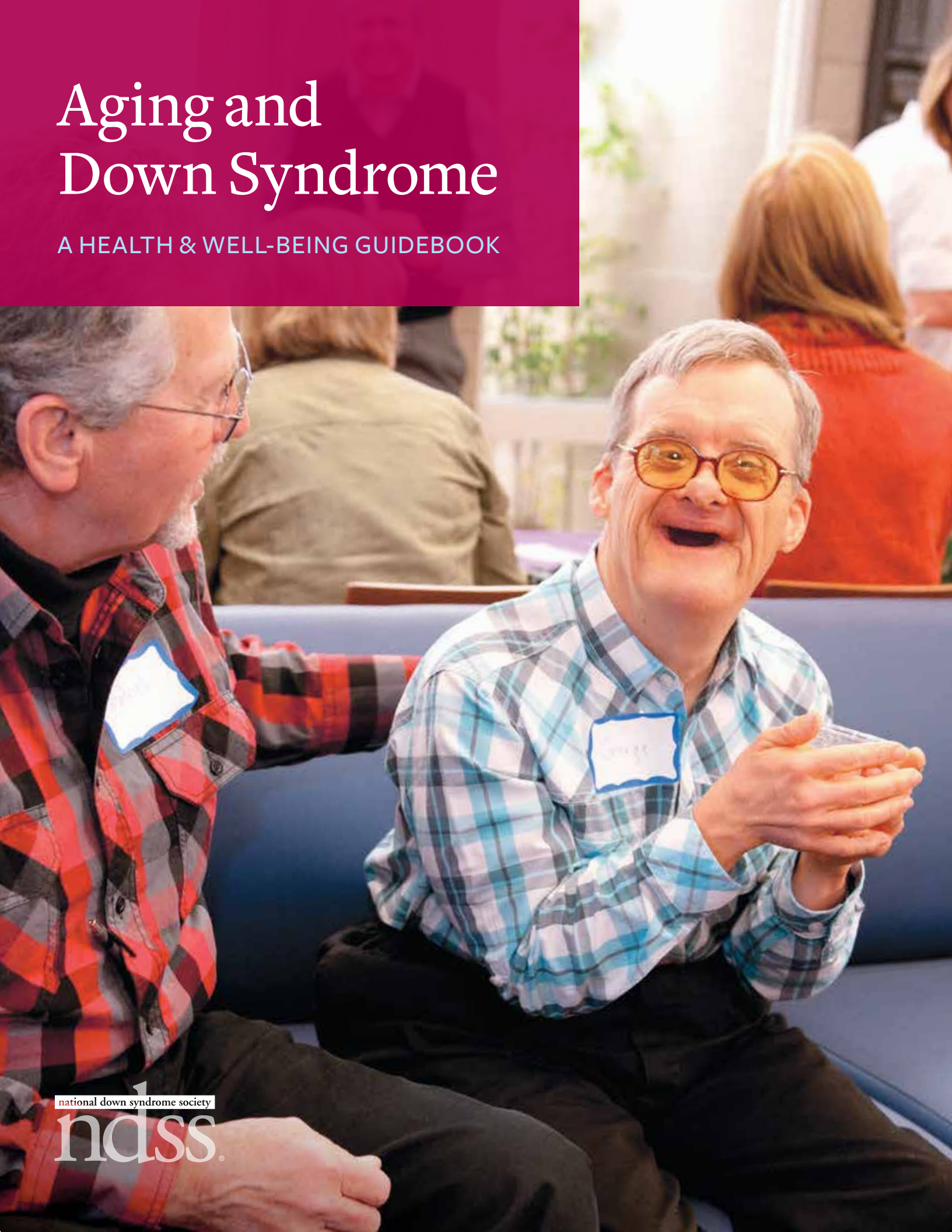
# Aging and Down Syndrome

## A HEALTH & WELL-BEING GUIDEBOOK



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*The National Down Syndrome Society advocates for the value, acceptance and inclusion of people with Down syndrome.*

*Image Courtesy of Victoria Will, Cover Image Courtesy of Joseph Guidi*

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## LOOKING AHEAD

*People with Down syndrome are living longer than ever before. Learning about common conditions and issues encountered in adulthood can help prepare for a healthy future.*

*Image Courtesy of Trinnica*

# Introduction

Adults with Down syndrome are now reaching old age on a regular basis and are commonly living into their 50s, 60s and 70s. While there are many exciting milestones that accompany growing older, old age can also bring unexpected challenges for which adults with Down syndrome, their families and caregivers may not feel adequately prepared. In order to enjoy all the wonderful aspects of a longer life, it is important to be proactive and learn about issues that may lie ahead.

Adults with Down syndrome, along with their families and caregivers, need accurate information and education about what to anticipate as a part of growing older, so they can set the stage for successful aging. The purpose of this booklet is to help with this process. It is intended to be used by various learners: families, professionals, direct caregivers or anyone concerned with the general welfare of someone with Down syndrome.

The goals of this booklet are as follows:

- Provide guidance, education and support to families and caregivers of older adults with Down syndrome
- Prepare families and caregivers of adults with Down syndrome for medical issues commonly encountered in adulthood
- Empower families and caregivers with accurate information so that they can take positive action over the course of the lifespan of adults with Down syndrome
- Provide an advocacy framework for medical and psychosocial needs commonly encountered by individuals affected by Down syndrome as they age

# General Overview of Aging with Down Syndrome

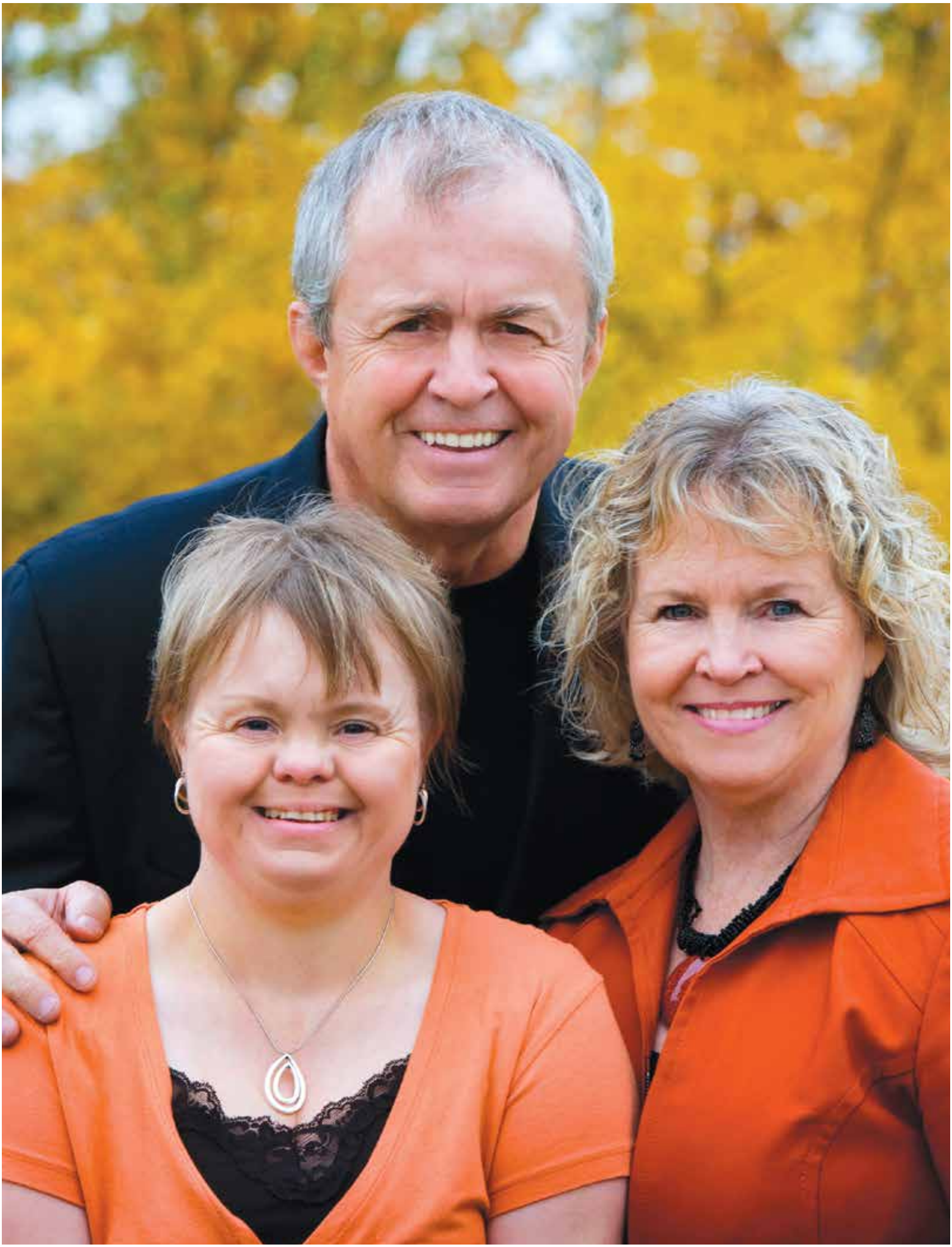
Adults with Down syndrome experience "accelerated aging," meaning that they experience certain conditions and physical features that are common to typically aging adults at an earlier age than the general population.

The reason for this is not fully understood, but is largely related to genes on chromosome 21 that are associated with the aging process. This chromosome is important because Down syndrome is characterized by a third full or partial copy of the 21st chromosome.

Generally, the experience of accelerated aging can be seen medically, physically and functionally. Many family members and caregivers commonly observe that people with Down syndrome appear to "slow down" once they enter their late 40s or 50s.

Complicating this picture is that "normal aging" in adults with Down syndrome is still not completely understood, and therefore predicting and preparing for the aging process becomes more challenging. This requires more attention and investigation from the medical community, but keeping eyes and ears attuned to early changes allows for responding to these changes in a proactive fashion.

The next section will outline the medical and physical issues that are common with aging and will help point out the key issues to look for over the lifespan.



**ACCELERATED AGING**

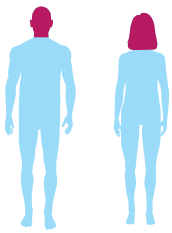
*Adults with Down syndrome experience "accelerated aging," meaning that in their 40s and 50s they experience certain conditions that are more commonly seen in elderly adults in the general population.*

*Image Courtesy of Blair Williamson*

# Common Medical Conditions

This section focuses on medical issues that are commonly encountered in individuals with Down syndrome throughout adulthood and into older age. These are issues to watch for over time and to ensure are being monitored by a doctor or other health care provider.

## Sensory Loss



**Eyes**: Adults with Down syndrome are at risk of early cataracts and keratoconus. Cataracts cause a clouding of the lens of the eye, producing blurry and impaired vision. Keratoconus causes the round cornea to become cone shaped, which can lead to a distortion of vision. Both of these conditions can be screened for by an eye doctor and should be assessed regularly.

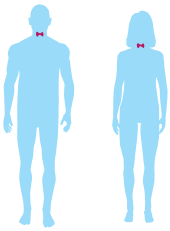
**Ears**: Adults with Down syndrome are at high risk for conductive hearing loss. In addition, they tend to have small ear canals and frequently can have ear wax impactions that can impair hearing. Routine ear examinations can assess wax impactions, and periodic screening with an audiologist can formally assess hearing loss.

Undiagnosed sensory impairments (vision or hearing) are frequently mistaken as stubbornness, confusion or disorientation in adults with Down syndrome. These conditions are quite common and, when properly identified, can be greatly improved with glasses, hearing aids, ear cleanings and environmental adaptations.

### TAKE HOME POINTS

- ✓ *Screen for vision and hearing impairment and get regular exams to assess overall eye and ear health.*
- ✓ *Check for ear wax impactions and request formal audiology testing to detect hearing loss.*

## Hypothyroidism

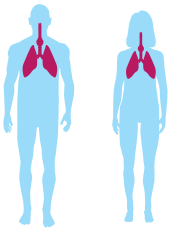


The thyroid gland is involved in various metabolic processes controlling how quickly the body uses energy, makes proteins and regulates hormones. Thyroid dysfunction is common in adults with Down syndrome and can lead to symptoms of fatigue, mental sluggishness, weight fluctuations and irritability. Thyroid dysfunction is easily detected via a screening blood test that can be performed by a primary care doctor, and treatment will usually involve taking thyroid medication that regulates abnormal hormone levels.

### TAKE HOME POINTS

- ✓ *Test for thyroid abnormalities periodically through screenings and blood tests.*
- ✓ *Discuss screening with the primary care doctor and consider checking for thyroid dysfunction if new symptoms of sleepiness, confusion or mood changes occur.*

## Obstructive Sleep Apnea



Adults with Down syndrome are at increased risk for sleep apnea, a sleep disorder that leads to poor quality, non-restorative sleep. Signs of possible sleep apnea include snoring, 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. In some cases, sleep testing can be arranged in the home.

### TAKE HOME POINTS

- ✓ *Sleep apnea is common and can frequently go undetected in adults with Down syndrome.*
- ✓ *Monitor sleep patterns, particularly if there is a change in mood, behavior or ability to concentrate.*
- ✓ *Discuss concerns with a primary care doctor to see if a sleep study is necessary.*

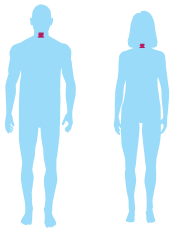
## Osteoarthritis

People with Down syndrome are typically hyperflexible. Over the years they can put increased wear-and-tear on their large joints (hips, knees, etc.). This leads to increased risk of osteoarthritis. Adults who are overweight or who were previously overweight are at increased risk. Arthritis is painful and can lead to decreased mobility and decreased willingness to participate in activities. For some individuals, the pain can express itself through negative behavioral changes. Untreated pain increases the risk of further immobility and deconditioning due to reluctance to participate in activities or exercise.

### TAKE HOME POINTS

- ✓ *Pay attention to changes in walking or activity level, looking for signs of stiffness or discomfort.*
- ✓ *Keep in mind that many adults with Down syndrome may under-report pain or appear to have a high pain tolerance. If pain is suspected, discuss the possibility of underlying arthritis with the primary care doctor.*

## Atlantoaxial Instability and Cervical Spine Concerns



The region of the spine located in the neck is called the cervical spine. In adults with Down syndrome, there is increased risk of instability between the 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 is known as atlantoaxial instability. If instability is present and arthritis changes occur in the spine, there is increased risk of damage to the spinal cord in that region.

A gradual narrowing of the spinal canal may also occur due to development of severe arthritic changes in the bones of the spine. This is called spinal stenosis.

When chronic changes occur in the cervical spine that affect the spinal cord, symptoms including weakness in the arms or hands, walking abnormalities or incontinence may be observed.

### TAKE HOME POINTS

- ✓ *Remain mindful that the bones of the neck are more vulnerable as adults with Down syndrome grow older.*
- ✓ *Further imaging or referral to a specialist may be necessary if new symptoms occur.*
- ✓ *A screening cervical spine x-ray is generally recommended at least once during adulthood.*

## Osteoporosis

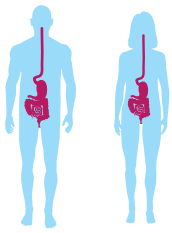
Osteoporosis causes a thinning of bone mass that leads to risk of fracture. People with Down syndrome are at higher risk for disease, especially if there is immobility, low body mass, family history of osteoporosis, early menopause or longtime exposure to certain anti-seizure medications. Osteoporosis is screened for via a bone density test and can be treated through medication, as well as other exercise and lifestyle modifications.

### TAKE HOME POINT

- ✓ *Talk to the primary care doctor about screening bone density tests, particularly if there are additional risk factors.*

*Image Courtesy of Jamie Kaplan*

## Celiac Disease



Celiac disease is a condition where one's body cannot digest wheat gluten and wheat products, causing damage to the lining of the intestine and preventing absorption of certain nutrients.

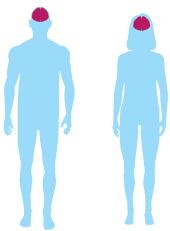
When celiac disease is present it can cause gastrointestinal distress, nutritional deficiencies and sometimes general irritability or behavior changes. There is a higher risk of this condition in individuals with Down syndrome.

Celiac disease can be screened for by a blood test but requires a biopsy and evaluation of the small intestine to confirm the diagnosis. A visit with a gastroenterology specialist is usually necessary to formally make the diagnosis. Celiac disease is usually primarily treated with a wheat-free diet.

### TAKE HOME POINTS

- ✓ *Consider the possibility of celiac disease when there is weight loss, poor nutrition or persistent changes in bowel habits.*
- ✓ *Talk to the primary care doctor about the increased risk of celiac disease and, if it was never performed in adulthood, consider a screening blood test.*

## Alzheimer's Disease



Early-onset Alzheimer's disease is more common in adults with Down syndrome than in the general population. It is important to be aware of the connection between Down syndrome and Alzheimer's disease so that proper surveillance can be done to look for signs or symptoms of the disease. This topic will be discussed in detail in another section.

## Medication and Prescription Considerations

The purpose of this section is to review general principles to keep in mind with regard to medication. It is beyond the scope and purpose of this document to discuss specific medications or treatments. Please be sure to review any specific medication questions with your physician.

As individuals grow older, they often acquire multiple doctors and specialists. While it is common for several doctors to be involved in prescribing medications for one individual, they may not be communicating with one another at all. It is important to be proactive with management of the medication list, making sure that both prescriptions and over-the-counter drugs, along with their doses and frequencies, are up to date.

As a general rule, it is advisable to start new medications at a low dose and slowly increase them if necessary. Be sure to understand why a medication is being recommended and inquire about side effects. Avoid making multiple medication changes at once or starting or adjusting two medications at the same time. Changing or adding one thing at a time allows for a clearer picture of the impact of the medication on its own. All medications, including over-the-counter and herbal medications, should be periodically reviewed, especially with the primary care doctor at times of transition (leaving the hospital, transferring to a new living situation, etc.).

### TAKE HOME POINTS

- ✓ *A periodic review of the medication list is essential.*
- ✓ *When reviewing the medication list, consider: Is each medication necessary? Do the benefits of each medication outweigh the risks of side effects? Is there room to simplify?*
- ✓ *Always think of medications when observing a new change in mood, behavior or physical symptoms. Was a new prescription just started? A dose increased? A medication suddenly discontinued?*

**MANAGING MEDICAL HISTORY**

*With aging, adults with Down syndrome may acquire various doctors and specialists, each of whom may make medication recommendations or adjustments. Often the various prescribers are not in direct contact with one another, so it is critical to carefully oversee the medication list.*

*Image Courtesy of Dennis Wilkes / Orange Grove Center*

# Emotional and Psychiatric Well-Being

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. A sudden or abrupt change in mood or behavior patterns warrants further investigation. 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.

Psychiatric illnesses can have different features in adults with Down syndrome, thus an evaluation from a mental health provider with special training or expertise in adults with intellectual disabilities is recommended. 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 that the individual may have experienced, including loss of a parent, loss of a housemate, departure of a beloved staff member, conflict at the workplace, etc. The effects of these changes should not be underestimated as individuals may experience great difficulty coping.

### TAKE HOME POINTS

- ✓ *People with Down syndrome can have psychiatric illness (depression, anxiety, etc.) just like anyone else.*
- ✓ *Monitor closely when there is a significant change in mood or behavior and seek attention from a primary care doctor or mental health specialist if features persist or interfere with day-to-day life.*
- ✓ *Don't overlook other new medical or physical issues that may be contributing to these changes.*
- ✓ *Pay attention to any other situational changes that may also trigger or exacerbate sadness, anxiety, etc.*

## A THOUGHTFUL APPROACH

*Adults with Down syndrome are at increased risk of Alzheimer's disease as they grow older, but Alzheimer's disease is not inevitable. There are many other possible issues to consider when concerns about memory arise, so a thoughtful approach is very important.*

*Image Courtesy of*
*Dennis Wilkes | Orange Grove Center*

# An Introduction to Alzheimer's Disease

Alzheimer's disease and Down syndrome share a genetic connection, leading to the increased risk of dementia at an earlier age. Understandably, many families and caregivers are especially worried about this possibility, which is one reason why this topic is covered in detail in this section. Getting accurate information and education about the risk of Alzheimer's disease is an important way of empowering oneself to prepare for the future.

## The Connection Between Alzheimer's Disease and Down Syndrome

Down syndrome occurs when an individual has a full or partial third copy of chromosome 21. (Typically, people have two copies of each chromosome.) Chromosome 21 plays a key role in the relationship between Down syndrome and Alzheimer's disease as it carries a gene that produces one of the key proteins involved with changes in the brain caused by Alzheimer's. Additionally, scientists have located several genes on chromosome 21 that are involved in the aging process and that contribute to the increased risk of Alzheimer's disease. It is this unique property of chromosome 21 that makes the disease a more acute concern for people with Down syndrome than those with other forms of intellectual disability.

### GENERAL DEFINITION AND OVERVIEW

Alzheimer's disease is a type of dementia that gradually destroys brain cells, affecting a person's memory and their ability to learn, make judgments, communicate and carry out basic daily activities. Alzheimer's disease is characterized by a gradual decline that generally progresses through three stages: early, middle and late stage disease. These three stages are distinguished by their general features, which tend to progress gradually throughout the course of the disease.

Alzheimer's disease is not inevitable in people with Down syndrome. While all people with Down syndrome are at risk, many adults with Down syndrome will not manifest the changes

of Alzheimer's disease in their lifetime. Although risk increases with each decade of life, at no point does it come close to reaching 100%. This is why it is especially important to be careful and thoughtful about assigning this diagnosis before looking at all other possible causes for why changes are taking place with aging. Estimates show that Alzheimer's disease affects about 30% of people with Down syndrome in their 50s. By their 60s, this number comes closer to 50%.

### TAKE HOME POINTS

- ✓ *There is an increased risk of Alzheimer's disease (dementia) in adults with Down syndrome. The risk increases with age.*
- ✓ *However, Alzheimer's disease is not inevitable in people with Down syndrome.*

## The Span of Alzheimer's Disease

### EARLY STAGE

- Short term memory loss (difficulty recalling recent events, learning and remembering names and keeping track of the day or date; asking repeated questions or telling the same story repeatedly)
- Difficulty learning and retrieving new information
- Expressive language changes (word finding difficulties, smaller vocabulary, shorter phrases, less spontaneous speech)
- Receptive language changes (difficulty understanding language and verbal instructions)
- Worsened ability to plan and sequence familiar tasks
- Behavior changes
- Personality changes
- Spatial disorientation (difficulty navigating familiar areas)
- Worsened fine motor control
- Decline in work productivity
- Difficulty doing complex tasks requiring multiple steps (including household chores and other daily activities)
- Depressed mood

*Alzheimer's disease is a progressive disease, gradually and steadily moving from early, to middle, to late stage. As the disease progresses, it is expected that abilities and skills decrease and the need for support and supervision increases, so aim to prepare proactively for each next step.*

## MIDDLE STAGE ALZHEIMER'S DISEASE

- Decreased ability performing everyday tasks and self-care skills
- Worsened short-term memory with generally preserved long-term memory
- Increased disorientation to time and place
- Worsened ability to express and understand language (vocabulary shrinks even further, communicates in short phrases or single words)
- Difficulty recognizing familiar people and objects
- Poor judgment and worsened attention to personal safety
- Mood and behavior fluctuations (anxiety, paranoia, hallucinations, restlessness, agitation, wandering)
- Physical changes related to progression of the disease including:
  - New onset seizures
  - Urinary incontinence and possible fecal incontinence
  - Swallowing dysfunction
  - Mobility changes (difficulty with walking and poor depth perception)

## ADVANCED STAGE ALZHEIMER'S DISEASE

- Significant memory impairment (loss of short term and long term memory, loss of recognition of family members and familiar faces)
- Dependency on others for all personal care tasks (bathing, dressing, toileting, and eventually, eating)
- Increased immobility with eventual dependence on a wheelchair or bed
- Profound loss of speech (minimal words or sounds)
- Loss of mechanics of chewing and swallowing, leading to aspiration events and pneumonias
- Full incontinence (both urinary and fecal)

# Recognizing Alzheimer's Disease

## ESTABLISHING A "BASELINE"

Alzheimer's disease is suspected when there is a change or a series of changes seen in an individual as compared to their previous level of functioning. Thus, in order to observe change effectively, one must be informed about what the individual was capable of doing at his or her very best. This could be considered the individual's "baseline."

The primary importance of having a good description and understanding of an individual's baseline is so it can be used as a basis of comparison if changes are observed as the individual grows older. It is extremely helpful to record baseline information throughout adulthood – noting basic self-care skills, personal achievements, academic and employment milestones, talents, skills and hobbies. A baseline can also be established formally at an office visit with a memory specialist, where these components can be reviewed and memory abilities can be tested.

Formal screening for memory concerns should be a priority throughout mid-to later-adulthood. Alzheimer's disease is a clinical diagnosis. That means that it requires a doctor to make the diagnosis based on his or her judgment. There is no single blood test, x-ray or scan that will

*Image Courtesy of Dennis Wilkes / Orange Grove Center*

make or confirm the diagnosis. The diagnosis depends largely on an accurate history detailing progressive loss of memory and daily functioning. It is vitally important that a history be provided by someone (a family member, a longtime caregiver, etc.) who knows the person well. It is important to seek the opinion of a specialist who will take all factors into account to arrive on a diagnosis thoughtfully. It is worth the effort to not rush the diagnosis. Make sure that the assessment has been thorough and that all other possibilities were given careful consideration.

*Most adults with Down syndrome will not self-report concerns about memory. Instead, it will take an astute caregiver who knows the individual well to identify early changes or concerns and bring them to the attention of a medical professional.*

Note that many of the common conditions related to aging and Down syndrome outlined in the beginning of this brochure can be mistaken as dementia if not identified properly (hearing loss, low thyroid function, vision loss, pain, sleep apnea, etc.). If the individual is showing change compared to their baseline memory or functioning, it is important to consult with the primary care doctor to assess for the presence of these other potentially treatable or correctable conditions.

## SEEKING A MEMORY EVALUATION

Look for a memory specialist (a geriatrician, neurologist, psychiatrist or neuropsychologist). Ideally, the specialist would have experience assessing individuals with intellectual disabilities. Assessments should be comprehensive and adapted appropriately for each patient's baseline intellectual disability. A thorough assessment should take into account all other potential contributing factors (medical, psychiatric, environmental, social) that could also account for, or contribute to, the reported changes (refer to Common Medical Conditions on page 6).

## AFTER THE DIAGNOSIS IS MADE

First, make sure that the diagnosis seems accurate. Was it arrived upon in a thoughtful and thorough manner, carefully excluding other possible causes that may explain the changes that were observed and reported?

Next, be proactive in building a support network. The key feature of Alzheimer's disease is that it is a progressive disorder, meaning it is expected that the individual's needs are going to increase over time. The support network encompasses the primary care doctor, memory specialist and other related medical specialists, caregivers, day program or workshop staff, state or agency support staff, other family, friends, etc.

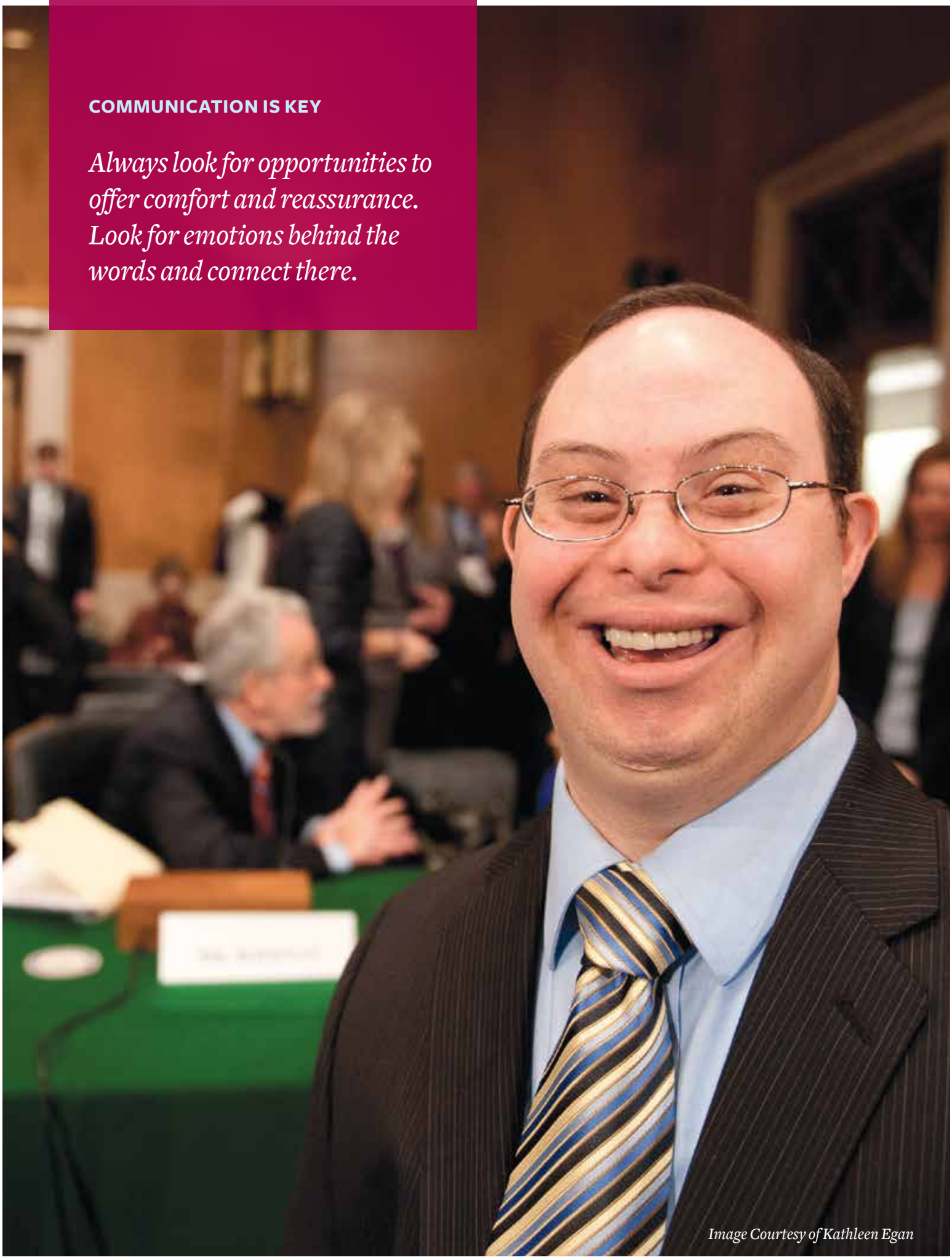
## LEARN ABOUT DEMENTIA

This booklet aims to provide a basic introduction to this topic, but one should seek out other resources to learn more and to get support. Some resources are provided at the end of this booklet. Stay closely partnered with the medical team. Get regular follow up appointments and periodic reassessments by the memory specialists to track changes and to review treatment strategies.

A large part of the management of dementia is providing appropriate supports as the disease progresses. It is very important to learn general caregiving principles and strategies to help effectively care for an individual with Alzheimer's disease. On the next few pages there is a brief primer on caregiving principles to help provide a basic introduction.

### TAKE HOME POINTS

- ✓ *Regular screening for memory impairment is important. Look for symptoms of confusion or memory loss, as well as changes in skills and daily functions that are declining from previous "baseline" abilities.*
- ✓ *When dementia is suspected, it is important to pursue a comprehensive evaluation that takes into consideration other common medical conditions that could be contributing to the individual's symptoms. Psychiatric or emotional contributors should be considered as well.*
- ✓ *If Alzheimer's disease is diagnosed, become familiar with the general features of the disease across the lifespan to help plan proactively and set proper expectations.*
- ✓ *Create formal (physicians, social workers, case managers, support staff) and informal (extended family, caregivers, respite workers) support networks to help cope with the progression of the disease.*



**COMMUNICATION IS KEY**

*Always look for opportunities to offer comfort and reassurance. Look for emotions behind the words and connect there.*

*Image Courtesy of Kathleen Egan*

# A Caregiver's Guide to Down Syndrome and Alzheimer's Disease

A large part of the management of dementia consists of providing appropriate support as the disease progresses. To help effectively care for an individual with Alzheimer's disease, it is extremely important to learn general caregiving principles and strategies specific to their changing needs. This section aims to serve as a brief primer and basic introduction to caregiving principles in the setting of dementia.

## Approach to Caregiving

### THE TRUTH ABOUT ALZHEIMER'S DISEASE

Alzheimer's disease is not a normal part of aging. It is progressive and ultimately fatal. Unfortunately, there is no cure for Alzheimer's disease, but it is possible for caregivers to maximize the independence and quality of life of the individual with Alzheimer's and Down syndrome, despite the presence of dementia. Living through this experience requires tremendous support. Build a team by recruiting, accepting and utilizing whatever resources are available.

One of the key features of Alzheimer's disease is a loss of short term memory and inability to learn and recall new information. Thus, expectations must be readjusted to accept that the goal is no longer to teach new skills or increase independence.

### COMMON BEHAVIORAL PITFALLS

Traditional methods of offering incentives or rewards become counterproductive, as they require the individual to remember the incentive in the short-term, i.e., "if you can keep quiet while we're in the van, I'll take you for ice cream." The ability to learn and recall new rules is no longer possible for someone with Alzheimer's disease and can lead to frustration for everyone involved. Similarly, attempting to negotiate with someone with dementia using logic or reason will often be a fruitless and frustrating experience, as these skills are progressively impaired. Behavior changes are often

beyond the control of the individual with dementia. They are not done to spite the caregiver, although at times it may be difficult not to take certain actions personally.

## EMPHASIZING A POSITIVE APPROACH

Non-verbal communication is critical. As dementia progresses, individuals rely more heavily on emotional cues to interpret communication, tuning into the tone of voice, facial expressions and body language. Pay attention to non-verbal communication and create an atmosphere that conveys a sense of safety and nurturing. Smile and avoid negative tones to your voice, as the individual may feel threatened or scared by this and react negatively. Avoid negative words like "no," "stop" or "don't." Use positive or neutral language to redirect the conversation. Listen for the emotion and connect on that level. What is it that he or she is really trying to say? I'm anxious? Confused? Depressed? Scared? Frustrated? Angry?

## FIRST STEPS TO IMPROVED COMMUNICATION

Always look for opportunities to offer comfort and reassurance. Join in the person's reality; begin where they are. Don't correct them. Always look for emotions behind the words and connect there. Try to avoid these common problems:

- Trying to convince, negotiate or appeal to logic or reason
- Expecting an individual to follow new rules or guidelines
- Engaging in an argument
- Correcting

## GENERAL VERBAL COMMUNICATION TIPS

- Use short, simple words and sentences
- Give one-step directions and ask one question at a time
- Patiently wait for a response
- Avoid open-ended questions. Provide choices or suggestions:
  *For example, instead of "What do you want for breakfast?"*
  *Say, "Do you want oatmeal or toast?"*
- Expect to repeat information or questions
- Turn negative statements into positive statements. *For example, instead of "Don't go into the kitchen." Say, "Come with me, I need your help with something."*
- Make statements rather than asking questions. *For example, instead of: "Do you want to go?" Say, "Let's go!"*

*Image Courtesy of Dennis Wilkes / Orange Grove Center*

## THE ART OF REDIRECTING THE CONVERSATION

Redirection is an important and powerful communication tool at times of frustration, anger and anxiety. The technique redirects the tone or focus of the conversation back to something positive or pleasantly distracting. Try not to create a totally false story. Focus on a piece of the information that will make things okay for the person. Eliminate details that will not help the person, or that may cause anxiety, fear or defensiveness.

## INTERVENING ON BEHAVIORS

Behavior is a form of communication, although it's not always clear what these behaviors might communicate. Problem behaviors can pose a safety risk to self or others. These include physical and verbal aggressiveness, self-injury, inappropriate sexual behavior, wandering or getting lost. Nuisance behaviors increase frustration and anxiety for self and others, but are generally not a safety risk. These include pacing, hiding, hoarding, rummaging or clinging.

Behaviors are sometimes expressed as a reaction to something specific. This is commonly referred to as a behavioral "trigger." Common triggers to look out for are:

- Communication problems (misunderstanding what is being said)
- Frustration due to tasks that are too difficult or overwhelming
- Environmental stressors (loud sounds, including loud voices, poor lighting, disruptive housemate)
- Personal upheaval (family illness, death of loved one, change in staff member)
- Medical status (physical pain, discomfort, illness)
- Stress of the caregiver or environment

Caregivers can attempt to modify the trigger by intervening before, or at the onset, of agitation in the following ways:

- Provide reassurance and, if appropriate, a gentle touch
- Use redirection techniques or distraction to something pleasurable
- Keep in mind that different approaches work at different times
- Be patient and flexible

### TAKE HOME POINTS

- ✓ *An understanding of the basic features of Alzheimer's disease can allow for effective and successful communication.*
- ✓ *As dementia progresses, the content of what is being said is less important than the emotion and the tone behind what is being said.*
- ✓ *Use positive redirection to avoid confrontation and frustration.*

## Steps to Successful Communication

| GETTING STARTED | FACIAL EXPRESSION | TONE OF VOICE | BODY LANGUAGE |
|---|---|---|---|
| • Approach from the front<br>• Smile<br>• Identify yourself<br>• Use the person's name<br>• If possible, be at eye level | • Establish & maintain eye contact<br>• Be friendly & relaxed<br>• Always remember humor: smiles & laughter go a long way<br>• Be patient and supportive | • Speak slowly & clearly<br>• Use a gentle & relaxed tone of voice<br>• Convey an easy-going manner | • Avoid sudden movement<br>• Be open & relaxed with your stance<br>• Remain calm & confident to provide reassurance<br>• Use gestures such as pointing<br>• Give visual cues |

*Image Courtesy of Dennis Wilkes / Orange Grove Center*

# Planning for Old Age

As with much of the guidance provided in this book, this is an area in which it is important to remain proactive. Planning ahead for the future is tremendously important as many of the issues discussed below do not lend themselves to being decided in the setting of a crisis. Making a plan that is sustainable throughout the lifespan requires thinking a few steps ahead at all times.

## Staying Socially Connected

Individuals with Down syndrome are generally very social. However, as they grow older, "slowing down" may require adjustments in, and more flexibility with, lifestyle activities and schedules. Maintaining sources of enrichment, pleasure and stimulation are critical for individuals with Down syndrome, just as they are with aging individuals in the general population. Boredom in particular can lead to depressed mood and negative behaviors.

Social interaction can help maintain physical and mental well-being, so provide leisure time activities that are based on the individual's interests, maximize stimulation and provide an opportunity for pleasure. For adults with Down syndrome and Alzheimer's disease, identifying options for entertainment that do not frustrate the individual will be important. 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 identify and make adjustments that will help maintain good health, independence, privacy and dignity while ensuring safety. Take into consideration all aspects of needs: medical, physical, social, emotional and personal safety. Are they being adequately met in the current living arrangement?

Incorporate the preferences of the individual with Down syndrome, with attention to safety and quality of life. Look for living environments that support "aging in place," meaning that they can

accommodate physical and functional changes that may be encountered with aging. For adults with Alzheimer's disease, plan ahead for an environment that can support increasing needs over the span of the disease. A calm, predictable, familiar environment can foster a sense of security for individuals experiencing memory changes.

## CONSIDERATIONS WHEN RESIDING IN THE FAMILY HOME

When aging adults with Down syndrome remain at home, parents may find themselves in their 70s, 80s or 90s and still functioning in a hands-on primary caregiver role. Sometimes this role shifts to other family members: siblings, cousins, etc. When an individual lives at home into adulthood, it is important that the family think proactively about future plans.

Keep in mind that aging is a dynamic process. Things are always changing, for both the parents, siblings and other family members, as well as for the individual being cared for. Make an effort to be proactive, thinking ahead to anticipate needs and concerns.

- Develop a plan that may avoid a potential crisis situation created by illness, disease progression, incapacitation or death. Make a plan that can be sustainable for the lifespan. Dependence on one family caregiver can be tremendously stressful and unrealistic over the course of many years.
- Explore and, where possible, define roles of siblings or extended family members. Recruit necessary support for the family member(s) who assume the bulk of the responsibility for coordination of care and advocacy. Anticipate change with aging, and initiate a dialogue about family roles in future care planning.

## CONSIDERATIONS WHEN RESIDING IN A GROUP HOME

Advocates, whether family, friends or guardians, can play an important role in this setting, especially if the individual is unable to communicate his or her needs. The following considerations may improve both quality of life and quality of care of an individual aging within a group home setting:

- Inquire about homes experienced in caring for adults with Down syndrome throughout the lifespan.
- Talk about the impact the aging process has on the individual and peers, with an eye toward quality of life for all.
- Be proactive and look for options that allow individuals to age in place. Such settings provide modifications in the physical environment and caregiving structure to adapt to the needs that emerge as the person ages.

## TRANSITIONING INTO A NEW LIVING ARRANGEMENT

Changes in living arrangement are increasingly common throughout adulthood, particularly in later life. This change may be related to safety concerns, changes in the family, staff limitations,

peer issues or lack of continuous care with the same provider. In the event that a change in living arrangements is required, it will be important to consider the following:

- Consider the physical, social, emotional and medical needs of the individual. Look for a living situation that allows for 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 that will be part of any major life change. Be proactive. 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."

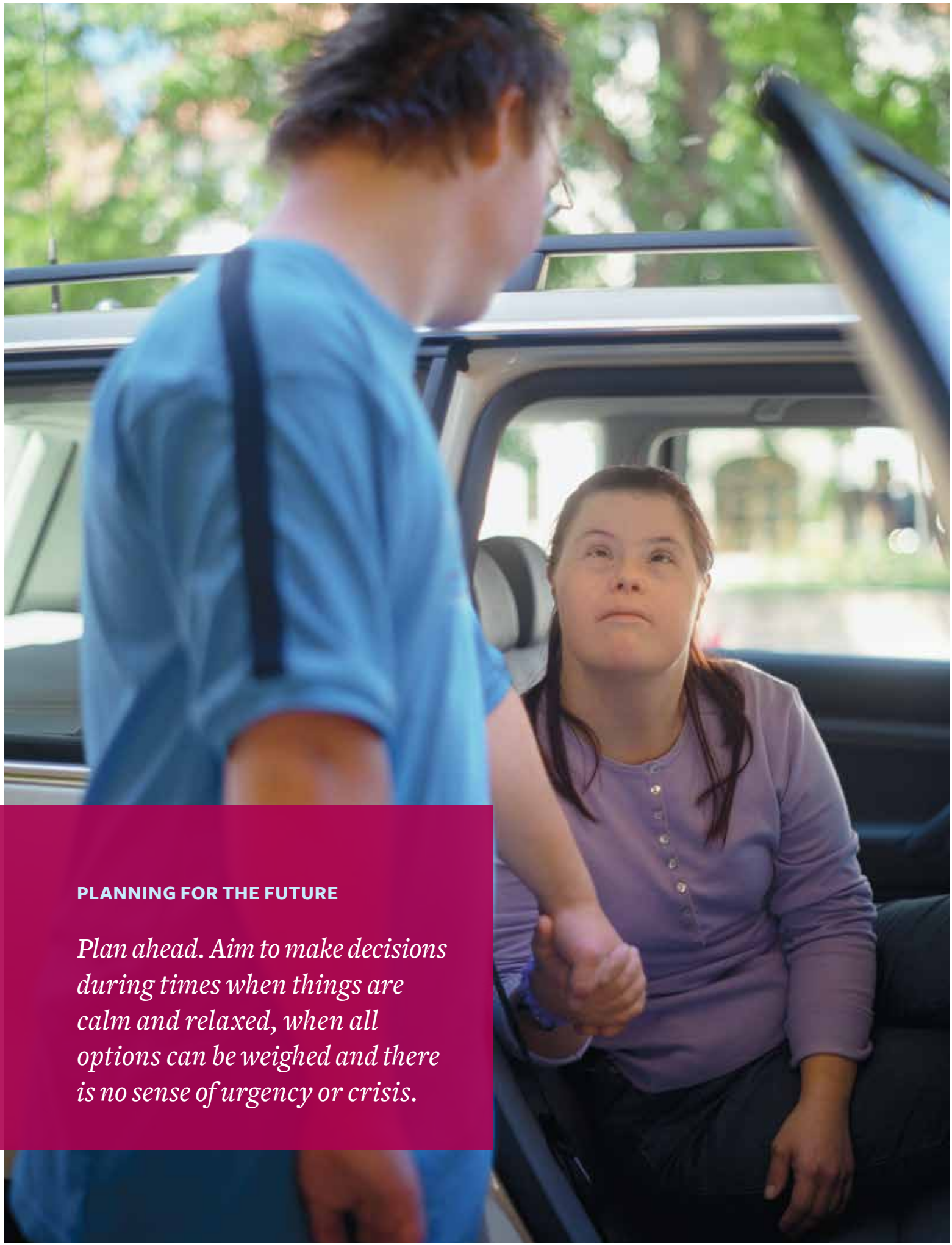
## Thinking About Retirement

Many individuals have been engaged in a work setting or day program for many years. Some have been gainfully employed for long periods, often on a part-time basis. Individuals with Down syndrome may wish to retire at an earlier age than typical retirees. Some may wish to continue to work as they age, sometimes with a modified schedule or simplified routine. If physical, functional or memory changes occur over time, 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 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 a day program on a daily basis far too stressful. Flexibility allowing for an individual's schedule to be altered as the disease progresses will be important.

### TAKE HOME POINTS

- ✓ *Maintaining social connectedness is a priority throughout every stage of life.*
- ✓ *Thinking proactively is the key to maintaining a successful and sustainable living situation.*
- ✓ *Adults with Down syndrome are routinely living into older age. Transition out of the family home or into other types of living arrangements is a common situation. Start these discussions early to avoid the need to make any arrangements during crisis.*
- ✓ *Just like the general population, some adults with Down syndrome will want to reduce the demands and expectations placed on them as they age. Consider exploring ways in which retirement could be a reality.*



**PLANNING FOR THE FUTURE**

*Plan ahead. Aim to make decisions during times when things are calm and relaxed, when all options can be weighed and there is no sense of urgency or crisis.*

## Coordination of Care

Coordination of care is a person-centered and shared decision-making process to identify and provide needed care, services and support. For people with Down syndrome, the need for support is a lifelong process that evolves, transitions and changes based upon multiple factors. A proactive and comprehensive approach, grounded in collaboration, continuous communication and teamwork is necessary for effective and accountable coordination of care.

While coordination of care is an overall ongoing process, there are times when coordination focuses on specific and periodic care needs. For example, when a person is taken to an emergency department (ED) or hospitalized, that 'transition' for admission to the ED or hospital and for the return home, requires communication, collaboration and coordination among family, caregivers, health care providers and others to understand the care and support needed for the person with Down syndrome.

In person-centered care, coordination should be planned by a team of individuals that includes the person with Down syndrome ("the center person"). Team members may vary over time depending on the support and services needed. Team members may include, but are not limited to: parent(s) and other family members; staff and caregivers from the group home, day program, or other support services; primary care physician and other physician specialists; nurses; dentist; psychologist or behavior specialist; social worker; nutritionist; physical therapist or occupational therapist; speech pathologist; resource coordinator or case manager; community support services staff; hospice care provider or others as applicable.

During any care coordination meeting, medical care visit, hospitalization or other similar situation, someone must initiate and lead the care planning with the team. This "team leader" may identify key participants; ask for input from other team members; initiate discussion about strengths and challenges; facilitate development and collaboration for a plan and goals that are understood by all. Frequently, a team leader may be a caregiver coordinator, family member, group home manager or registered nurse, case manager or resource coordinator. The team leader may change depending on the care coordination situation.

For example, if the center person is being discharged from the hospital, the hospital case manager might be the team leader to get family member(s), group home staff representative and day program representative together to be sure discharge instructions and follow-up care are understood. Or, if the center person is having difficulty eating solid foods at home, and must transition to a pureed diet and thickened liquids, the team leader may be a dietitian who meets with a speech pathologist, representative(s) from the family caregivers and day program staff to help caregivers learn about food preparation, feeding techniques and food and drink aspiration precautions.

## COORDINATION OF CARE

The following graphic depicts the process in coordination of care. Team members, including the individual with Down syndrome (the center person), communicate, collaborate and coordinate to identify the center person's strengths and challenges; plan and set goals; initiate the action plan; and evaluate or reassess progress in meeting needs and goals.

Be mindful to:

- Share relevant information about the center person, such as observations, signs, symptoms, medications, etc.
- Discuss care needs that impact hospitalization stays such as history of wandering, food preferences, unstable walking, verbal skills, etc.
- Clearly understand follow-up care needs and treatments and share with others that are not part of team member discussions.

**FIGURE 1**

*Example of person-centered care. The team members surround the center person, and the steps of care coordination are an ongoing and evolving process between all members.*

### COMMUNICATION, COLLABORATION AND COORDINATION

Coordination of care encompasses a comprehensive approach to provide the right care for the right reason, by the right people at the right time, for the person aging with Down syndrome. As described in this guidebook, there are many aspects about health, medical conditions and living arrangements that must be considered throughout a person's lifespan. Keep in mind that the frequency of coordination of care meetings and discussions, along with team member participation, varies depending on the needs of the center person. Discussions may be held annually, monthly or more frequently, or at the time of an acute or sudden change in behavior, hospitalization or change in living arrangements.

When identifying and evaluating strengths and challenges, the following table outlines various domains of the center person's abilities, capabilities, challenges, environment, preferences and resources that can be considered when providing comprehensive care planning and coordination.

## Topics to Consider in Care Coordination

| ABILITIES & CAPABILITIES | ENVIRONMENT & ACTIVITIES | CONDITIONS | RESOURCES |
|---|---|---|---|
| • Physical<br>• Psychological/ Behavioral<br>• Cognitive<br>• Functional Abilities (activities of daily living)<br>• Sensory (vision, hearing, touch, smell)<br>• Communication | • Living Arrangement<br>• Employment/ Retirement<br>• Social Engagement/ Activities<br>• Day Program Activity<br>• Daily Routines<br>• Spiritual Support<br>• Likes/Dislikes<br>• Safety Risks | • Nutrition<br>• Oral/Dental<br>• Elimination Pattern<br>• Sleep Pattern<br>• Medical Conditions<br>• Allergies & Intolerances<br>• Medications<br>• Prevention Care<br>• Treatment & Services<br>• Palliative & End of Life Care Needs | • Community Services & Support<br>• Funding<br>• Staffing Requirements<br>• Transportation Needs<br>• Legal |

In addition, when developing a plan, the following elements can be useful when considering a specific challenge or goal:

- Strengths/Opportunities
- Problems/Challenges
- Goals/Outcomes
- Person(s) Responsible
- Education Required
- Timeline/Goal Date(s)
- Evaluation
- Next Steps

Coordination, collaboration and communication (the 3C's) throughout the lifespan of a person with Down syndrome are the core components of person-centered care. Sharing information, observations and best practices; keeping the center person involved; learning from each other; and ensuring continuity and consistency in the plan of care illustrate the 3C's in action.

### TAKE HOME POINTS

- ✓ *It is common for individual needs to become more complex with aging. Providing care to an older adult with Down syndrome becomes an increasingly collaborative effort that requires both teamwork and leadership.*
- ✓ *Keep lines of communication open and seek opinions and input of other members of the team that participates in the day-to-day life and care of the individual.*
- ✓ *Maintain the individual with Down syndrome as the focal point to foster a collaboration that enables the individual to thrive and succeed throughout the lifespan.*
- ✓ *Seek legal consultation for health care proxy, power of attorney and a living will.*

## CULTIVATING A COMMUNITY

*Growing older has its ups and downs for everyone. Adults with Down syndrome, as well as their families and caregivers, need a support network to help celebrate victories and offer guidance during challenging times. Remember to reach out for help and stay connected.*

*Image Courtesy of Victoria Will*

# End-of-Life Considerations

Discussing wishes about end-of-life is difficult for most people. However, tackling these topics proactively, at a moment when there is no crisis or urgency, allows time to think, reflect, ask questions and ultimately arrive at an informed decision. End-of-life discussions generally encompass resuscitation wishes, thoughts regarding artificial feeding and overall goals of care, including any limitations in the aggressiveness of care, particularly in the setting of serious or terminal illness.

Prior to any discussion of this sort, there needs to be proper identification of the health care decision-maker. Some individuals make decisions for themselves, whereas others will have legal guardians. It is extremely important to clarify this information and periodically review and update it.

In the setting of Alzheimer's disease, these discussions are particularly important, as the disease is eventually terminal. Having a proactive discussion before dementia is at an advanced stage is preferred, minimalizing the risk of an unexpected crisis. Hospice is an option that can be very beneficial to adults with advanced Alzheimer's disease if in line with the overall goals of care.

### TAKE HOME POINTS

- ✓ *Identify who the medical decision-maker is: the center person, a family member, a court-appointed guardian?*
- ✓ *Engage the decision-maker proactively regarding end-of-life wishes. Have a discussion with the primary care doctor to help clarify any unfamiliar terms and to formally document any wishes or goals.*
- ✓ *Tackle the tough discussions at a time when there is no crisis, when decisions can be made in a relaxed fashion so that all aspects can be properly considered and explored.*

# Resources

### ADULT CONGENITAL HEART DISEASE ASSOCIATION
www.achaheart.org
Informative website on topics concerning congenital heart conditions

### ALZHEIMER'S ASSOCIATION (NATIONAL OFFICE)
www.alz.org
800-272-3900 (24-hour hotline)
The nation's leading resource for information and resources on Alzheimer's disease

### 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
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

### 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 DISABILITIES AND DEMENTIA PRACTICES / NTG
www.aadmd.org/ntg
Dedicated to dissemination of information and training related to screening, health care, family / community based supports and long term care related to intellectual disability and dementia

The National Down Syndrome Society advocates for the value, acceptance and inclusion of people with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.

Aging and Down Syndrome: A Health and Well-Being Guidebook is dedicated to Jane Davey Hamilton, her son Peter, and her legacy of devotion to him. NDSS thanks Peter's family for funding this guidebook for families, friends, and caregivers of people with Down syndrome.

To learn more about NDSS and for further information about Down syndrome, please visit www.ndss.org.

national down syndrome society
ndss

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