISTENT NIGHTTIME ROUTINE

Routine plays a vital role in toilet-training. This includes: the same activities each night, patterns leading up to bedtime, and giving your child clear and consistent cues when it's nearly time to go to bed. For example, 30 minutes before bedtime, start some quiet activities, like tidying up or reading books. Some parents may even opt to use timers during this period. Forming a pattern leading up to bedtime will start to make connections for your child that this is also a time to void. Introduce a new pattern to your child, to void one last time before being tucked in. While voiding right before bed does not guarantee there will be no accidents that night, it can help reduce the size of accidents, and introduce a healthy sleep hygiene habit.

KEEP TRACK OF YOUR CHILD'S NORMAL BATHROOM ROUTINE

If possible, keep a journal of how often your child goes to the bathroom throughout the day. This includes: what time they went, how much, and any other relevant details. Knowing roughly when and how your child uses the bathroom will give you an idea of when they might need to go again. This allows you to remind them that it may be time to use the restroom, before an accident occurs. If your child attends school or daycare during the day, ask if the teachers or aids could keep track of this, or when you pick up your child, check in to see the last time they voided at school. Tracking your child's bathroom breaks is not an exact science, but can serve as an orientation point for your bathroom schedule, for the remainder of the day. Don't forget to include your child in this activity, as well! Sticker charts or drawing in the journal will help your child feel a part of this routine, and have autonomy in toileting decisions.

FOCUS ON LIQUID AND FOOD INTAKE

Parents can provide their children with a healthy diet full of fluids and fiber in order to avoid constipation or worsening bladder issues. Consider getting a child-size water bottle, and encouraging your child to bring it along with them, throughout the day taking sips. By keeping your child hydrated with a water bottle, you are also encouraging good bladder health practices, and increasing the likelihood that they will have to void when prompted. It's important to stay away from highly sugary or caffeinated drinks, such as: juice, chocolate milk, tea, or soda, as these do not hydrate as well as plain water. Consider adding some fruit to make the water more flavorful, but don't cut the pieces too small, to avoid choking. If your child is having bowel-related problems, ensure that they are consuming enough dietary fiber to stay regular. Don't forget to incorporate the use of probiotics daily, to establish healthy gut bacteria for improved bowel movements. If the problem persists, it may be time to consult a dietician or nutritionist. Pelvic floor physical therapists can also serve as support for behavioral techniques during toileting.

WHERE TO TURN FOR EXTRA RESOURCES AND SUPPLIES

There are various products and devices to assist a child with ASD, with toilet-training. For starters, diapers and training underwear come in all sizes. Despite your child's age, there are diapers and training pants available in a size comfortable for them. If your child uses flash cards or visual supports in their communication, be sure to have a clear card or image for using the bathroom. As previously mentioned, the use of a bathroom journal, in addition to a food and drink journal, can help with tracking your child's bathroom use, as well as, food and liquids consumption. Sometimes, the best learning tools are books and stories. With no shortage of toilet-training books on the market, feel free to incorporate story time into your toilet-training.

IN CONCLUSION

Toilet-training is a natural part of childhood. For parents raising a child with ASD, toilet-training can take longer, with testing periods of different patterns and practices. Don't forget, toilet-training regression is completely normal and natural. Toilet-training, like learning the colors, eating vegetables or brushing hair, will look different for every family and every child.

Experimenting and patience are key. If your child's toilet-training difficulties persist, consider meeting with a urologist to explore options available. Supporting your child during the process can be hard and frustrating. Be sure to surround yourself with people that will support you and your self-care. •

ABOUT THE AUTHOR:

Aleece Fosnight, MSPAS, PA-C, CSC-S, CSE, NCMP, IF, HAES is a board-certified physician assistant specializing in urology, and a Medical Advisor for Aeroflow Urology (**https://aeroflowurology.com**).

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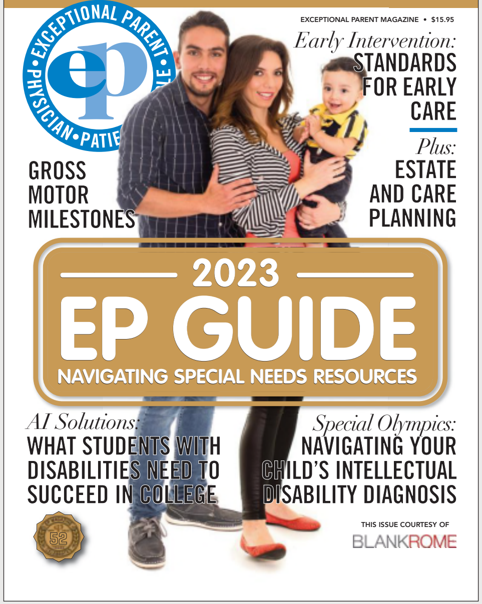

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MILITARY SEPARATION AND RETIREMENT

AS AN ACTIVE-DUTY SERVICE MEMBER, YOU RECEIVE NUMEROUS BENEFITS. WHAT HAPPENS TO THEM WHEN YOU RETIRE?

Transitioning to civilian life is just like everything else in military life. The more preparation you do, the more smoothly everything goes. Whether you're moving on after one tour of duty or you've put in 20 years or more, you have a lot to do as you bring your military career to a close.

KNOW YOUR SEPARATION REQUIREMENTS

Your first step should be connecting with the Transition Assistance Program of your service branch. Here, you'll find detailed information about what's included and how to connect with your service branch's program. Make sure you schedule your pre-separation counseling no fewer than 90 days before separation. Arrange your final medical exam. Attend an employment workshop. Give yourself time when scheduling your final move.

PLAN YOUR POST-RETIREMENT BUDGET

Review your military retirement pay, benefits and expenses to plan your budget and calculate what you'll have each month, including your monthly retirement pay. Remember that federal and state taxes will be withheld from your retirement, and just like your active-duty pay, your retirement pay adjusts annually based on cost of living to protect your income against inflation. Find out if you qualify for the one-time lump sum payment for Disability Severance Pay by visiting the Defense Finance and Accounting Service website at **www.dfas.mil/retiredmilitary/plan/separation-payments/disability-severance-pay/**

LEARN ABOUT THE BENEFITS YOU'VE EARNED

As an active-duty service member, you receive numerous benefits. What happens to them when you retire? It can vary greatly.

Keep your health care: Effective Jan. 1, 2018, you must enroll yourself and eligible family members in TRICARE or risk losing your benefit.

Make your last move count: You have one calendar year from your retirement date to use your last government-paid move anywhere within the U.S. or to your home of record outside the country.

Plan for life insurance: Your Servicemembers Group Life Insurance plan continues uninterrupted for 120 days after separation.

Use your GI Bill: You have up to 10 or 15 years after separation to use your GI Bill (depending on the program).

HELPFUL LINKS

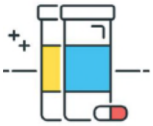
Military Compensation; Basic Pay: This site provides information about military compensation, including paygrades for active-duty and reserve pay, allowances, annual pay adjustments,

TRANSITIONING SERVICE MEMBERS : MUST-DOS FOR SEPARATING

You've made the decision. Now it's time to make the most of it. There's a list of tasks to accomplish, and most of them come with a due date:

DO get your plans in place. Think about your post-military goals and the income you'll need. Start researching how your military experience could translate to a civilian career. Attend the Transition Assistance Program to learn the benefits and resources available to help you and your family prepare for a successful transition.

DO start TAP early. You must complete a mandatory initial counseling session with a transition counselor and complete pre-separation counseling no less than 365 days prior to your separation or retirement date. During TAP, you'll also receive briefings and resources from the Defense Department, the Department of Veterans Affairs and the Department of Labor. For extra assistance in your transition, check out Military OneSource's specialty consultation for transitioning veterans. And remember, you can attend TAP more than once!



DO schedule a final separation health assessment and dental exams. You'll need a mandatory, final medical and dental exam with your installation's medical clinic no later than 90 days before you separate. The SHA may be used to file a VA disability compensation claim.

DO schedule the move of your household goods. The earlier, the better. You'll have one year after leaving active duty to complete your final move. The sooner you can schedule, the better your chances of getting the dates you want.

DO talk to your spouse about participating in the Military Spouse Transition Program and the self-directed MySteP: Stepping Beyond. This program is designed to guide military spouses through the military to civilian transition, including post-military benefits, health care, finances and transition training.

Finally: DON'T wait until the last minute. Give yourself plenty of time to complete all the tasks required. You must complete some tasks 365 days before you separate. Also, some benefits have a timeline in which to be used.

the Blended Retirement System and benefits, including those for survivors. It also includes answers to frequently asked questions regarding military compensation. www.militaryonesource.mil/benefits/military-compensation

TRICARE Reserve Select: A premium-based health plan for selected reserve members (and their families) who qualify. Purchasing TRICARE Reserve Select is a two-step process. Individual Ready Reserve members, including Navy Reserve Voluntary Training Units, do not qualify. www.militaryonesource.mil/benefits/tricare-reserve-select

Montgomery GI Bill Selected Reserve: Offers up to 36 months of education and training benefits. If you're a member of the Army, Navy, Air Force, Marine Corps or Coast Guard Reserve, Army National Guard or Air National Guard, you may be eligible for MGIB-SR. www.militaryonesource.mil/benefits/montgomery-gi-bill-selected-reserve

Find Your Installation Relocation Assistance: Whether you're planning a move to your next installation or want to know more about your current duty station, MilitaryINSTALLATIONS, one of many free resources from Military OneSource, is the place to get answers. Use it to find installation overviews, contacts for programs and services, check-in procedures and community information for installations worldwide. www.militaryonesource.mil/benefits/militaryinstallations-relocation-assistance

Veterans Affairs Life Insurance: VA life insurance can offer financial security for veterans, service members and their spouses and dependent children. www.militaryonesource.mil/benefits/veterans-affairs-life-insurance

FURTHER READING

Re-enlist, Reserves, or Transition? 4 Things to Consider: Maybe you're just ending your first tour of duty. Maybe you've fulfilled your obligation to your country. Now, you're at a crossroads – re-enlist, reserves, or transition out? How do you know you're making the right call? www.militaryonesource.mil/transition-retirement/separation/re-enlist-reserves-or-transition-4-things-to-consider

Make Your Final Military Move a Success: During your military career, you've probably moved a few times – each one a new adventure. For most service members leaving the military, either at retirement or at their end of active service separation, a final move at government expense is authorized. Make your final move the easiest one yet with these tips. www.militaryonesource.mil/moving-pcs/plan-to-move/make-your-final-military-move-a-success

Life Insurance Needs Calculator: Answer a few simple questions to estimate the amount of life insurance coverage you need to take care of your family.

TRICARE Retiring: You have 90 days after your retirement date to enroll in a TRICARE health plan. You may also qualify to enroll up to 12 months after retiring from active duty. www.tricare.mil/LifeEvents/Retiring

GET CUSTOMIZED SUPPORT

You want your transition out of the military to go smoothly. Take advantage of the professional assistance provided by Military OneSource for service members and military spouses. You can receive personalized support to help you navigate the resources, benefits and programs available to you and your family.•

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Connect to Protect:
Support is Within Reach

September 2023

Suicide Prevention Month

How You Can Help?

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U.S. MILITARY ★ BOOK EXCERPT 10TH OF A SERIES

THE RESILIENT WARRIOR

NINJUTSU: THE ZEN SIDE OF WARRIOR LIFE

BY STEPHEN SUCHY

Book Editor's Note: Featuring self-help, mental health, and mind and body tactics from a variety of sources – veterans, former and active U.S. Marines, Navy, Army Rangers, Green Berets, family members and caretakers – ***The Resilient Warrior*** *is collaborative collection providing needed wisdom for complete well-being for all of us. The first step to thriving is surviving, and the first step to surviving is knowing how to get what you need, when you need it. The following excerpt of this essential self-help guide to living a healthy, resilient, fulfilled and better life is the tenth in a series that EP Magazine has featured over the last several months.*

Cultivate your passion and channel your energy into a productive art that enhances your clarity, and brings peace to your everyday life. From PT to 5Ks, every veteran knows that working out can be one of the best outlets for the mental challenges that comes with service. However, after years of martial arts training and meditation, I discovered working out was my form of self-medication to block out the anger I'd been holding onto well before I became a Marine.

At 13 years old, I had the unfortunate experience of finding my father dead of a heart attack. I attempted to give him CPR, not knowing my attempts were futile, and immediately became an extremely angry young man. I didn't realize why I was so mad, though it was probably so clear to everyone else. All I knew was that I couldn't focus enough to do anything, or sleep at the end of the day, unless I was exhausted.

I started working out before school, going to football practice after school, and heading back to the gym after dinner, for another two-hour session, usually riding my bike there and back. After getting through some homework when I got home, I would collapse into bed, completely exhausted. I kept the two to three workouts a day routine, throughout high school, and joined the Marines in my junior year, after being inspired by classmates who had joined up. I found my training at Camp

Lejeune challenging, and I loved that they worked me out until exhaustion, particularly at boot camp. But, I would often head back to the gym at night to get in a few more hours.

I was fortunate that there were no wars when I was in the Marines, but I volunteered for any training I came across, such as advanced communications and martial arts. I had found a connection with martial arts and never stopped training in it, throughout active duty. When I went back to New Haven and enrolled in college during my time in the reserves, I continued my martial arts training in Shotokan karate. I competed on my college team, and sought more ways to exhaust my body, to ensure some form of sleep.

In 1982, I was hired as a police officer and continued to feel the need for pre-sleep exhaustion, but now, on a rotating schedule. Throughout my career as a direct first responder, I came across a lot of horrific things, from suicides to confrontations on SWAT, to children who lost their lives tragically: all of which increased the PTSD, that likely started when my father died.

A few years and two kids later, I inadvertently found a new level of martial arts training in ninjutsu, when my children questioned one of my friends about his "ninja" training, that he was explaining to them. After heading to the club where my friend trained, I quickly learned his sensei, Greg was one of the best martial artists I had ever found or met. Greg is the one who started my Zen training. He's a warrior, but he's also a hippie. According to Greg, you become the best warrior you can, so you don't have to hurt anyone. Peace through superior power. Walk away if you can, but if you can't, learn how to win (but only when absolutely necessary).

Our nightly training included everything from stretching and technique, to meditation and breathing exercises, sometimes in the middle of sparring. When you slam pause on your movement as you're pumping with adrenaline, you learn how to get quiet, make things disappear, calm your body. This self-regulation of adrenaline was something that transferred to my police work. It helped slow my movements, especially during SWAT calls to navigate situations.

Ninjutsu is the art of war. It's not your average martial arts class. There is always inner meditation, slowing down, listening, and having a Zen element to your warrior experience: listening to your world, internally checking in with your body, breathing, heart rate, etc. If you become part of the attack, it can't hurt you. The same goes for mental anguish.

Ninjutsu has taught me: whether a physical or a mental threat, identify it, accept it, and get rid of it. When working out your body, it is equally important to connect with your mind. The meditative aspect of martial arts allowed me to become a better person, and started me down a path of inner peace.

Maybe eight or nine years after getting into the meditative warrior concept, Greg brought us on a 48-hour woods meditation retreat, in northern Pennsylvania. You picked a tree in the woods, Greg drew a circle around it, and you were not to leave the circle except to go to the bathroom. All I had was water… and my thoughts. I thought I knew how to breathe and meditate and quiet my thoughts. I thought I'd been doing that all along, but it was only after the first 24 hours or so, after I had thought about anything and everything, that my mind truly quieted, and I began to deal with my feelings, particularly the death of my father. This experience by myself ,put cracks in my bubble, and I started getting better from then on.

A few months later, I was on a midnight shift in the dead of winter. It was so peaceful as I sat in my cruiser and looked out over New Haven, when it just hit me. I was pissed that my father had died. I was an absolute mess for a day or two, really letting it sink in, that I had been holding onto so much anger at his

THE ART OF MINDFULNESS: "Martial arts kept me going and was my life saver. But ultimately, it was meditation that broke that bubble of anger. "

death. The 48 hour meditation was the catalyst for this realization, and I finally realized why I'd worked myself to exhaustion for so many years. I think I've been improving who I am since then. Society's increasing openness to counseling for police and other first responders, allowed me to be more open. If I see something horrible, I deal with it emotionally, because everyone gets injured from that exposure, even if you don't realize it at the time. I'm still dealing with stuff, but now on a much more open level, and I can express those emotions more now.

Martial arts was the drug that kept me sane, but at times, overtraining prevented me from dealing with what I truly had to deal with. It kept me going and was my life saver. But ultimately, it was meditation that broke that bubble of anger. Greg was always there to point me in the right direction. Spiritually, I got better with church when I met my wife. Faith gives me another source of strength, in addition to meditations and the Zen I find through martial arts.

If you don't unearth your mental pain, the physical work you put in won't be as beneficial for processing your actual problems. Workouts kill the pain, but somewhere in there, a system of Zen meditation is the key to unlocking that peace, and bringing you back into your own self, your own world, and that's where you ultimately have to be to get growth. •

ABOUT THE AUTHORS:

Stephen Suchy joined the US Marines October 28, 1975 and served three years active duty. He spent four years in the reserves, while finishing college. In 1982, he became a police officer and worked as a patrolman until 2009. As a dedicated first responder for his whole career, he also served as a SWAT officer for 24 of his 28 years of service. In 2009, Suchy retired from the department and became a state investigator for the public defender's office, serving his first 10 years in a major CT city. He was promoted to an investigator with the CT Innocence Project, a subunit of the public defender's office that investigates cases of those serving life in prison for murder.

Nick Benas grew up in Guilford, Connecticut. The author of *Mental Health Emergencies, Warrior Wisdom, Tactical Mobility,* and co-author of *The Warrior's Book of Virtues,* Benas is a former United States Marine Sergeant and Iraqi Combat Veteran with a background in Martial Arts (2nd Dan Black Belt in Tae Kwon-Do and Green Belt Instructor in Marine Corps Martial Arts Program). Nick attended Southern Connecticut State University for his undergraduate degree in Sociology and his M.S. in Public Policy. He has been featured for his business success and entrepreneurship by more than 50 major media outlets, including *Entrepreneur Magazine, Men's Health,* ABC, FOX, ESPN, and CNBC.

Richard "Buzz" Bryan is currently the Outreach Coordinator for the West Palm Beach VA medical center. The co-author of *The Warrior's Book of Virtues,* Buzz previously served as the OEF/OIF Transition Patient Advocate (TPA) for the Veterans Integrated Service Network (VISN4) based in Pittsburgh, PA for ten years, working specifically with Iraq and Afghanistan veterans. Buzz was a member of the Navy/Marine Corps team and retired from the United States Navy in July 2011 after 22 years of honorable service as a Fleet Marine Force Senior Chief Hospital Corpsman.

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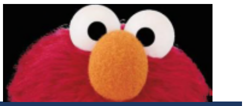

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SESAME STREET

Say Cheese

About two weeks ago, Mark realized that Broden's military ID card expired. If you do not have a military ID card, you can't get on the installation, and you can't access healthcare.

About five years ago, my entire family rented a house on the southern tip of the North Carolina coast to celebrate our parents' 50th wedding anniversary. I have fond memories of that vacation, because it is a rare occurrence these days to have everyone together under one roof. To instill our time together, my sister-in-law, Melissa, contacted a photographer and scheduled a time to meet us on the beach for a few pictures. Of course, there was a color theme assigned to everyone in the family. We were instructed to wear a shade of blue and the males were to wear khaki shorts, and if not in a blue sundress, the females wore white jeans. Everyone followed the assignment religiously, and our family was ready for a photo shoot fit for the latest coastal tourist guide.

THE REAL BRODEN: "The photographer said you can see his iPhone in the picture. I looked at Mark, 'Well, then that is the perfect picture. We'll take it.'"

Once the photographer met us at the beach, Melissa greeted her and told her everyone was here for the photo shoot. Melissa then discussed with the photographer that she wanted pictures with each family entity, and then all of us together. I stood back and watched Melissa work. Our side of the family is not known for their photogenic qualities, unlike my brother, Shaun's side of the family. The first group, Shaun's family, knocked it out of the park. They were professionals. Shaun's children were leaping into the air and performing beautifully. The photographer would say, "Yes! Just like that! Do that again. Beautiful. Fantastic. Yes!"

The photographer looked over at Mark and me, "Ok. You're next." I looked at Mark uncomfortably and said under my breath, "This is going to suck." I looked at Broden and said, "We're just going to take a few pictures, and then you can take a break." He clasped his iPhone in his hand and shrugged his shoulders up yelling, "Say cheese!" Mark and I looked nervous, and painfully smiled. The photographer sounded less enthusiastic with our family, "Ok. Well, can he move his iPhone down a little? Hayden, can you bring it in a little bit? Ok, alright. I think I got a few that we can work with." I wanted to cry. Well, jealously, I first wanted to tell my brother and his wife that they suck, and then I wanted to cry.

After she took some pictures of my parents, we then squeezed in together to get a few shots of us under the pier. Broden screamed, "Say cheese!" I think there was some talk of

PHOTOS PROVIDED BY SHELLY HUHTANEN

photoshopping his best smile, if needed. His iPhone was in just about every photo. Mark reminded me that this task was a lot to ask of Broden, and in all fairness, he did pretty well. After the fifteenth picture, I looked at Hayden. I think he wanted to rip his shirt off and run into the ocean. Hayden kept it together, and for that, I'm grateful. I was exhausted from keeping Broden together, and I don't think I had enough energy to appease two children.

The pictures were posted online and of course, Shaun and Melissa's pictures were tourist catalog ready. My parent's pictures were beautiful. Mark and I were able to pick out a few that could make it on a Christmas card. I told my mom of what I thought of the photoshoot. She had picked out a picture of all of us together, and had a huge print made. She hung it in their dining room. When I saw it, I was checking to see what Broden looked like in the photo, and to see if you could see his iPhone. Mom said, "Shelly, who cares if you see Broden's iPhone. That's Broden. I love it." I realized at that moment; it really didn't matter what he had in his hand. What mattered was that everyone was together, and we were able to capture that moment to enjoy, for years to come.

About two weeks ago, Mark realized that Broden's military ID card expired. If you do not have a military ID card, you can't get on the installation, and you can't access healthcare. In the military world, it's a big deal if you have an expired military ID card. The ID card office was able to squeeze Broden in the next morning, to update his card, and updating his picture was part of the process. When the office opened, it was crawling with people. I stopped Broden in the hallway, and Mark ran into the crowded office to find someone to work with us. Mark stuck his head out the door and waved us into the large room separated by cubicles. I had ahold of Broden's shoulders and helped navigate him through the crowded room. There was a gentleman in the back ready to work with us, "Broden has autism. You need to be quick with pushing the button to take the picture." I could feel the walls closing in on us, as more people shuffled into the office. It was getting louder, and I was afraid it would be too much for Broden.

Broden sat in the chair across from the camera. I stood next to him to help guide him through the picture. Mark stood across from us and next to the camera, to encourage Broden to look forward. The gentleman taking the picture said, "Ok, I'm ready." Mark hung over the top of the camera, "Ok Broden smile!" Broden yelled out, "Say cheese!" and then moved away from the camera. The gentleman looked over and said, "I missed it. He moved away." I snapped "You must be quick! You must push the button faster." Mark reminded me that the system to make these ID cards is slow, and that it may take some time to get a good picture.

After two more failed attempts, Broden was getting annoyed at the whole process. He started to squirm, and asked to leave and go back to the car. I looked at him, "One more time and this is it." Mark leaned over the camera and yelled, "Look at me!" I crunched down next to him just out of of the camera's view and yelled, "Cheeeeeeeeeeeese!" I yelled the word "cheese" for about 10 seconds. The gentleman smiled and said, "I think we got it. He's looking into the camera, but you can see his iPhone in the picture. I looked at Mark, "Well, then that is the perfect picture. We'll take it." •

OUR JOURNEY IN CAMO

Shelly Huhtanen is an Army wife stationed at Fort Jackson, SC. She enjoys sharing her experiences of her day-to-day life caring for her son with autism. Shelly authored ***Giving a Voice to the Silent Many*** that encompasses many stories of raising a child with autism in the military. She also teaches Public Communication at the University of South Carolina and has contributed to *EP Magazine* for over 10 years.

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