AGING AND DOWN SYNDROME

A HEALTH AND WELL-BEING GUIDEBOOK

ALZHEIMER'S® ASSOCIATION

national down syndrome society ndss®

ntg National Task Group on Intellectual Disabilities and Dementia Practices

The first edition of the *Aging and Down Syndrome: A Health and Well-Being Guidebook* in 2011 was dedicated to Jane Davey Hamilton, her son Peter, and her legacy of devotion to him.

This second edition of the *Aging and Down Syndrome: A Health and Well-Being Guidebook* is dedicated to Joseph E. Ransdell.

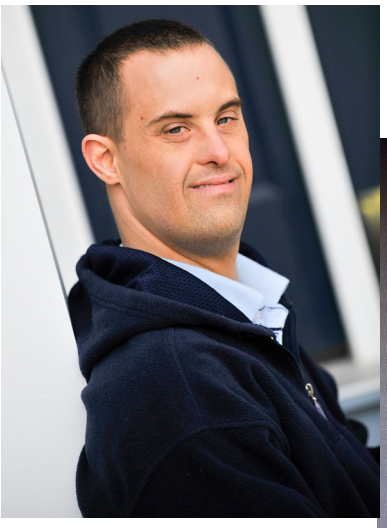


TABLE OF CONTENTS

ACKNOWLEDGEMENTS

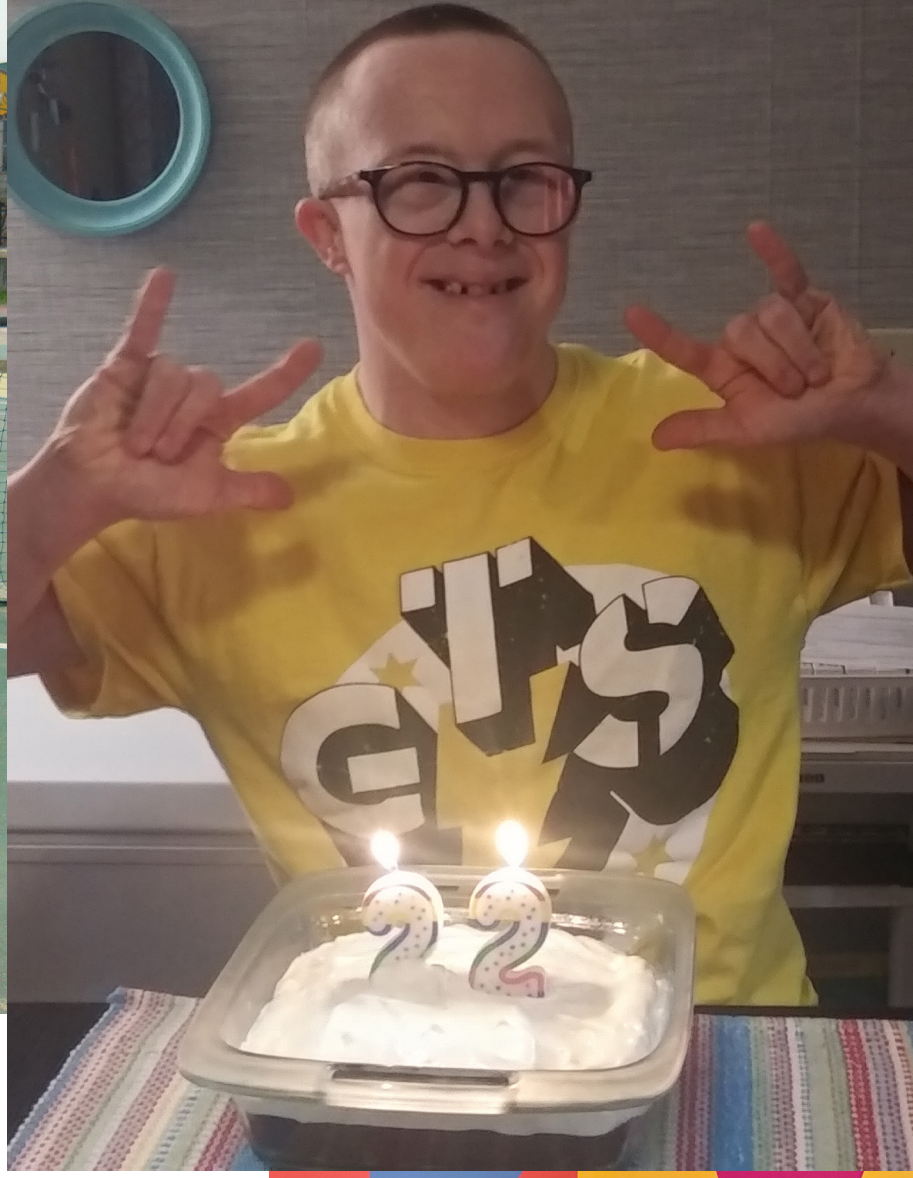
LEAD AUTHOR, JULIE MORAN, DO

Dr. Moran is a board-certified geriatrician/internist specializing in older adults with intellectual and developmental disability (I/DD). Dr. Moran is an attending physician for the specialty inpatient unit at Tewksbury Hospital serving adults with I/DD and also runs a busy statewide outpatient consultation service for older adults with I/DD through the support of the Massachusetts Department of Developmental Services (DDS). Dr. Moran is a Clinical Instructor of Medicine at Harvard Medical School and participates in the teaching and training of geriatric medicine fellows, residents, and students.

ADDITIONAL CONTRIBUTORS

Dr. Moran and the National Down Syndrome Society (NDSS) extend their thanks and gratitude to the dedicated working group who helped make this guidebook possible: Jane Boyle; Brian Chicoine, MD.; Katie Frank PhD, OTR/L; Teresa A. Galbier, MPA; and Ley Linder MA, M. Ed., BCBA.

Design by dosidodesign.com



THE GOALS OF THIS GUIDEBOOK

- **To provide guidance, education, and support to families and caregivers of older adults with Down syndrome.**

- **To prepare families and caregivers of adults with Down syndrome for the medical, functional, emotional, and psychosocial needs that may be encountered as they age.**

- **To empower families and caregivers with current information so that they can take positive action over the course of the lifespan of adults with Down syndrome.**

INTRODUCTION

In recent decades, adults with Down syndrome are living into their 50s, 60s, and beyond, reaching new and exciting milestones in older age.

AGING SUCCESSFULLY can be accompanied by challenges and obstacles for which adults with Down syndrome and their families and caregivers may feel inadequately prepared. Learning more about aging and the common concerns that may arise in later life can help individuals feel ready for what lies ahead. This guidebook aims to provide education and practical guidance for individuals with Down syndrome to more confidently prepare for a healthy adulthood into old age.

CONCEPTS OF AGING WITH DOWN SYNDROME

Adults with Down syndrome experience a phenomenon of "accelerated aging," meaning that certain conditions and physical features of aging arise at an earlier age than would typically be seen in the general population.

PART OF THIS PROCESS is rooted in the unique genetic changes that cause Down syndrome. Down syndrome, or trisomy 21, is characterized by an additional or partial third copy of the 21st chromosome, which also is associated with various genes affecting the aging process. The additional copy of the 21st chromosome plays a role in the emergence of premature aging as well as other alterations in the immune system impacting aging.

Generally, the effects of accelerated aging can be seen medically, physically, and functionally in individuals with Down syndrome. To family members and caregivers this might be observed as a general "slowing down" as individuals grow older. In addition, it is common for features of aging such as cataracts, hearing loss, or arthritis to develop earlier than what would be expected for their chronological age.

Complicating this picture is the fact that “normal aging” in adults with Down syndrome is not something that is neatly and predictably defined. Like all adults, they feel and express the effects of aging differently, so there is no exact timeline that can forecast these changes. In contrast, it is not typical, normal, or expected to experience a sudden, dramatic, or rapid decline with age. These scenarios should always prompt further investigation and evaluation to uncover a root cause of these changes. In general, it is important to watch for any early changes or differences in individuals with Down syndrome as they grow older and to seek further help as needed.

SETTING THE STAGE FOR SUCCESS

Building a solid foundation of healthy living throughout adulthood is important for optimizing physical, emotional, spiritual, and social health and minimizing illness and conditions that can affect adults with Down syndrome at a younger age than typical adults. These conditions include but are not limited to, obesity/overweight, sleep disorders, and mental health issues.

ADULTS WITH Down syndrome may face additional barriers to good health like poor or limited opportunities for physical activity, limited options for social and leisure activities, poor eating habits, limited access to healthy and nutritious food options, and limited education on basic nutrition. Thus, embracing a healthy lifestyle that emphasizes good nutrition, exercise, and overall mental and physical well-being may help to reduce the risk factors that lead to poor health.

** For more information on suggested programs, please see the Resources page.*

HEALTHY LIFESTYLE HABITS TO CONSIDER

• Follow a heart-healthy diet with a variety of nutritious foods to maintain a healthy body weight.

• Aim to get regular physical exercise including cardiovascular (aerobic) exercise to help maintain healthy circulation, weight-bearing/strength training exercise to help maintain and improve bone health, flexibility to improve posture and muscle coordination, and balance to improve the ability to control and stabilize the body.

• Find activities that are enjoyable and can be easily incorporated into a lifelong routine or habit.

• Develop healthy sleep habits and routines to achieve restful and restorative sleep each night.

• Be watchful for symptoms of disordered sleep such as sleep apnea (see page 19). Seek help in diagnosing sleep dysfunction early to work towards optimizing overnight sleep quality.

• Keep an eye out for changes in mood and emotional health and address concerns early. Look for resources like NDSS' *321go!* program to help with processing feelings, sharing emotions, building coping skills, and managing stress.

HEALTHY LIFESTYLE HABITS TO CONSIDER

FOLLOW A HEART-HEALTHY DIET

KEEP AN EYE OUT FOR CHANGES IN MOOD AND EMOTIONAL HEALTH

GET REGULAR PHYSICAL EXERCISE

DEVELOP HEALTHY SLEEP HABITS

VISIT A DOCTOR REGULARLY

AVOID SOCIAL ISOLATION, LONELINESS, AND BOREDOM

WATCH FOR DEFICITS IN HEARING AND VISION

STAY ENGAGED IN A WIDE VARIETY OF ACTIVITIES

LEARN NEW THINGS AND TAKE ON NEW CHALLENGES TO HELP STIMULATE LIFELONG LEARNING AND GROWTH

• Watch for any evidence of deficits in hearing and vision, and seek out help in evaluating and addressing any changes in ear or eye health and function.

• Avoid social isolation, loneliness, and boredom.

• Stay engaged in a wide variety of mentally stimulating, pleasurable, and fun activities. Aim to learn new things and take on new challenges to help stimulate lifelong learning and growth.

• Seek out activities that are recreational, social, and fun, especially those that help build and strengthen friendships and connections with the community.

• Keep up with health maintenance and screening guidelines for adults with Down syndrome.

ASSEMBLING YOUR TEAM

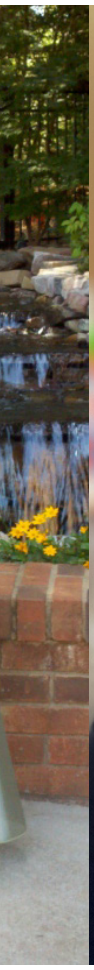
There are many steps to good health that individuals, families, and caregivers can seek out and create for themselves, and it is empowering for adults with Down syndrome to make their own positive personal changes in this regard.

IN ADDITION, lifelong health also depends on a network of support that extends far beyond the individual. This 'team' should include members who all play various roles in supporting the well-being and health of an individual with Down syndrome throughout their life.

A strong team includes health care professionals and other trusted care providers and supports. One cornerstone of a medical care team is the primary care provider who may be a physician (MD or DO), a nurse practitioner, or a physician assistant. The roles and specialties of the other members of the care team can vary depending on individual needs and concerns. The team can include medical subspecialists such as gastroenterologists, psychiatrists, cardiologists, social workers, physical therapists, occupational therapists, speech therapists, art therapists, massage therapists, counselors, psychologists, behavior analysts, and dieticians.

In addition to medical providers, specialists, and other health professionals, the team can also include professional, personal, and community-based support. A true team is often many layers deep, consisting of caregivers, friends, relatives, support groups, members of a spiritual/religious community, state or agency support staff, day program staff, volunteer/employment staff, colleagues, etc. Building this network takes time, and the process usually changes and evolves. Proactively adding team members over time helps ensure care is being adapted to suit an individual's needs.

For many families and caregivers, assembling a team for an adult with Down syndrome is much easier said than done. There are often significant challenges to finding medical providers with the knowledge, confidence, comfort, and expertise to care for adults with Down syndrome. Providers with dedicated expertise can be few and far between, and this can make the transition process from pediatric to adult services a particularly daunting one. The process of finding adult providers who are a good fit for an individual may take time and some trial and error, but it is important to connect with other families and caregivers



to help share resources. In general, it is helpful to find a provider who is a good communicator, who seems adaptable and open to collaboration with the care teams and other colleagues, who is open to learning about Down syndrome, and who portrays a sense of comfort and ease during in-person encounters.

There are online resources that can be helpful in identifying providers, and specialists for adults with Down syndrome, and there are now innovative clinical programs available with remote or virtual access to leading experts who can provide input, especially in areas where specialists are very limited or non-existent in number.

WHAT TO BRING TO THE DOCTORS/WORK/ DAY PROGRAMS/COMMUNITY HOMES

- Updated medication list with dosages
- List of all medical providers and contact information
- List of health conditions/ diagnosis and year of diagnosis
- List of vaccinations
- List of hospitalizations
- List of surgeries
- List of dietary restrictions
- List of allergies
- A symptoms journal
- GLOBAL Medical Care Guidelines for Adults with Down Syndrome

COORDINATION OF CARE

For people with Down syndrome, the need for support is a lifelong reality that evolves and changes based upon multiple factors.

CARE COORDINATION is a term that broadly refers to the collaboration, communication, and teamwork that is essential to maintaining health and well-being. Successful care coordination is a highly engaged, proactive process that involves those who are most closely connected with an individual with Down syndrome. Effective care coordination should be timely to avoid any serious, preventable communication gaps or errors, particularly when multiple people are involved and when decisions or changes are being made quickly or simultaneously.

For this reason, it is important for key family members, caregivers, and any other relevant team members to stay actively engaged in the coordination of care.

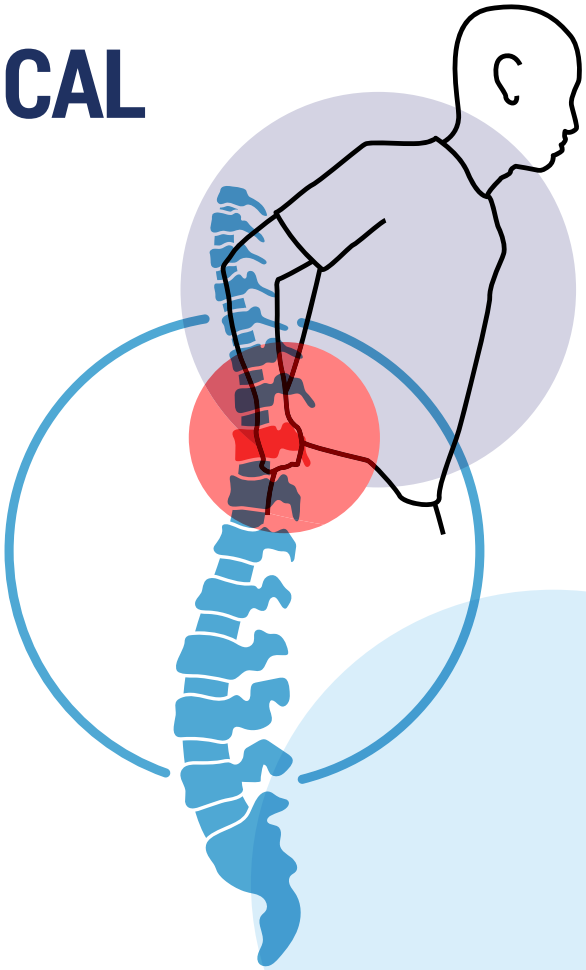
Tasks may include facilitating communication across various settings and in various scenarios, like sharing information between a workplace or day program and a community residence or family home. In medical settings, coordination of care may consist of providing an updated medication list at all healthcare appointments and cross-checking medication lists to ensure information is updated and accurate across settings.

Routine tasks of care coordination can occur on a daily basis through family or care team members communicating and sharing day-to-day information. At times of change, such as in the setting of an acute illness or hospitalization, a move between living environments, or the loss of a loved one, care coordination and communication are even more critical.

In these scenarios many changes may be happening at the same time, and information may be changing rapidly with the involvement of multiple networks of people. For example, during a hospitalization, there may be updates during a short period of time. Clear coordination of care becomes important during these times of change or transition to help keep the individual with Down syndrome thriving. A proactive approach is especially helpful, as there is usually a large amount of information being exchanged, and it is important to take an active role in ensuring that there is clear communication and that team members are on the same page.

**For more information on suggested programs, please see the Resources page.*

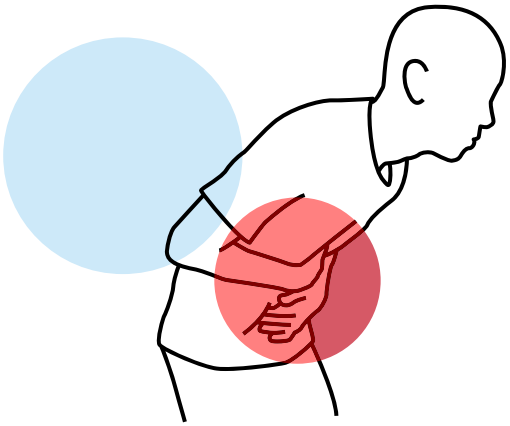
COMMON MEDICAL CONDITIONS



There are many medical conditions commonly encountered in individuals with Down syndrome throughout adulthood and into old age.

OVER THE PAST several decades, awareness of these common concerns has grown, leading to earlier screening and detection. For those with limited access to quality medical care, however, common medical problems or concerns can remain undetected or undiagnosed until much later in life.

To proactively support healthy aging, it is important for caregivers, families, and loved ones to be aware of the various health concerns an individual with Down syndrome may encounter throughout the lifespan. The aim of the following section is to help empower, not overwhelm. This extensive list of common conditions seen in adults with Down syndrome provides an overview to help raise awareness and to encourage further discussion with health care providers as appropriate.



Celiac Disease

Celiac disease is a condition where one's body cannot digest wheat gluten and wheat products, causing an immune response that damages the lining of the small intestine and prevents absorption of certain nutrients.

When celiac disease is present, it can cause gastrointestinal distress, nutritional deficiencies, and sometimes more vague symptoms like general irritability or increased negative behaviors.

There is a higher risk of this condition in individuals with Down syndrome. Signs and symptoms suggestive of celiac disease include fatigue, irritability, anemia, stomach distress, and unexplained weight loss. Celiac disease can be screened for initially by a blood test but requires a biopsy and evaluation of the small intestine to confirm the diagnosis. A discussion with the primary care provider is recommended, which may lead to a visit with a gastroenterology specialist to help formally make the diagnosis. Celiac disease is usually primarily treated with a wheat-free and gluten-free diet.

Cervical Spine Disease

The region of the spine located in the neck is called the cervical spine. In individuals with Down syndrome, there is increased risk of instability between the "atlas" and the "axis," the first and second spinal bones in the cervical spine that are located directly below the base of the head. This condition is known as atlantoaxial instability. If instability is present and arthritic changes occur in the spine, there is an increased risk of damage to the spinal cord in that region. Atlantoaxial instability can develop at any time in life, even if previous exams and x-rays were negative.

In older adults with Down syndrome, it is common to see generalized arthritis and degenerative changes throughout the cervical spine. This can contribute over time to more severe arthritic changes in the bones of the spine that then start to affect the underlying spinal cord. Spinal stenosis is the condition that occurs when the cord is compressed. Cervical myelopathy occurs if it is significantly compressed and there is pain and associated changes in one's coordination, motor function in the upper and lower extremities, and other bodily functions (incontinence).

Caregivers should be watchful for any patterns of change in walking, coordination, balance, or new incontinence, as these could suggest the presence of cervical spine disease. Any spinal health concerns should be discussed with a primary care provider.

Dental Disease

Adults with Down syndrome can experience a wide range of dental issues, including periodontal disease and cavities. This is due to a range of causes including poor oral hygiene, abnormalities with closure of the mouth, and irregularities in tooth formation.

There are widespread disparities in access to dental care for people with intellectual disabilities. It can be challenging to find a provider who has expertise or comfort in treating patients with Down syndrome, many of whom struggle to tolerate routine dental care. Good, consistent home-based oral hygiene practices are very important to maintaining oral health, along with regular routine visits to a dental provider for a more detailed evaluation.

Diabetes

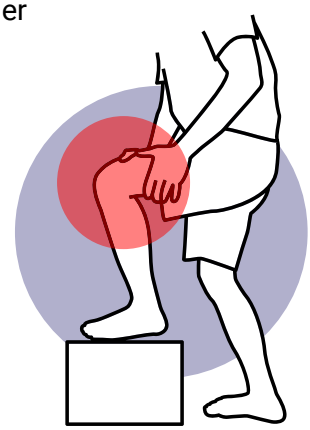
Risk of type 2 diabetes increases in individuals with Down syndrome who are overweight or obese. Type 2 diabetes is not due to an insulin deficiency but due to an impaired or resistive response to the body's insulin, making it harder to properly manage and store the sugar broken down from a meal. Diabetes is associated with a wide range of physical health complications and can damage vision and nerve function over time. Overweight or obese adults should be monitored and screened for diabetes regularly throughout adulthood.

Functional Decline

Adults with Down syndrome may commonly experience a general, slow decline in physical abilities due to a variety of issues related to growing older, such as impaired vision and hearing, a declining sense of balance and depth perception, weakened muscles, or more sensitive or tender joints. Many of these changes are a byproduct of accelerated aging and can lead to a gradual decline in stamina or overall confidence and capability in performing activities of daily living, like walking or dressing.

For some individuals, the ability to perform tasks may start to decline for physical reasons – like worsening arthritis that makes joints stiff and more painful to use. For others, a decline in skills could be related to increased confusion or forgetfulness about how to perform these tasks. These changes could also be due to a combination of both physical and cognitive/memory difficulties, where there are physical limitations that make tasks more challenging, and it may also seem harder to remember the sequence of how a task is performed.

It is important for caregivers to observe for other suggestive symptoms like verbal or physical evidence of pain/discomfort, a more visible change in the use of arms and legs, etc. If there is concern for physical changes like weakness, pain, or loss of balance, these observations should be brought to the attention of the primary care provider. A review of these concerns may lead to further investigation like x-rays or other testing, or a referral to a specialist, like physical or occupational therapy, orthopedics, or physiatry.



Menopause

Women with Down syndrome often experience menopause at younger ages than the typical population. Menopause can be accompanied by a variety of common symptoms, including mood fluctuations, fatigue, weight changes, and physical sensations of aches, pains, and hot flashes. The evolving symptoms accompanying menopause may be mistaken for other conditions, unless the connection is made between these observed changes and the evolving changes in a woman's menstrual cycles or patterns. Further discussion with a primary care provider and gynecologist may be very helpful in assessing these issues and providing further guidance.

Mental health

As adults with Down syndrome grow older, there is increased risk of experiencing certain common mental health disorders like depression, anxiety, obsessive compulsive disorder, and behavioral disturbances. Psychiatric illnesses may have different features in adults with Down syndrome, and it takes careful observation to detect subtle changes or to accurately assess changes that are more dramatic or disruptive. Families and caregivers are advised to stay vigilant for changes in mood, personality, and behavior and to raise concerns about any underlying mental health problems if changes arise.

In addition to medical and psychological contributors to mood changes, it is important to be sensitive to any significant change in environment or social structure. Pay attention to any recent emotional upheavals the individual may have experienced, including loss of a parent, loss of a housemate, departure of a beloved staff member, conflict at the workplace, and any suspicion of trauma or abuse. The effects of these changes should not be underestimated as individuals may experience great difficulty coping or adapting to stress or loss of routine or familiarity.

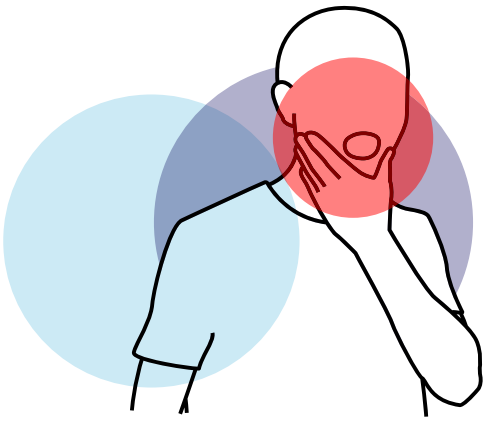
A sudden or abrupt change in mood or behavior patterns should warrant further investigation, typically starting with a primary care provider. A thorough medical assessment is recommended to look for any new and potentially correctable physical or medical conditions that may be contributing to the change in behavior or mood. Further steps could be undertaken by the primary care provider, or an individual could be referred for an evaluation from a mental health provider, preferably a provider with either expertise or at least a basic comfort level and range of experience in assessing and treating adults with intellectual disabilities.

Careful observation of mood changes is also important when observing for any changes or differences in memory or thinking. Mood changes often co-occur with memory changes, and mood symptoms and underlying mental health problems can directly contribute to symptoms that appear like confusion or forgetfulness.

Obesity/Overweight

Adults with Down syndrome are at increased risk for obesity and overweight due to a combination of a slower metabolism and various barriers to regular physical activity, exercise, and good nutrition. Obesity and overweight can contribute additional risk for other common problems encountered in adulthood such as sleep apnea,

osteoarthritis, and diabetes. Weight and body mass index (BMI) should be tracked at physical examinations, and overweight and obese individuals should receive additional guidance about strategies for improving diet and increasing physical activity. All adults with Down syndrome are advised to follow a healthy diet with regular exercise for overall weight management and quality of life.

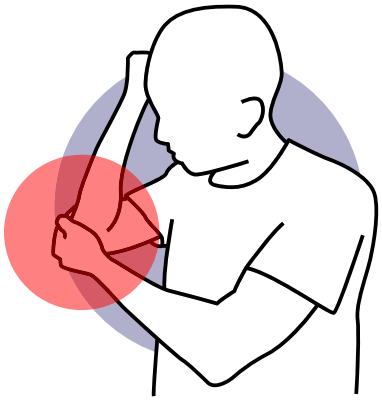


Obstructive sleep apnea

Adults with Down syndrome are at increased risk for sleep apnea, a sleep disorder that causes episodes of interrupted breathing and leads to poor quality, non-restorative sleep. Signs of possible sleep apnea include snoring, audible gasping noises, daytime sleepiness, morning fatigue, difficulty getting out of bed, excessive napping, and fragmented sleep. Undiagnosed or untreated sleep apnea leads to symptoms of irritability, poor concentration, behavior changes, and impaired attention. It also can put a strain on the heart and lungs and cause high blood pressure. Sleep apnea can be detected via a sleep study performed at a sleep lab or in a home-based study. If diagnosed, it is important to discuss and seriously pursue treatment options since relieving or improving the symptoms of sleep apnea can have substantial impact on the overall mental, physical, emotional, and cognitive well-being of an individual.

Osteoarthritis

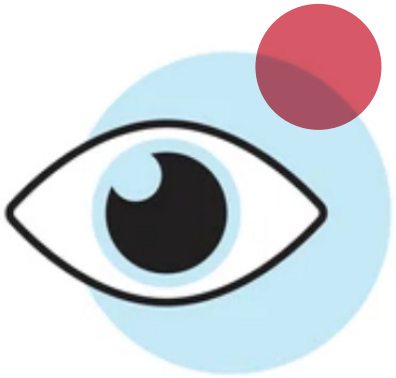
Many adults with Down syndrome are hyper flexible. Over the years, they can put increased wear and tear on large joints like their hips and knees leading to increased risk of osteoarthritis, resulting in pain and stiffness. Adults who are overweight or who were previously overweight are at increased risk due to the strain placed on the joints over time. Arthritis can cause pain on a regular basis and can lead to decreased mobility and willingness to participate in activities. For some individuals, pain can express itself through negative behavioral changes, particularly if the individual typically does not communicate feelings or symptoms of pain verbally. Untreated pain increases the risk of further immobility and deconditioning due to reluctance to participate in activities or exercise. Many adults with Down syndrome may under-report pain to caregivers. Thus, family and caregivers are advised to look for non-verbal signs of pain or discomfort and to pay attention to any changes in activity level. A professional evaluation for underlying arthritis changes may be very helpful.



Osteoporosis

Osteoporosis causes a thinning of bone mass that leads to risk of fracture. Some adults with Down syndrome may have higher risk for the disease, especially if there are additional factors of immobility, low body mass, family history of osteoporosis, early menopause, or longtime exposure to certain anti-seizure medications. Adults with Down syndrome who sustain a bone fracture should be considered for further evaluation of additional contributors

to osteoporosis, such as thyroid dysfunction, vitamin D deficiency, celiac disease, or low testosterone levels. In addition to this evaluation, a review of medications associated with adverse effects on bone health should be performed. A more detailed review of bone health can start with the primary care provider, then this can be further discussed with an endocrinologist or geriatric specialist to help guide next steps in evaluation and treatment.



Sensory losses

Vision and hearing deficits are increasingly common in adults with Down syndrome.

Vision deficits are often the result of early cataracts, which cause a clouding of the lens of the eye and produce blurry and impaired vision. Adults with Down syndrome are also at risk for keratoconus, which causes the rounded outer layer of the eye [cornea] to become cone shaped, which can lead to vision distortion. An eye doctor can and should screen for both conditions regularly.

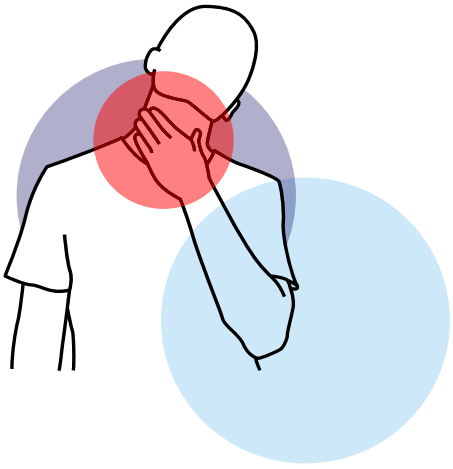
Adults with Down syndrome are at higher risk for conductive hearing loss. They also tend to have small ear canals and frequently can have ear wax impactions that impair hearing. Routine ear examinations can assess wax impactions, and periodic screening with an audiologist can formally assess hearing loss over time.

Undiagnosed sensory impairments of vision and/or hearing could frequently be mistaken as stubbornness, confusion, or disorientation in adults with Down syndrome. These conditions are quite common and can be improved with interventions like updated prescription glasses, hearing aids or amplification devices, routine ear cleanings, and environmental adaptations in the home.

Thyroid dysfunction

The thyroid gland is located in the center of the neck and is involved in various metabolic processes controlling how quickly the body uses energy, makes proteins, and regulates hormones.

Thyroid dysfunction is common in adults with Down syndrome and can lead to symptoms of fatigue, mental sluggishness, weight fluctuations, constipation, and irritability. This condition can be easily screened for and detected via blood tests performed by a health care provider. Treatment will usually involve taking thyroid medication that regulates abnormal hormone levels.



**For more information on suggested programs, please see the Resources page.*

COMMON MEDICAL CONDITIONS AND TREATMENTS

CONDITION & DISCIPLINE	WHAT'S NEXT?	
Alzheimer's Disease • Neurologist • Geriatrician • Occupational therapist (OT) • Neuropsychologist • Speech language pathologist (SLP)	A **neurologist** or **geriatrician** diagnoses and monitors the progression of Alzheimer's disease. An **OT** develops home modifications	for safety and compensatory strategies to prolong independence. An **SLP** facilitates communication of wants and needs as verbal skills decline.
Celiac Disease • Primary care physician (PCP) • Gastroenterologist • Dietician • Nutritionist	Your **PCP** can order a blood test for celiac disease. A **gastroenterologist** can perform an endoscopy to confirm a diagnosis.	A **dietician or nutritionist** helps you transition to a gluten-free diet.
Cervical Spine Disease • Neurologist • Physical therapist (PT) • Neurosurgeon	Typically diagnosed using x-ray or MRI by a **neurologist** or **neurosurgeon.**	**PT** treats asymptomatic cases with strengthening and teaching protective techniques. Surgery is an option for symptomatic cases.
Dental Disease • Oral and maxillofacial surgeon • Periodontist • Endodontics • Orthodontics • Implant Dentistry • Dentist	An **oral and maxillofacial surgeon** is trained to handle a wide variety of conditions and injuries that affect the head, neck, mouth, jaw, and face including performing dental implants. A **periodontist** focuses on the structures supporting the teeth,	such as gums and bones, and also performs dental implants. An **endodontist** cares for the roots and inside of teeth. An **orthodontist** treats teeth and jaw irregularities.
Diabetes • Primary care physician (PCP) • Endocrinologist • Dietician • Nutritionist	Your **PCP or endocrinologist** can order initial tests for diabetes. An **endocrinologist** is a specialty doctor who treats diabetes.	A **dietician or nutritionist** can help develop a healthy diet plan.
Functional Decline • Geriatrician • Occupational therapist (OT) • Physical therapist (PT)	A **geriatrician** or a **PCP** should monitor functional decline and rule out medical conditions.	An **OT** and **PT** will improve and maintain body strength for as long as possible and provide accommodations to increase independence in daily activities.
Medications • Primary care physician (PCP) • Pharmacist	Your **PCP** should be aware of all current medications and dosages to prevent potentially harmful drug interactions.	A **pharmacist** who fills your medications can also help to avoid this.
Menopause • Primary care physician (PCP) • Gynecologist	A **PCP or gynecologist** can diagnose menopause based on symptoms and blood tests.	If symptoms are bothersome, treatments may be recommended.

CONDITION & DISCIPLINE	WHAT'S NEXT?	
Mental Health • Psychiatrist • Psychologist • Social worker • Counselor • Family therapy support • Primary care physician (PCP) • Psychiatric nurse practitioner (Psych NP) • Psychiatric registered nurse clinical specialists (Psych RNCs)	Mental health disorders can be treated by a variety of professionals including: **Psychiatrists** who are medical doctors and can diagnose and treat patients including prescribing medication.	**Psychologists** who typically have a PhD, or PsyD, can diagnose and treat patients. **Social workers/counselors/ therapists** typically have at least a master's degree and diagnose and treat patients.
Obesity • Primary care physician (PCP) • Bariatrician • Dietician • Nutritionist	Your **PCP** can diagnose obesity. They may refer you to a **bariatrician** who specializes in medical weight management.	A **dietician or nutritionist** can help develop a healthy diet plan.
Obstructive sleep apnea • Sleep specialist • Ear, nose, and throat/ otolaryngologist (ENT) • Occupational therapist (OT) • Primary care physician (PCP) • Behaviorist • Psychologist	**Sleep specialists** perform sleep studies to diagnose sleep disorders. **ENTs** treat obstructive sleep apnea.	If there are issues wearing a CPAP machine, an **OT, psychologist, or behaviorist** may also be able to help.
Osteoarthritis • Primary care physician (PCP) • Rheumatologist • Orthopedist • Occupational therapist (OT) • Physical therapist (PT)	Your **PCP** may order x-rays or other tests before referring you to a specialist. A **rheumatologist** treats arthritis due to autoimmune disorders.	An **orthopedist** is a bone specialist who treats all other types of arthritis. An **OT and PT** can help to increase strength, improve mobility, and recommend assistive devices.
Osteoporosis • Endocrinologist • Primary care physician (PCP) • Rheumatologist	Your doctor may order a bone density scan. **Endocrinologists** treat metabolic diseases including osteoporosis.	**Rheumatologists** treat bone and joint conditions.
Sensory Losses • Optometrist • Ophthalmologist • Audiologist • Occupational therapist (OT)	**Optometrists** provide vision exams as well as glasses and contacts. **Ophthalmologists** treat medical conditions of the eye and perform surgeries.	**Audiologists** diagnose and treat hearing problems. **OTs** help with home modifications to maintain independence.
Thyroid dysfunction • Primary care physician (PCP) • Endocrinologist	Your **PCP and/or endocrinologist** can order bloodwork to test thyroid function.	**Endocrinologists** treat thyroid dysfunction.

MEDICATIONS

As people age, it is common to accumulate multiple doctors and specialists — this can certainly be true for adults with Down syndrome as they grow older.

MULTIPLE PROVIDERS can also equate to multiple prescribers, which increases the likelihood of receiving new prescriptions, medication changes, or suggestions from different specialists at once. Unfortunately, in this scenario it is also quite common for the multiple providers to not be in direct communication with one another. Further, there may be discrepancies in the medication lists of each of the providers. If they are not in a system that is electronically linked, then provider "X" today might be completely unaware of what provider "Y" started yesterday. With age, there is additional risk for polypharmacy, which is defined as having multiple or too many medications. This also more specifically refers to the dilemma caused by having medications that may be contradictory, excessive, or redundant to one another. Knowing communication is often not ideal across providers and prescribers, it is especially important to take a proactive approach in managing the medication list, ensuring that doses and frequencies for prescription medications are up to date (both routine and 'as needed' medications), over-the-counter drugs, supplements, and vitamins.

This list should be cross-referenced frequently with all health care providers involved and with the pharmacist where prescriptions are typically filled. The support team should have a fully updated and accurate list of what is taken and dispensed each day, the dose/strength, and how frequently it is taken. Many also find it helpful to keep a written log that tracks when medications are given.

Accuracy of a medication list is especially important during times of transition, such as when being discharged from a hospital or when being moved to a different setting such as a short-term rehab facility or to a residential community. This is a time when cross-referencing and double-checking a list is critically important to ensure there is full understanding of any medication changes or adjustments, any medication discontinuations, and any new instructions or guidance that has been made to the medication regimen.

Generally, in older patients it is advisable to start a new medication at a low dose and slowly increase if needed to achieve the desirable result. Whenever possible, it is typically best to avoid starting two or more medications simultaneously or making two or more adjustments at once, as this will cloud the ability to clearly interpret the impact of these changes.

A periodic review of the medication list is also advised to ensure a clear reason for each medication. Some medications may not need to be used indefinitely, but without cross-checking, certain medications can just remain endlessly renewed on a patient's medication list. For each new medication, it is recommended there is a clear explanation for its use and for any expected or possible side effects. It is important to weigh the risks and benefits of introducing multiple medications, and this is a discussion to continue to have with the primary care provider and other prescribers over time. Overall, benefits should always outweigh risks of medications in most scenarios, but a clear understanding of what risks are being taken is an important piece of the discussion to proactively pursue. Don't be afraid to ask questions like:

- Is this medication necessary?
- Is there room anywhere to simplify?
- Do the benefits outweigh the risks?

Always consider medications and medication effects when observing any new changes in mood, behavior, or physical symptoms, particularly if changes arise suddenly.

- Was a new prescription started?
- Which one? When?
- Has the dose of chronic medication increased or decreased recently?
- Was medication recently discontinued?

** For more information on suggested programs, please see the Resources page.*

MEDICATION LIST

	MEDICATION	DOSAGE	TIME OF DAY	SIDE EFFECTS	DATE STARTED	DOCTOR WHO PRESCRIBED

*Visit ndss.org for a printable medication list

ALZHEIMER'S DISEASE

Alzheimer's disease is the most common form of dementia diagnosed in individuals with Down syndrome. This disease is a progressive condition characterized by a gradual and irreversible loss of memory, overall skills, and functioning that continues until the end of life.

ALZHEIMER'S DISEASE affects brain cells and brain function, causing progressive decline in memory and ability to learn, make judgments, communicate, and carry out basic daily activities.

Alzheimer's disease is seen at significantly higher rates and at earlier ages for adults with Down syndrome compared to the general population. Awareness of this potential risk can create feelings of worry and fear for families, caregivers, and loved ones who are trying to support healthy, vibrant aging in an individual with Down syndrome. The precise statistics can vary in research studies, but there is a consistently strong trend of elevated risk with advancing age. Risk of dementia due to Alzheimer's disease is rare before age 40, slowly increases as one moves through their 40s, and then becomes more common with age in one's 50s, 60s, and beyond.

The uniquely elevated risk is genetic and is associated with chromosome 21, the chromosome that is present either as a full or partial third copy in people with Down syndrome. Chromosome 21 carries a gene that produces one of the key proteins involved with changes in the brain caused by Alzheimer's disease and, as described earlier, also carries other genes that are involved in the accelerated aging process. It is this property of chromosome 21 that makes the disease a more unique concern for people with Down syndrome than those with other forms of intellectual disability.

It is important to be well informed of the connection between Down syndrome and Alzheimer's disease, as this can empower caregivers and families to take proactive steps and act early if any concerns arise. Readers are recommended to refer to the comprehensive guidebook from NDSS, *Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers*. This guidebook provides useful information for any family member, loved one, or caregiver of an adult with Down syndrome.

Recognizing Alzheimer's

As stated in *Mental Wellness in Adults with Down Syndrome*, written by Dr. Dennis McGuire and Dr. Brian Chicoine [Woodbine House 2021], "Alzheimer's disease is one of the most commonly diagnosed and misdiagnosed mental disorders in adults with Down syndrome." All too often, individuals with vague changes or new symptoms may be inaccurately or prematurely diagnosed with Alzheimer's disease without going through a proper and thorough diagnostic evaluation. The diagnosis needs to be arrived upon carefully and thoughtfully, making efforts to evaluate and consider other factors that may be making an individual appear to be confused or forgetful.

Many medical conditions commonly seen in aging adults with Down syndrome can have features that are mistaken as primary features of dementia if not evaluated properly by experienced medical professionals. Awareness of these common conditions can lead to more proactive evaluations for other factors if an individual with Down syndrome shows any changes in functional ability. A careful evaluation of common medical conditions such as hearing loss, abnormal thyroid function, vision loss, pain, and sleep apnea is recommended.

Baseline and diagnosing Alzheimer's

Alzheimer's disease may be suspected when there is a change, or a pattern of changes, observed in an individual compared to their previous level of functioning. This distinction is often especially challenging for medical providers to conceptualize when assessing someone with an intellectual disability, as one's previous level of functioning can vary broadly for an adult with Down syndrome. Some individuals may have always required assistance with even basic daily tasks like getting dressed or bathed, while others may have had a high level of independence in sophisticated tasks like using public transportation to get to a full-time job or living independently in a community apartment. An individual's previous level of functioning is broadly referred to as their baseline, which describes what an individual could do when they were at their best. Awareness of an individual's baseline level of ability

is crucial to early detection of changes or losses that may emerge as they grow older. Because the baseline is used as a basis of comparison in assessments, it is extremely helpful to record baseline information on an ongoing basis throughout adulthood — noting basic self-care skills, personal achievements, academic and employment milestones, talents, skills, interests, and hobbies. *Medical Care of Adults with Down Syndrome: A Clinical Guideline* highlights the importance of a baseline assessment with a medical professional starting at age 40 with annual re-assessments and discussions to screen for any changes.

There are tools that can be used to document baseline abilities and track skills over time, such as the NTGEDSD [National Task Group-Early Detection Screen for Dementia], which is an early detection and screening instrument designed for caregivers to identify the first signs of change that can be seen in adults with an intellectual disability. In addition to these more formal tools, it can also be incredibly helpful to document information in a more narrative format, where abilities are described and recorded by caregivers who know the individual well. A few sentences or a small paragraph about one's abilities in personal care, day-to-day skills, academic abilities, hobbies, basic memory skills, and language skills can provide a rich picture of an individual's baseline, especially when combined with other descriptions about their overall personality and mood and any behavior issues that they may have had throughout their life.

Alzheimer's disease is a clinical diagnosis, which means it must be made by a doctor or other similarly qualified health provider based on a comprehensive assessment and review of the symptoms and features. There is no single blood test, x-ray, or scan that conclusively makes the diagnosis. An appropriate evaluation should involve a thorough review of an individual's symptoms of concern within the context of a description of the individual's unique baseline level of abilities. An assessment of the individual's memory skills is needed, as well as a review of other contributing factors or conditions, which could require additional testing such as blood work, imaging, or testing specifically for one or more of the conditions listed in this guidebook.

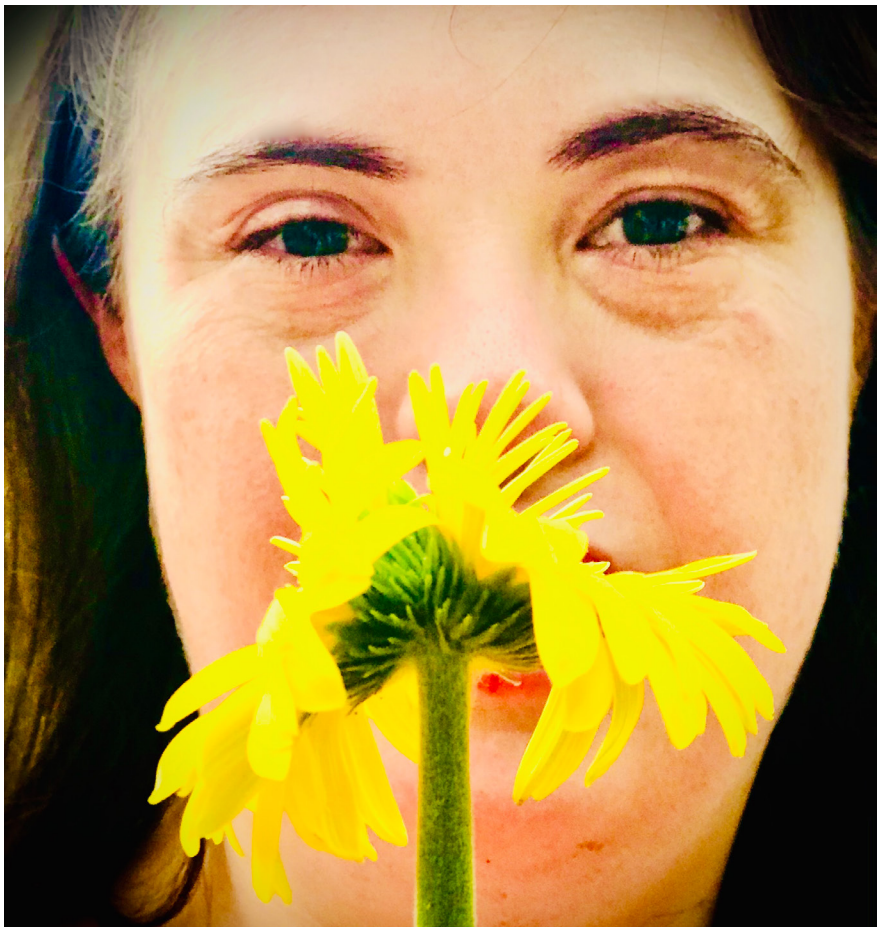
**For more information on suggested programs, please see the Resources page.*

PLANNING FOR SUCCESSFUL AGING

Staying socially connected and increasing quality of life

Continuously focusing on a person's quality of life as they age is a critical component of successful aging. Maintaining sources of enrichment, pleasure, and preferred activities can ensure a person stays active and engaged throughout adulthood. Developing robust activity schedules based on preferences, which can include work, community involvement, friends, family, and preferred leisure activities, can increase happiness, increase desired behaviors, and promote positive mental health.

However, as individuals grow older, "slowing down" may require more flexibility and adaptability with preferred activities and schedules. Social interaction can help maintain physical and mental well-being, and it is best to provide leisure time activities based on the individual's interests and preferred times of day for interaction and socialization. Familiar pictures and music enjoyed in the past may be both comforting and pleasurable.



Living environments and housing

Throughout the aging process it is necessary to periodically assess the living environment to ensure it is suitable for good health, privacy, independence, dignity, and safety.

NEXT STEPS: Assess if these needs are being met in any living situation:
- Medical
- Physical
- Social
- Emotional
- Personal safety

After assessing a living environment, further consideration should be given to whether this living environment is sustainable for the long term and what barriers or challenges are starting to arise that might compromise safety or well-being in the future.

The concept of "aging in place" implies a living environment and caregiver supports could be adaptable and modifiable over time to help serve the changing needs of an individual while they age without having to move to a new environment. This could include many types of adaptations such as ramps, handrails, raised toilet seats, grab bars, handheld shower heads, shower seats, and so on. The specific adaptations would vary based on the layout and design of the home and the needs of the individual.

NEXT STEPS: Obtain a home safety evaluation and input from specialists in physical and occupational therapy to meet an individual's changing needs.

Home safety evaluations are important to consider as a loved one ages in order to plan for an environment that can support increasing needs over the stages of the disease. The security and comfort of a predictable, familiar, structured, calm living environment, coupled with accommodations for safety, accessibility, and home care, can be very beneficial to an individual who is experiencing the decline of Alzheimer's disease and invaluable to caregivers.

Transitions and changes in routine or environment can be additionally distressing or destabilizing for individuals with dementia, so proactive planning for supports and sustainability in a living arrangement is critical.

Caregiving considerations

When aging adults with Down syndrome remain living in the family home, they are often aging alongside elderly parents, siblings, or other family members functioning in a hands-on primary caregiver role. Considering that adults with Down syndrome commonly live well into their 50s and 60s or longer, it is important for the family to consider the sustainability of a plan relying on the individual remaining in the family home.

NEXT STEPS: Have a discussion with involved family members and caregivers about alternative living arrangements if living with family no longer becomes possible. Depending on one or a small number of family members can add stress to caregivers over an extended period of time and maintaining this living arrangement over the course of many years may become more unrealistic and unsafe as time goes on.

It is important to think proactively about alternate caregiving or living situations to help avoid a crisis created by a caregiver's unexpected illness, incapacitation, or death, especially if these topics have never been explored.

NEXT STEPS:

- Anticipate change with aging and initiate a dialogue about family roles in future care planning.
- Define current roles of parents, siblings, and extended family members.
- Recruit necessary support for the family members who assume the bulk of the responsibility for coordination of care and advocacy.
- Explore and help define the caregiving and support roles of siblings or extended family members.

As a loved one with Down syndrome ages at home and their needs for support increase, families are encouraged to learn about and access federal and state benefits for which they may qualify. These programs may provide critical help with in-home support like personal care aides, home modifications, medication cost assistance, adaptive equipment, and transportation.

Transitioning to a new living arrangement

Changes in living arrangements are increasingly common throughout adulthood, particularly in later life. The change may be prompted by safety concerns, changes in the family, staff limitations, peer issues, or lack of continuous care with the same provider. In the event a change in living arrangements is required, it will be important to:

- Understand the physical, social, emotional, and medical needs of the individual. Look for a living situation that allows opportunities for a continued active lifestyle and proximity to extended family and friends.
- Define what factors would help contribute to a smooth transition, while acknowledging certain challenges will be part of any major life change.
- Plan ahead. Remember, it is often easier for individuals to adjust to change when they are comfortable and not overwhelmed by circumstances or in the midst of a major loss or family crisis. When moving out of the family home, acknowledge how emotionally difficult this transition may be for parents as lifetime caregivers.

Thinking about retirement

Many individuals with Down syndrome spend a large portion of their adulthood engaged in a work setting or day program. Some may wish to continue to work as they age, sometimes with a modified schedule or simplified routine, and some may wish to retire altogether. If physical, functional, or memory changes occur, a modified routine with a greater focus on recreational activities may be very beneficial.

Life at a slower pace should not equal life without stimulation or opportunity. Access to and connection with the community will contribute to a sense of well-being. Individuals with Down syndrome who have been diagnosed with Alzheimer's disease may eventually find the demands of leaving their home and being transported to work, community events, or a day program far too stressful to be beneficial. Others may still seem to enjoy the familiarity of keeping up the ritual of attending each day.

NEXT STEPS: If possible, adapt plans and expand flexibility to accommodate an aging individual's schedule as well as their preferred needs and habits to make them more comfortable.

End-of-life considerations

Discussing end-of-life wishes is difficult for most people. However, tackling these topics at a moment when there is no crisis or urgency will allow time to think, reflect, ask questions, and ultimately arrive at an informed decision. End-of-life discussions generally encompass overall goals of care, resuscitation wishes, and thoughts regarding artificial feeding and breathing supports, including any limitations in the overall focus of care in the setting of serious or terminal illness. Some individuals make decisions for themselves, whereas others will have legal guardians or health care proxies. It is extremely important to clarify this information and periodically review and update it over time. Determining end-of-life wishes early can minimize the potential impact of an unexpected crisis. Families and caregivers are encouraged to think ahead, ensure wishes are known, have plans in place, and confirm that authority for medical decision making has been properly conveyed through legal guardianship, medical power of attorney, or other tools available in your state. Readers are recommended to refer to the comprehensive guidebook from NDSS, *End of Life and Down Syndrome: A Companion Guide to Aging and Down Syndrome: A Health and Well-being Guidebook*. This guidebook provides useful information for any family member, loved one, or caregiver of an adult with Down syndrome who is planning for the future and desires to learn more information about person-centered end-of-life care.

CONCLUSION

This guidebook is written with deep and abiding gratitude to the wisdom of adults with Down syndrome and all those who love and support them.

Aging can bring with it some unexpected changes and challenges, and it can be comforting to periodically pause and reflect on the memories and accomplishments of a life well lived. Taking preventative measures to increase positive health outcomes, as a caregiver or an individual with Down syndrome, can add both years and quality to one's life. Assembling a strong medical care team and acting as coordinator to keep all members updated on health changes allows your loved one to receive the best possible treatment for any age-related concerns that arise. Establishing a baseline of skills will help families and caregivers identify changes in functioning more quickly and accurately. Prioritizing your loved one's safety through careful planning of housing options prior to an emergency occurring will smooth any potentially difficult transition situations in the future.

As you and your loved one make plans for the future, it is helpful to make written records so others are also aware of the individual's wishes and preferences for social activity, living environment, work, transportation, and end-of-life arrangements.

Preventative measures, access to resources, access to quality care, and state and federal advocacy help address the challenges our community faces as we move towards creating practical solutions.

NDSS and the greater Down syndrome community are here for each other as we navigate the highs and lows of aging with Down syndrome and celebrating the joys of growing old with our loved ones.

RESOURCES

NATIONAL DOWN SYNDROME SOCIETY (NDSS)
www.ndss.org/

The NDSS Health and Wellness Program promotes improved health and well-being for all individuals with Down syndrome. Through collaboration, NDSS develops tailored and accessible resources for individuals with Down syndrome, families, and caregivers across the lifespan. Please visit our publications page for additional resources, such as *Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers*.

321GO!
www.ndss.org/321go

NDSS designed the *321go!* program to promote healthy lifestyle choices in physical activity, balanced nutrition, and emotional wellness among individuals with Down syndrome and their families.

ADULT CONGENITAL HEART DISEASE ASSOCIATION
www.achaheart.org

Informative website on topics concerning congenital heart conditions.

ADVOCATE MEDICAL GROUP: ADULT DOWN SYNDROME CENTER
www.adscresources.advocatehealth.com/search/people-with-down-syndrome/

The Adult Down Syndrome Center at Advocate Medical Group has a great library of videos and pamphlets that discuss a variety of health and wellness topics.

ALZHEIMER'S ASSOCIATION
www.alz.org/
www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome

The Alzheimer's Association aims to accelerate global research, drive risk reduction and early detection, while maximizing quality care and support. This website shares additional information about dementia and Down syndrome.

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY
www.aadmd.org

Aims to improve the quality of healthcare for individuals with neurodevelopmental disorders and intellectual disabilities.

AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
www.aaidd.org

Publishes a number of resources, including information on care and end-of-life planning.

AMERICAN SLEEP APNEA ASSOCIATION
www.sleepapnea.org

Promotes awareness and works for continuing improvements in treatments of sleep apnea.

AMERICAN THYROID ASSOCIATION
www.thyroid.org

Promotes thyroid health and the understanding of thyroid biology.

THE ARC OF THE UNITED STATES
www.thearc.org

The largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.

CELIAC DISEASE FOUNDATION
www.celiac.org

Dedicated to providing services and support regarding celiac disease.

DOWN SYNDROME CLINIC TO YOU
www.dsc2u.org/

Down Syndrome Clinic to You (DSC2U) is a way for families to get up-to-date personalized health and wellness information for their loved one with Down syndrome.

DOWN SYNDROME MEDICAL INTEREST GROUP

www.dsmig-usa.org/clinic-directory-map

A group of health professionals from a variety of disciplines who provide care to individuals with Down syndrome. DSMIG-USA® educates members on the best practices of care and supports the development of Down syndrome clinics.

GLOBAL DOWN SYNDROME FOUNDATION

www.globaldownsyndrome.org/medical-care-guidelines-for-adults/

The new GLOBAL Medical Care Guidelines for Adults with Down Syndrome (GLOBAL Adult Guidelines) provide first in-kind, evidence-based medical recommendations to support clinicians in their care of adults with Down syndrome.

MENTAL WELLNESS IN ADULTS WITH DOWN SYNDROME: A GUIDE TO EMOTIONAL AND BEHAVIORAL STRENGTHS AND CHALLENGES

McGuire, D., & Chicoine, B. (2021). Mental wellness in adults with Down Syndrome: A guide to emotional and behavioral strengths and challenges. Woodbine House.

This easy-to-read guide clarifies what are the common behavioral characteristics of Down syndrome, how some can be mistaken for mental illness, and what are the mental health problems that occur more commonly in people with Down syndrome. In addition, the authors discuss the importance of regular assessment and how behavior and mental well-being can be affected by environmental conditions, social opportunities, and physical health.

MY HEALTH PASSPORT

www.flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

My Health Passport was designed to be shared with many types of healthcare providers in clinic and hospital settings. It is useful for providing information to those who are not very familiar in providing care to individuals with intellectual and developmental disabilities.

NATIONAL EYE INSTITUTE

www.nei.nih.gov

Conducts and supports research, training, and information dissemination with respect to vision.

NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS CLEARINGHOUSE

www.nidcd.nih.gov

An extensive website with resources on all things communication.

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

www.ninds.nih.gov

Aims to reduce the burden of neurological disease.

NATIONAL TASK GROUP ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND DEMENTIA PRACTICES – (NTG)

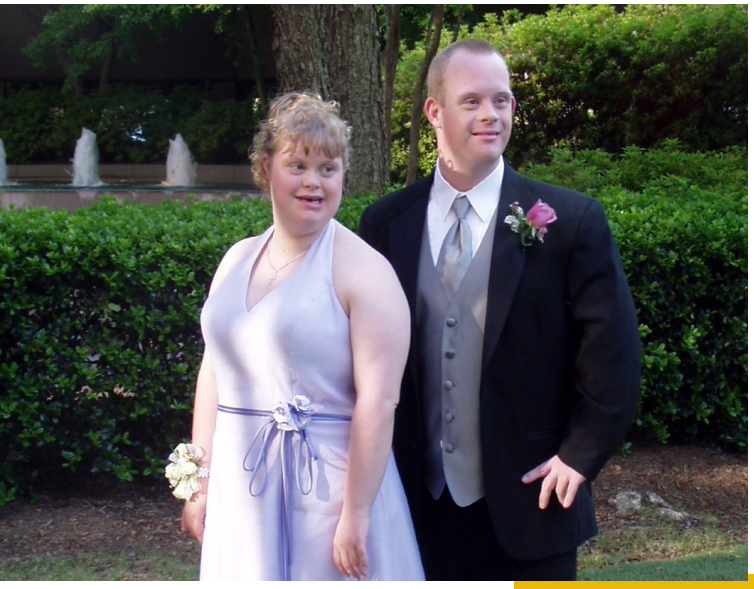
www.the-ntg.org/ntg-edsd

The NTG released the NTG-Early Detection Screen for Dementia (NTG-EDSD) which was developed to be used in starting the critical conversation with (and among) clinical personnel as to whether their observations merit more explicit assessment for MCI or dementia or – alternatively – signal behaviors that may be amenable to intervention and remediation.

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

www.ninds.nih.gov

Aims to reduce the burden of neurological disease.



Aging & Down Syndrome

A Health and Well-being Guidebook

Copyright © 2023 National Down Syndrome Society
All Rights Reserved

ALZHEIMER'S ASSOCIATION
www.alz.org

national down syndrome society
ndss
www.ndss.org

ntg National Task Group on Intellectual Disabilities and Dementia Practices
www.the-ntg.org