



ALZHEIMER'S DISEASE AND DOWN SYNDROME

A PRACTICAL GUIDEBOOK
FOR CAREGIVERS

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FOREWORD

The risk of Alzheimer’s disease in adults with Down syndrome can stir deep feelings of fear and anxiety for family, friends, and caregivers who are otherwise trying to focus on supporting and celebrating a healthy and fulfilling adult life for an individual that they love. Education is one way to reclaim some power over a situation where it is impossible to have total control. This booklet was created to help empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer’s disease, suggestions about how to carefully and thoughtfully evaluate changes that may be observed with aging, and guidance about how to adapt and thrive within an ever-changing caregiving role post diagnosis.

For those reading this booklet who are facing an Alzheimer’s disease diagnosis for the first time, this booklet aims to be a resource to return to again and again, as different caregiving questions and challenges emerge over time. For those readers who are supporting an individual who has mid- or late-stage disease and already bring with them their own expertise and wisdom from the daily practice of caregiving, perhaps there is information here that sparks new realizations or connections that can be put to use. For those who have lost a loved one with Down syndrome and Alzheimer’s disease, perhaps this booklet can help shed light on one unanswered question, provide insight on how to be a support to other caregivers, or help gain further closure on an undoubtedly difficult process.

For readers who are aging well and healthy or are just embarking on adulthood, this booklet aims to empower everyone to take proactive steps to improve and optimize physical, emotional, and cognitive health for a long and vibrant future.

In gratitude to all the caregivers of the world, thank you for taking time to learn about this important topic.

INTRODUCTION

Adults with Down syndrome are now routinely living into their 50s, 60s, and beyond. For many individuals this long and vibrant adulthood is marked by an array of milestones: moving out of the family home, getting a job, becoming an aunt or uncle, finding love, traveling to new places, and trying new and exciting things. The joys that these experiences bring can also be coupled with challenges that adults with Down syndrome may encounter with advancing age. One of the most serious and life-changing concerns that individuals with Down syndrome face as they grow older is the increased risk of developing dementia stemming from Alzheimer’s disease.

For anyone receiving the news for the first time, the diagnosis of Alzheimer’s disease can be overwhelming. Families and caregivers of adults with Down syndrome can find this diagnosis particularly devastating, as it is often marked by a profound grief for the loss of abilities that had been so hard-earned over the individual’s lifetime.

No matter how informed one might be about the increased risk of Alzheimer’s disease in Down syndrome, many people feel unprepared when the diagnosis becomes a reality. Family members, loved ones, and caregivers may find themselves in a state of disbelief when they witness changes occurring under their own roof or when the diagnosis is officially made in someone they love. This can be a very emotional time as individuals, caregivers, and families work to fully grasp the implications and impact of this diagnosis.

The intent of this publication is to address the specific concerns related to adults with Down syndrome and Alzheimer’s disease and the people who love and support them.

THE GOALS OF THIS BOOKLET ARE AS FOLLOWS:

- 1) To provide proactive and practical guidance about seeking help if early changes are noted, so that an evaluation of possible Alzheimer’s disease is made carefully and accurately
- 2) To empower families and caregivers with practical, directly applicable knowledge to help optimize the well-being of the individual with Alzheimer’s disease
- 3) To provide encouragement, solace, and support for individuals, families, and caregivers for a shared meaningful journey after a diagnosis is made
- 4) To highlight the importance of honoring the person with Down syndrome throughout their entire life, especially after an Alzheimer’s disease diagnosis is made

PERSON-CENTERED AND RELATIONSHIP-CENTERED PRINCIPLES

Everyone has a story.

An appreciation of an individual’s life story is a cornerstone in providing care that is person-centered, and which takes into account his or her culture, life history, lifelong personality, quirks, abilities, strengths, preferences, interests, and values. **Person-centered care** aims to honor the unique physical, medical, mental, social, emotional, and spiritual needs of each individual.

A complement to person-centered care is **relationship-centered care**, which stresses the importance of the various relationships in a person’s world that help to support and enhance his or her wellbeing. These nurturing relationships are built on emotional connection and help positively influence care experiences and outcomes for the individual, family, and caregivers.

Person-centered and relationship-centered care embodies humanistic ideals that represent fairly universal goals. While not entirely unique to the needs of individuals with Alzheimer’s disease, embracing these principles after a diagnosis can help keep the focus on what is most important when life feels overwhelming.

PERSON-CENTERED PRINCIPLES INCLUDE THE FOLLOWING:

- To be acknowledged as a person with a unique life story
- To feel loved and safe, while being treated with respect and dignity
- To be valued and included in his/her community throughout life
- To be self-directed in choice and decision-making to the greatest extent, whenever possible
- To be involved in meaningful activity, to feel useful and a sense of belonging
- To be provided comfort, care and support with patience, compassion and empathy
- To have care that is focused on what an individual *can* do and not what they can not

When caring for an individual with Down syndrome and Alzheimer’s disease, it is crucial to remember that the person being cared for is still the same unique individual, continuing on their own evolving and meaningful life story. Through the ebb and flow of the disease, the person’s essence remains, whether it’s felt directly or kept alive in the memory of those that love and care for him or her.

Life goes on after the diagnosis... it has to! In the coming sections, this booklet aims to provide a roadmap that will hopefully make the journey a little easier for everyone involved.

WHAT IS ALZHEIMER’S DISEASE?

Alzheimer’s disease is a cause of **dementia**. The term dementia does not describe a specific disease, but rather a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person’s ability to perform everyday activities. Alzheimer’s disease causes problems with memory, thinking, function, and behavior in a way that represents a *decline from the individual’s longstanding level of ability*. Symptoms usually develop slowly and get worse over time, eventually becoming severe enough to interfere with daily tasks.

The distinction between the terms Alzheimer’s disease and dementia is frequently a source of confusion. As mentioned above, the word dementia is a general “umbrella” term that describes a variety of more specific conditions that permanently affect memory and thinking. Alzheimer’s disease is the cause of the most common form of dementia that falls under this umbrella, and it is distinguished from other causes of dementia based on its specific characteristics. Practically speaking, the words dementia and Alzheimer’s disease are often used interchangeably, both in medical settings and in general conversation. This usage is not wholly incorrect, but it commonly causes confusion for people who are unfamiliar with how the two entities relate to one another. For the remainder of this booklet, the terms Alzheimer’s disease and dementia will be used, but do keep in mind that Alzheimer’s disease is a *cause* of dementia. Alzheimer’s disease affects the brain and causes the observed changes in dementia such as memory loss, functional decline, behavior and personality changes, and loss of language skills.

TEN EARLY WARNING SIGNS OR SYMPTOMS OF ALZHEIMER’S DISEASE INCLUDE:¹

- **Memory loss that disrupts daily life.** This can include confusion or forgetfulness in a recurrent pattern, enough to interfere with some aspects of the individual’s typical daily routine. Early on, forgetfulness typically involves

1 Adapted from the Alzheimer’s Association “10 Warning Signs of Alzheimer’s”. www.alz.org

- difficulty recalling immediate, short-term, or newly-learned information.
- **Challenges in planning or solving problems.** Individuals may show new or worsened difficulty with activities that require multiple steps or tasks of sequencing and planning that they could previously do well. Examples could include repeatedly forgetting to bring a towel or other necessary items into the bathroom at shower time, neglecting to pack more than a granola bar in his or her lunchbox when leaving for the day, or dressing in shorts to leave for work when it’s snowing outside.
- **Difficulty completing familiar tasks at home, work, or leisure.** This includes activity such as decreased work productivity or confusion completing common household or leisure tasks that he or she could previously do well. There may be an overall appearance of poor concentration when attempting to do a chore or a familiar daily activity.
- **Confusion with time or place.** An individual with Down syndrome and early memory problems may appear confused about where he or she is, and may lose track of the day of the week or appear less familiar with a typical daily routine.
- **Trouble understanding visual images and spatial relationships.** Individuals may experience confusion navigating familiar spaces, manipulating common objects, reading, or understanding visual information such as pictures or signs.
- **New problems with words in speaking or writing.** For individuals who have always had expressive verbal language skills (that is, speech), language and vocabulary may become more limited or simple. Difficulties in receptive language (the ability to hear and understand verbal language) may lead to a difficulty answering questions or following directions.
- **Misplacing things and losing the ability to retrace steps.** Individuals may appear more absent-minded and apt to misplace or lose items. Examples may include no longer putting a lunchbox away in its usual place in the kitchen at the end of each day or putting things in unusual places (an open mayonnaise jar left in a cupboard, dirty clothes mixed into the drawer with clean items, etc.). When individuals become more forgetful of where something was put down, there may be increased accusations that other people are stealing items that have been in fact misplaced.

- **Decreased or poor judgment.** Some individuals with early memory changes may forget to lock their front door, discard items of value, or show new impulsivity or poor/worsened safety awareness.
- **Withdrawal from social activities.** Individuals may start avoiding social opportunities due to the anxiety, stress, or confusion about the changes he/she is experiencing. Activities that may have once reliably provided joy and excitement may suddenly seem overwhelming for individuals experiencing memory problems.
- **Changes in mood and personality.** Individuals may show an array of new or worsening negative emotions along with confusion including suspicion, paranoia, anxiety, sadness, tearfulness, and depression.

KEY DISTINCTIONS REGARDING EARLY WARNING SIGNS

Everybody is entitled to have a bad day now and then. Misplacing a pair of eyeglasses once in a while or forgetting the name of a distant relative at a family reunion does not necessarily indicate that dementia symptoms are starting to emerge. When considering the warning signs listed above, note that these symptoms should constitute a regular pattern and interfere with daily activities in a way that represents *a change from the individual's previous level of ability*. This is a key distinction that will be reinforced throughout this booklet.

There are numerous other possible conditions that can cause symptoms of confusion or forgetfulness. A diagnosis of Alzheimer's disease needs to be approached carefully, and considered as a possibility only if there are no other identified medical or psychiatric causes that may have otherwise brought on symptoms or changes that are observed. The list of alternate explanations for early changes that may be observed is broad at first, and can include a wide range of possible causes. Examples include: an acute infection, a sudden medical illness, a stroke, new or recurrent seizure activity, an adverse reaction to a medication, worsening depressed mood, acute grief reaction, trauma or triggering of past trauma, worsened anxiety, or other ongoing personal stressors that are causing a significant emotional burden on the individual. Thus, it is important to think broadly at first, so as not to miss recognizing other common conditions contributing to observable changes.



WHAT IS THE CONNECTION BETWEEN DOWN SYNDROME AND ALZHEIMER'S DISEASE?

Alzheimer's disease is caused by changes to brain cells, causing irreversible damage that leads to a gradual slowing down and failing of brain function. The damage is brought on by the accumulation of protein substances in the brain that disrupt brain cell health and signaling between cells. The build-up of these proteins contributes to abnormalities that are commonly referred to as "plaques" and "tangles," based on the way in which they appear under a microscope.

Alzheimer's disease and Down syndrome share a unique genetic connection. In the typical population, people have two copies of each chromosome, to equal a total of 46. Individuals with Down syndrome have a full or partial third copy of chromosome 21 (hence, the name **trisomy 21**). Chromosome 21 carries a gene for the protein that is produced in excess in Alzheimer's disease, leading to the buildup of **beta-amyloid**, the protein responsible for forming the plaques that cause permanent damage to brain cells. Since individuals with

Down syndrome carry three copies of this chromosome in their cells, they have an additional overproduction of this brain-toxic protein. Scientists are still working to fully understand the role of all of the other genes located on chromosome 21, as several of them are believed to contribute to the accelerated aging process that's seen in Down syndrome. These unique properties of chromosome 21 are associated with elevated risk of premature Alzheimer's disease for adults with Down syndrome specifically. The same risk is not seen as distinctly in adults with other forms of intellectual disability.

While it is well-established that there is an elevated risk for Alzheimer's disease in adults with Down syndrome as they grow older, it is important to emphasize that this diagnosis is **NOT** inevitable. For reasons that are still not fully understood, some individuals with Down syndrome will develop Alzheimer's disease as they grow older, while some individuals will live their life without showing the outward changes of dementia. Current estimates suggest that Alzheimer's disease affects more than 30% of people with Down syndrome in their fifties and 50% or more of people in their sixties, with risk increasing incrementally with advancing age thereafter.

Although risk increases significantly with each decade of life after 50 for adults with Down syndrome, it is vitally important to make sure that a diagnosis of dementia is approached carefully, and not given prematurely or without a thorough investigation. At the first signs of someone acting even slightly differently than usual, it is important to keep in mind that there are many other possible contributors to changes that are seen with age. There are several common medical conditions that adults with Down syndrome experience as they move through adulthood and into older age, many of which can cause vague symptoms of confusion if not properly identified and addressed.

These common conditions were reviewed in more detail in the publication, ***Aging and Down Syndrome: A Health and Wellbeing Guidebook***, available through the National Down Syndrome Society. Readers are strongly encouraged to obtain this booklet for additional information on this topic, as well as other health-related resources for adults with Down syndrome who are growing older.

It is important that health care providers, family, and other caregivers remain vigilant for signs of these conditions, as many of them can have features or symptoms that can mimic some aspects of Alzheimer’s disease.

Available through the
National Down Syndrome
Society at ndss.org.

**COMMON MEDICAL CONDITIONS IN AGING
ADULTS WITH DOWN SYNDROME:**

- **Vision loss/impairment** due to early cataracts (a clouding of the lens of the eye) and keratoconus (a distortion of the shape of the eye, which can impair vision)
- **Hearing loss**, which occurs more commonly with age and is often made worse by wax impactions, especially in small and narrow ear canals
- **Hypothyroidism**, a condition that causes an underactive thyroid gland, which contributes to symptoms of fatigue and mental sluggishness
- **Obstructive sleep apnea**, a sleep disorder that leads to poor quality, non-restorative sleep that makes people feel sleep-deprived even if they appeared to have had a full night’s sleep
- **Osteoarthritis**, which can cause pain and stiffness that can make tasks more difficult to perform or can contribute to overall irritability
- **Atlantoaxial instability and cervical spine disease**, caused by congenital and/or degenerative changes in the region of the spine



located at the base of the skull and neck, which can have a variety of effects on normal movement, strength, and function

- **Osteoporosis**, a condition that causes thinning and weakened bones that can lead to fractures which cause pain and impaired mobility
- **Celiac disease**, an autoimmune disease that causes an inability to digest wheat and gluten, which can lead to stomach distress, vitamin deficiencies, weight loss, and overall irritability

STAYING HEALTHY: BRAIN AND BODY ¹

It is never too late or too early to incorporate healthy habits into everyday life! Maintaining good physical and brain health throughout life is an important goal for everyone to strive to achieve. There is also growing evidence that these habits and interventions can help lower the risk for the development of dementia. There are many practices that adults with Down syndrome can incorporate into their lifestyle that will help promote cognitive and physical health over their lifetime. These lifestyle habits are important for all individuals with Down syndrome whether they are young and thriving, if they’ve reached old age, or if they’ve developed Alzheimer’s disease.

¹ Adapted from the
Alzheimer’s Association “10
Ways to Love your Brain.”
www.alz.org

Incorporating the following into daily life can help to optimize overall health and well-being and minimize additional risk factors that can affect brain function over time.

- Engage in **regular cardiovascular exercise** that raises the heart rate. Healthy blood flow to the heart helps promote healthy blood flow to the brain.
- **Stay mentally stimulated and engaged.** Adults with Down syndrome are encouraged to continue to build and expand lifelong learning by trying new things and setting new goals that help keep their brains engaged and working hard. Aim to regularly add in challenges with a new game or jigsaw puzzle to activate the brain. For adults with Alzheimer's disease, it is important to stay engaged in familiar tasks that are both mentally stimulating and pleasurable, to help reinforce existing strengths and abilities.
- **Don't smoke.** Make every effort to quit smoking. Limit exposure to second-hand smoke as well.
- **Lower risk factors for stroke and heart disease**, including obesity, high blood pressure, high cholesterol, and diabetes. Make good heart health a priority and get regular checkups and screenings.



- **Avoid preventable head trauma.** Brain injury can raise the risk of dementia. Wear a seat belt, use a helmet when riding a bike, and take any other necessary steps to avoid any preventable trauma to the brain.
- **Eat a healthy and balanced diet.** Adults with Down syndrome are at high risk of being overweight in adulthood, but with a healthy diet and exercise, this risk can be reduced. Aim to eat a diet that is low in fat and high in vegetables and fruit to help maintain a healthy weight. Try to avoid foods that are high in sodium and sugar.
- **Get rest.** Poor sleep can affect memory, concentration, and thinking. Adults with Down syndrome are also at risk of sleep apnea. Pay attention closely to sleep habits, aim to get a restful and restorative overnight sleep, and bring any additional sleep concerns to the attention of a health care provider.
- **Take care of mental health.** Untreated depression and other mood disorders can cause impairment in thinking and memory. Seek out help for concerns related to depression or anxiety and help create strategies to help minimize and manage stress.
- **Stay socially engaged.** Keeping up a social network of family, friends, and peers and engaging in activities that are fun and meaningful is instrumental to emotional health and wellbeing throughout lifetime. Look for ways to be part of the local community through volunteering or joining a club. Keep up with hobbies and interests that bring joy.

THE IMPORTANCE OF AN ACCURATE DIAGNOSIS

The diagnosis of any form of dementia is based primarily on clinical information, i.e., the history, signs, and symptoms that are brought to the attention of a health care provider. Currently, there is not one laboratory test, neuropsychological examination, x-ray, or brain scan that makes the diagnosis of Alzheimer's disease. Instead, the determination falls primarily to the health care provider who is assessing the individual and making a judgment about whether there is ample evidence to support a dementia diagnosis. Alzheimer's disease remains a complex diagnosis to make in the general population, in part due to natural variability in how medical providers review and interpret the information that they are given. However, in the hands of an experienced health care provider, a carefully made diagnosis is absolutely possible.

Making a dementia diagnosis in adults with Down syndrome can seem daunting for many health care providers due to a variety of factors: the inherent variability of baseline intellectual ability, the lack of standardized diagnostic tests, and the lack of any specialty training among health care providers. Most health care professional training still lacks any dedicated education or clinical experience in working with adults with intellectual and

developmental disabilities, including adults with Down syndrome. Despite these challenges, it is entirely possible to achieve a careful and thorough assessment of an adult with Down syndrome and suspected memory changes. Currently, the best assessment starts with a well-informed review of the individual's history, accounting for longstanding baseline abilities and a description of how and when these abilities started to change.

The diagnosis of Alzheimer's disease is one that should not be given casually or hastily. It is important that the diagnosis is made with a confidence that all other possible conditions or issues have been thoroughly investigated and addressed. Many health care providers are aware of the connection between Alzheimer's disease and Down syndrome, but this knowledge also at times leads to diagnoses that are made prematurely, without exploring the multitude of other common health conditions that could be playing a primary or key contributing role.

Through increased awareness of and vigilance for common medical, psychiatric, and emotional contributing factors, caregivers can help call attention to the possibility of these coexisting conditions. As mentioned earlier, there are several common conditions that adults with Down syndrome may encounter, most of which can cause symptoms that can mimic memory loss. If these conditions are present but not properly investigated, identified, or treated, there is a missed opportunity to address conditions that could potentially modify or improve symptoms. The same is true of mood disorders, such as undetected or untreated depression or anxiety, which can contribute to symptoms of confusion, poor concentration, inattention, or loss of interest to participate in tasks or activities.

An accurate assessment should pay close attention to changes that may be occurring in one's mood or behavior. In some cases, an untreated primary mood disorder may account for all of the symptoms that may have otherwise been characterized as signs of memory loss. Even more commonly, mood changes may co-occur with the onset or progression of dementia and may worsen or intensify certain symptoms. Thus, identification of mood disorders allow an important treatment opportunity that may carry great positive impact.

In summary, it is imperative that a medical provider evaluates for other conditions that may be either causing directly or contributing to the changes observed, while also working to confirm that the key changes identified are indeed suggestive of Alzheimer's disease. The following sections will provide a basic framework about seeking out a thoughtful and thorough assessment to help caregivers advocate for an accurate and careful diagnosis.



THE IMPORTANCE OF A BASELINE ASSESSMENT

An individual's history is the cornerstone of any dementia diagnosis. Recall that the diagnosis is not based on a single test result or brain scan, but instead on the medical provider's assessment of all of the symptoms taken into context for each individual. A core feature of an Alzheimer's disease diagnosis is the progressive loss of memory and other daily skills that *represent a decline from the individual's longstanding level of ability*. Therefore, any judgments made by a medical provider must be based on some basic understanding of what comprised the individual's baseline ability throughout their lifetime.

In adults with Down syndrome, or any form of intellectual disability, so-called 'baseline' abilities are highly variable. Some individuals achieve high-level academic skills, are voracious readers or accomplished artists, live independently, and take public transportation to their jobs. Some individuals may have never learned to tie their own shoelaces or to use the bathroom without help. Each individual is different and unique. This wide variability in possible lifelong abilities means that no assumptions can be safely made at the time of first assessment without gathering information for a baseline description. *Recognition of a progressive change from these baseline abilities is the cornerstone of an Alzheimer's disease diagnosis.*

Baseline abilities can and should be documented and tracked in two forms, **objective** and **subjective** information.

1. **Objective memory performance** refers to a concrete, measurable demonstration of skills. This is achieved by documenting a range of skills, abilities, and strengths that the individual has achieved in life. Some form of objective memory testing is recommended to be undertaken by age 35 or 40 so that there is a formal record of memory performance that could be used for comparison in the future if changes are noticed.

Specialized assessments involving some form of formal memory testing can be performed by a memory specialist – a geriatrician, neuropsychologist, neurologist, or psychiatrist. Ideally, an evaluation should be performed by a specialist with experience and expertise in assessing individuals with intellectual disabilities, and availability of such specialists is worth inquiring about in your area. Assessments should be adapted appropriately for the individual’s baseline intellectual disability, as many standardized tests developed for the general population are inappropriate for individuals with intellectual disability. Unlike assessments that are done in the typical population, memory evaluations that are based on comparison to peers of a similar age have no practical use.

There are many simple ways of informally collecting objective examples of one’s baseline abilities as well. Writing samples, drawings, art projects, and math worksheets, and personal journals are valuable pieces of information that can be compiled and used for reference of baseline skills and used for comparison if abilities start to falter with age. A collection of this information could also be done in other forms, like a video recording of the individual performing typical activities or talents: swimming, singing, using the computer, counting coins, or helping make cookies. Compiling a ‘scrapbook’ of abilities and achievements over one’s adult life can be a very positive and fun activity that would also serve as very valuable reference later in life when tasked with reflecting back upon changes over time.

2. **Subjective memory performance** refers to a narrative description of the unique baseline abilities and characteristics of an individual. Family members or longstanding caregivers who have known the individual for several years or more are usually best equipped to describe baseline abilities and characteristics. For younger people, a baseline description of abilities is something that could be compiled like a journal or a story throughout adulthood, documenting achievements while the individual is thriving and doing well.

Baseline descriptions can also be reconstructed historically or retrospectively, detailing lifelong abilities, strengths, and weaknesses throughout the individual’s lifetime through the recollections of people who know the individual well. Subjective information is often what is heavily relied upon in memory assessments, especially if there are no

other objective measures or formal baseline memory testing that exists representing baseline abilities. A clear outline of baseline function provides a direct comparison that can specific observed changes and may prompt further discussion with a health care provider or specialist. Changes are noteworthy if they represent a significant difference based on their own individual lifelong abilities. This will be detailed further in the next section.

IDENTIFYING CHANGE BETWEEN BASELINE AND CURRENT ABILITIES

There are various strategies that one may use to document and track baseline abilities over time, but a structured and comprehensive approach is recommended to capture abilities in a range of skills. **The NTG-Early Detection Screen for Dementia (NTG-EDSD)** is an early detection and screening instrument designed specifically for use by caregivers and staff to identify early signs and symptoms of dementia in adults with intellectual disability. It is important to note that the NTG-EDSD is not used to diagnose dementia, but it can screen for specific areas of change that can further direct discussion and evaluation with a health care provider. The NTG-EDSD can be used to document baseline abilities and then tracked on a periodic basis to survey for any observed changes from baseline in areas such as memory, behavior, daily care abilities, and general functioning. This may be done yearly in preparation for an annual medical examination or done more frequently if other concerns arise. If changes are noted, this screening tool can help prompt caregivers to seek a formal assessment from a health care provider. Links to the NTG-EDSD and related materials can be found on the NDSS website as well as at www.aadmd.org/ntg.

Another strategy is to use a **narrative format**, which allows the caregiver or family member to be descriptive in detailing typical patterns or abilities. The worksheet that follows outlines an example framework in which such a narrative could be constructed, highlighting seven different categories of baseline ability that are important to track over time. The “**baseline**” portion is best completed by someone who has known the individual for several years or more and can confidently describe or recall typical abilities and milestones achieved over adulthood. The “**current**” portion is best completed by someone familiar with typical day-to-day abilities that are observed presently.

For individuals who are doing well and showing no signs of change or concern, this narrative worksheet is also highly useful for documenting baseline abilities in a proactive fashion. This helps provide an ongoing narrative record of what an individual has achieved throughout adulthood.

BASELINE ABILITIES AND CHARACTERISTICS

Describe the individual’s abilities that are/were typical of what he/she can/could do throughout adulthood. Be as descriptive as possible!

FUNCTION	How independent was the individual in performing self-care tasks throughout lifetime – i.e.; bathing, dressing, toileting, grooming, eating, and walking?
SKILLS	What academic skills were achieved? What chores or responsibilities could the individual perform around the house? What jobs has he/she held? What activities would he/she typically do at day program? Any other talents or abilities throughout lifetime? Hobbies, sports, other favorite activities?
MEMORY	Could the individual learn and recall names of familiar people? Keep track of the day of the week and daily or weekly schedule? Know his/her way around familiar areas? Reliably remember short term or newly-learned information? Could he/she reliably recall recent past events? Any particular memory talents or skills?
BEHAVIOR	What behaviors have been present throughout adulthood? Self-injurious behaviors? Aggression towards others, either verbal or physical? Self-talk or imaginary friends? Any other quirks or rituals? Has the individual required a behavior plan? If so, what strategies have been helpful? Any other typical pattern or triggers to behaviors over lifetime?
LANGUAGE	Could the individual express him/herself verbally to let his/her basic needs be known? Speak in full sentences? Hold a conversation? If he/she was never verbal, how were needs expressed? Could the individual understand verbal language and answer questions appropriately or follow a verbal instruction?
PERSONALITY	Did the individual seek out peer relationships? Was he/she social? Well-liked by others? Did he or she show preference for routine and structure? How else would you describe his or her personality?
MOOD	What was the individual’s mood like most days? Were there mood swings? Any mood/psychiatric issues that recurred or persisted throughout adulthood? Did he/she receive psychiatrist or therapist? Any past psychiatric hospitalizations?

CURRENT ABILITIES AND CHARACTERISTICS

Now describe the individual’s current abilities - highlighting, when applicable, the areas in which changes are noted compared to what was described above in the baseline section.

FUNCTION	Lately, how independent is the individual in performing self-care tasks? Bathing, dressing, toileting, grooming, eating, and walking? Have changes been observed in functional abilities compared to baseline? Describe.
SKILLS	Compared to what was outlined at baseline, how have typical daily skills and abilities changed? Is the individual still participating in baseline abilities, routine tasks, and household chores? Has job performance or participation in day program activities changed?
MEMORY	What concerns are there about memory skills? Increased forgetfulness, confusion, disorientation, poor concentration? Repeated stories or repeated questions? Forgetting names, mixing up days of the week, etc? What has changed compared to baseline?
BEHAVIOR	How have behaviors been lately? Are new behaviors emerging? Has there been a change in the frequency or intensity of typical behavior patterns? Any other new triggers for behaviors noted? What tends to make behaviors better?
LANGUAGE	Have language abilities changed lately? Is the individual able to let his or her needs known per usual? Has vocabulary gotten smaller or verbal output declined overall? Difficulty finding words? Difficulty hearing and answering questions, or difficulty following verbal instructions?
PERSONALITY	Any recent shifts in personality? Increased irritability, stubbornness, intolerance to change, withdrawal? Any other observed changes compared to baseline?
MOOD	Have there been observed changes in typical mood? Increased mood swings, tearfulness, sadness, withdrawal? Hearing voices? Seeing or hearing things that are not there?

After reading through each section individually you are encouraged to *compare and contrast baseline vs. current abilities and note if any patterns are present*. Observe if any domains, i.e., mood, behavior, personality, are starting to shift noticeably while others staying stable over time? Is there a time frame when changes started to emerge? Are there any other observations or thoughts that arise when reviewing the information altogether?

Both the NTG-EDSD and this narrative exercise can be used as a stepping stone to help identify patterns of change and to prompt further thought about what else may be contributing to observable changes. Caregivers should look at the timeline over which changes have been noted and reflect upon whether any other important event or change may have happened at the same time. Was there a significant life event, a loss, a personal stressor, a change or upheaval in the home setting or day program? Was a new medication started? A medication stopped? Were there any injuries, acute illnesses, surgeries, or hospitalizations?



OTHER SYMPTOMS TO CONSIDER WHEN MEMORY CONCERNS ARISE:

In addition to the narrative information included in the worksheets, **reflect further on key symptoms**, looking either for entirely new concerns or a worsening of longstanding symptoms. This can help identify other contributing factors that may need further evaluation.

- Any new **change or decline in vision**
- Any new **change or decline in hearing**
- Any **dental concerns**, especially those that could be contributing to pain or change in eating habits
- **Seizure activity**, either new suspected seizure activity or an increase in seizure frequency in an individual with a known seizure disorder
- New or worsened **incontinence of bowel or bladder**
- **Weight fluctuations**, either a noticeable gain or loss
- **Change in appetite**
- Any observed **swallowing difficulties**
- **Sleep difficulties** or other abnormal sleep patterns or habits
- New **difficulty walking** or changes in walking abilities
- **Falls** or increased risk of falls
- **Pain**, either directly reported or suspected through observation of facial expression or other non-verbal clues

Applying the same approach used in the narrative worksheets, it is important to highlight the areas where *change* is noticed compared to the individual’s typical lifelong symptoms. Sharing this information with a health care provider can help prompt additional investigation for other underlying causes of change.

SEEKING AN ASSESSMENT

When memory concerns first arise, many individuals seek attention first from a health care provider. There are several common medical conditions that may occur in adults with Down syndrome as they grow older. Many of these conditions can cause symptoms that can be misinterpreted as confusion or poor concentration, so it is important to keep these in mind when seeking out an evaluation for the first time.

EXAMPLES OF NEXT STEPS COULD INCLUDE:

- **Vision and/or hearing testing** to assess for sensory losses
- **Blood work** to evaluate for any disturbances in electrolytes, vitamin deficiencies, or thyroid dysfunction, or to screen for celiac disease
- A **sleep study** to assess for sleep apnea
- **X-rays or other imaging** to assess for arthritis or degenerative changes in the large joints or cervical spine (neck)
- **Assessing for depressed mood** or other underlying mood disorder



THE IMPORTANCE OF A MEDICATION REVIEW

A thorough review of the individual's medication list is an important initial step in the evaluation of any new onset change or decline from baseline. Aging individuals may see multiple doctors and specialists, many of whom may prescribe medications or change treatment plans without collaborating with one another. Anytime the medication list expands or new prescriptions are started, there is an increased risk that prescribed medications may interact negatively with one another or may combine to make side effects more potent.

There are numerous types of medications that can have adverse effects on alertness and mental clarity, which can contribute to symptoms of confusion, dizziness, and walking/balance disturbances. All medications, including prescribed, over-the-counter, and herbal medications should be periodically reviewed with a health care provider to make sure that all medications are necessary and that their benefits outweigh any unwanted risks. This is especially true at times of transition, such as when an individual is being discharged from the hospital, seeing a new doctor, or moving to a new residence. When a concern is raised about new or worsening confusion, a careful evaluation of the medication list is always an important and necessary step. A thorough review may reveal a new medication that the individual may not be tolerating, or may call attention to a recent dose adjustment or discontinuation of a longstanding medication.

ARRIVING AT A DIAGNOSIS

Alzheimer's disease is a diagnosis of both *inclusion* and *exclusion*. In other words, evidence supporting a diagnosis should *include* a convincing history (progressive loss of memory and skills compared to one's baseline functioning) and should *exclude* all other plausible conditions that could have caused the changes observed (i.e., grief, acute infection, depressed mood, medication side effects, untreated severe sleep apnea, dehydration and so on).

If any coexisting medical or psychiatric conditions are identified, efforts should focus on treating them to the fullest extent possible. For example, if an individual is found to also have depression, sleep apnea, or an underactive thyroid, a treatment plan to address these underlying issues should be devised with a health care provider. Identifying and treating any and all potentially correctable or modifiable conditions is vitally important, followed by observation of any effect the treatment had on the individual's thinking and function. If the decline is still noted despite best efforts to improve or treat all other contributing conditions, then this further strengthens evidence of an Alzheimer's disease diagnosis.

NOW WHAT?

As earlier sections have emphasized, it is critically important to ensure that an Alzheimer's disease diagnosis is made thoughtfully, methodically, and carefully. However, oftentimes medical encounters are so focused on making the diagnosis, that there may be little time left for discussion about the various implications of the diagnosis. This "now what?" discussion that should follow an Alzheimer's disease diagnosis should ideally be both person-centered and relationship-centered, addressing the practical, day-to-day concerns that can affect the wellbeing of the individual and his or her caregivers. This topic is of paramount importance, and this section aims to provide more clarity to the questions that commonly arise after the diagnosis is made.

THE NATURAL PROGRESSION OF ALZHEIMER'S DISEASE

Alzheimer's disease is very broadly characterized by a gradual decline that progresses through three stages: **early**, **middle**, and **late stage**. These stages are distinguished by their general features, which tend to progress gradually throughout the course of the disease, accompanied by incremental loss of abilities and skills and increased need for support, supervision, and assistance.

Each individual is different and will experience changes in his or her own unique way. The stages of Alzheimer's disease do not appear as one pure complete cluster of symptoms or features, but rather a range of losses and changes, as some features may appear earlier or later than others and may be intermittent. The table that follows provides a general description of the type of changes that are typically seen at each stage. It is helpful for caregivers to have a general sense of where an individual may stand along the overall progression of Alzheimer's disease, whether it is early, middle, or late stage. This awareness helps prompt vigilance for other changes that may be encountered later in the disease course and can help with broader concepts of decision-making and priority-setting in an individual's overall care.

SHARING THE DIAGNOSIS

It is important that the diagnosis of Alzheimer's disease be shared with the individual with Down syndrome in words and concepts that can be readily understood. A lengthy discussion about the nature of the disease may not be appropriate for most individuals, but it is important to look for an opportunity for a direct and honest discussion about the diagnosis and the effect it may have on him or her. For some individuals with Down syndrome, explaining that feelings of forgetfulness and confusion are due to a disease may even bring a sense of relief. Validation of feelings of frustration, anger, or sadness is important as the individual copes with these changes, emphasizing that the forgetfulness is not his or her fault.



Similarly, sharing the diagnosis, even in very general terms with housemates, friends, and peers can be very helpful, as they may often be confused or scared by changes that they are witnessing. Friends can be a great support and often want to be helpful, particularly if they're given the basic understanding that the individual has a problem with his or her memory. If not addressed, often housemates or peers will have difficulty understanding why their friend's behavior is changing or why they're getting 'extra' attention or not following rules like they should. Allowing friends to be involved in the process can be a great way of letting them follow their own natural instincts to help while allowing the individual to maintain lasting connections with his or her friends and housemates.

STAGES OF ALZHEIMER’S DISEASE

Adapted from “Stages of Alzheimer’s”, Alzheimer’s Association, www.alz.org

EARLY STAGE	MIDDLE STAGE	LATE STAGE
Episodes of short term memory loss	More pervasive short term memory loss with some decay of long term memories	Profound memory impairment, including long-term memories
Difficulty recalling recent events	Daily forgetfulness and confusion	Difficulty recognizing family
Telling the same story repeatedly	Deterioration or loss of some or all household chores or other daily tasks	Full dependency on others for all personal care tasks
Asking the same question repeatedly	Increased level of assistance needed for some aspects of personal care (e.g., bathing, tooth brushing, shaving)	Loss of mobility – primarily wheelchair or bed bound
Difficulty learning new information (like names)	Dependent on the prompts and reminders of caregivers to get through an average day	Significant loss of expressive speech (i.e., 6 words or fewer in vocabulary, mainly just vocalizations)
Difficulty finding the right word	Disorientation to concepts of day of week, recurring events, routine schedule	Total incontinence of bowel and bladder
Vocabulary becomes smaller or simpler	Increased difficulty recognizing people and recalling names	
Difficulty following verbal instructions	Poor judgment and safety awareness	
Appearing more “lost”, confused, or distracted	Difficulty navigating familiar places, getting lost	
Difficulty performing routine tasks, or forgetting steps of complex tasks	Mood and behavior fluctuations – agitation, poor frustration tolerance, difficulty coping with times of transition or change	
Decreased/impaired work performance or participation in day program activities	Wandering, restlessness	
Needing more reminders to get through a routine day	Physical changes related to progressive dementia: -New onset seizures -Urinary incontinence, possibly fecal incontinence -Swallowing dysfunction -Worsened gait and mobility, more unsteady, weak, or timid	
Mood or personality changes – more irritable or easily frustrated, paranoid or anxious		
Misplacing things or difficulty finding things in their usual location		

COMMON PHYSICAL COMPLICATIONS OF ALZHEIMER’S DISEASE

As Alzheimer’s disease progresses, physical functioning can become progressively impaired and can mirror the changes occurring with brain function and memory. While every individual with Alzheimer’s disease will not encounter all of these issues, the conditions occur frequently enough that caregivers are encouraged to be aware of them so they feel better prepared to seek help early if changes arise.

SWALLOWING DYSFUNCTION AND EATING DIFFICULTIES

As Alzheimer’s disease progresses, it is common to develop progressive difficulty eating or safely swallowing certain foods or fluids. This is due in part to memory loss, as individuals may not: 1) readily remember that they have or haven’t eaten, 2) remember how to properly chew/swallow or handle certain foods or utensils, or 3) recognize certain hunger or thirst cues. As the disease progresses, coordination and strength of swallowing muscles deteriorate, and the cough reflex that protects food/fluid from going into the lungs may weaken. As swallowing and eating become slower and more challenging, mealtime may take much longer than usual and there may be a further risk of decreased nutritional intake and weight loss. Swallowing difficulties also increase the risk of taking food or fluid accidentally into the lungs, which can lead to choking and possibly an infection. This process is called **aspiration**, with the resulting lung infection typically referred to as **aspiration pneumonia**.

CAREGIVER STRATEGIES TO HELP WITH SWALLOWING AND EATING DIFFICULTIES:

- Allow more time for eating.
- Provide finger foods that are easy to pick up.
- Provide smaller portions of food more frequently during the day.
- Observe for any changes in swallowing abilities, such as coughing or gagging while eating.
- Discuss swallowing or eating concerns with a health care provider to determine whether a more formal evaluation of swallowing is necessary.
- Cut food into smaller-sized bites.

INCONTINENCE

Bladder and bowel control deteriorates as brain function worsens, so the development of incontinence very commonly occurs as Alzheimer’s disease progresses. Memory impairment leads to: 1) difficulty interpreting bodily

cues that indicate the urge to use the bathroom, 2) inability to find the bathroom or properly ask for help, or 3) difficulty sequencing the typical toileting routine when in the bathroom. Individuals are often physically slower and less steady on their feet, and thus less able to dash off to the bathroom quickly, which can lead to accidents.

CAREGIVER STRATEGIES TO HELP WITH INCONTINENCE:

- Provide verbal reminders to use the bathroom.
- Mark the bathroom door with something familiar to the person.
- When an individual loses independence with toileting skills, help bring him or her to the bathroom every 2-3 hours while awake to help avoid accidents.
- Check for soiled sheets or wet bed clothes overnight.
- Aim to limit fluids before bedtime.

SEIZURES

Individuals with Alzheimer’s disease and Down syndrome are at increased risk of developing seizures as dementia progresses. It is important to be aware of this possible eventuality, to be watchful for any symptoms and act quickly to get medical attention. Caregivers should watch for any new, sudden onset of a change in alertness, uncontrollable rhythmic jerking of the arms or legs, unexplained staring spells, startled movements or episodes of loss of consciousness.

First-time seizures are not always witnessed, so it’s important to keep the possibility of seizures in mind if an individual with Alzheimer’s disease is found on the ground or floor for unknown reasons or if there is a new pattern of unexplained falls. If new seizure activity is witnessed or suspected, then further attention from a health care provider is recommended. Caregivers can greatly enhance the medical assessment for seizures by providing as richly detailed a description of the event as possible.



CAREGIVER STRATEGIES FOR CONCERNS ABOUT POSSIBLE SEIZURE ACTIVITY:

- Observe for any signs of involuntary jerking of arms or legs, rigid posturing or stiffening of the body, or loss of consciousness.
- Keep possible seizure activity in mind as the reason for unexplained unwitnessed falls that may be occurring.
- Seek attention from a health care provider with detailed description and discuss whether further testing or consultation is necessary to evaluate for seizure activity.

GAIT INSTABILITY AND FALLS

Gait (walking) and balance changes can occur over time due to a combination of memory loss and physical decline. Memory impairment adversely affects an individual’s ability to recognize and navigate his or her environment, to coordinate more complex skills, like climbing stairs or stepping off of a curb, and to be aware of how his or her body moves and occupies space. Many other factors that may occur with aging also impair walking and balance, such as worsening eyesight and hearing, loss of muscle strength, arthritis that causes pain and stiffness, and medications that can cause dizziness or poor balance. Falls can be a devastating and life-changing consequence of the deterioration of walking skills, especially if they result in injury or fracture that causes further physical setbacks.

CAREGIVER STRATEGIES TO HELP WITH GAIT AND BALANCE DIFFICULTIES:

- Offer or provide assistance, if possible, when in unfamiliar areas and on stairs, curbs, over thresholds or uneven terrain.
- Provide adequate lighting.
- Use sturdy, supportive, well-fitting footwear and clothing that fits properly.
- Seek assistance from a health care provider or physical therapist for recommendations about an assistive device (i.e.; a cane or walker) or other strategies to help make walking more safe and steady.
- Keep walkways and living spaces at home well-lit and free of clutter, throw rugs, and other tripping hazards.

PHYSICAL AND COGNITIVE WELLNESS IN ALZHEIMER’S DISEASE

Maintaining good physical, emotional, and cognitive health is a lifelong endeavor for everyone and one that should remain a top priority for individuals with Alzheimer’s disease. As dementia progresses, individuals experience increased vulnerability for physical, cognitive, or functional setbacks from even seemingly minor stresses, like a viral illness or a mild infection. Thus, an important aim is to preserve good physical and mental health and to avoid any preventable medical setbacks to the fullest extent possible. Below are some simple recommendations that serve as an important defense against pitfalls that can cause a more serious cascade of physical setbacks.

STRATEGIES TO HELP ENHANCE AND MAXIMIZE PHYSICAL HEALTH AND WELLBEING:

- **Avoid preventable illness** by using good hand hygiene and by avoiding contact with other people who have contagious illnesses like viral infections and common colds.
- Ensure the individual keeps up with **regularly recommended vaccinations**.
- **Schedule regular checkups** with a health care provider.
- Provide **adequate nutrition**, aiming to keep weight in a stable and healthy range.
- Provide **adequate hydration** to avoid complications like dehydration or constipation.
- Maintain good **daily oral hygiene**.
- **Preserve healthy skin integrity and maintain foot care**. Watch for redness, irritation, or breaks in the skin especially in the skin folds and groin. Moisturize dry skin and perform regular skin checks. Bring any new changes to the attention of a health care provider.

A NOTE ABOUT SUDDEN CHANGES

The natural progression of Alzheimer’s disease is typically a slow and steady decline over time. **Sudden or abrupt decline or rapid acceleration of losses is not consistent with the typical expected course of Alzheimer’s disease.** Therefore, any sudden change in mental status or physical functioning should prompt medical attention to look for other root causes that brought on these new changes.

Caregivers are advised to be watchful for any sudden changes rather than the typical gradual losses seen with Alzheimer’s disease. Examples of a sudden change may include: an individual with Alzheimer’s disease who usually can walk normally but suddenly is unable to stand or walk on his or her own power, or an individual with early stage Alzheimer’s disease and only mild forgetfulness who suddenly becomes completely disoriented and confused. Alzheimer’s disease alone does not provide the complete explanation for the dramatic changes seen in both of these scenarios, and more investigation would be warranted to look for other causes.

Sudden changes in mental status should be evaluated promptly, as **delirium** (a state of acute confusion) can occur with any number of other physical illnesses. Adults with Alzheimer’s disease are at greater risk of developing delirium, and the range of underlying acute causes is broad, including infection, dehydration, medication intolerance, medication side effects, pain, and so on. In delirium, the underlying cause must be identified and treated to help reverse the course of acute confusion. Be vigilant for acute or sudden changes and do not dismiss them as part of underlying dementia. Seek medical guidance or attention for any sudden or unexpected dramatic change in mental or physical functioning.



TREATMENT OF ALZHEIMER'S DISEASE

Dementia treatment revolves largely around the day-to-day care and support provided by caregivers. Unfortunately, currently there is no cure for Alzheimer's disease, and medications are not the cornerstone of treatment. The medications that are used to target the cognitive symptoms of Alzheimer's disease typically provide a modest impact on the individual by treating the symptoms of dementia without impacting the underlying disease process. At their best, they may help slow the progression of the disease, but they do not restore memory or stop further memory loss.

It is beyond the scope of this booklet to discuss available Alzheimer's disease medication treatments in detail, but readers are highly encouraged to discuss this in more depth with a health care provider or seek information from the Alzheimer's Association or similar resource. While medical treatments for Alzheimer's disease are often not dramatic in their impact, medications that address other coexisting conditions do carry great potential for visible results. Treatment of common coexisting conditions that may be identified in adults with Down syndrome may help by relieving pain, disorientation, depression and other discomforts.

A few examples of treatment of coexisting conditions include:

- Starting thyroid hormone replacement medication if an underactive thyroid is discovered
- Starting an antidepressant medication if the individual is felt to have depression
- Initiating medication to help alleviate pain if arthritis or other pain sources are felt to be contributing to mobility limitations and/or irritability or behavior changes.

GENERAL PRINCIPLES OF CAREGIVING FOR ADULTS WITH ALZHEIMER'S DISEASE

As memory loss progresses, life becomes ever more focused on the present moment. The loss of short term memory makes 10 minutes ago seem like ancient history and the concept of 10 minutes from now too abstract to grasp. If there is a moment to breathe and appreciate it, there is some beauty to be found in being forced to think *only* of right now. By accepting this core fact, caregivers can enter the present here-and-now with the individual and help meet them where they are at that very moment.



Knowing that dementia is a dynamic process, the ability of a caregiver to adapt to change is helpful. Change is one of the guarantees that accompanies an Alzheimer's disease diagnosis. Whatever works today may not be effective six months from now, so stay attuned to the changing needs or patterns of the individual and try to continually reassess what is working and what is not.

Keep in mind that feelings and emotions remain accessible in adults with Alzheimer's disease. Even as memory changes, emotions can provide a good opportunity for connection that supersedes words or logic, and this can be quite a powerful tool to help both the individual and the caregiver feel heard and understood. Alzheimer's disease makes the world more confusing and disorienting, which can stir up feelings of fear, panic, and anxiety. Awareness of these key emotions can allow the caregiver to find solutions that defuse those feelings and move towards a feeling of comfort and security.

**PRACTICAL PRINCIPLES AND TIPS FOR CAREGIVERS
OF ADULTS WITH DOWN SYNDROME AND
ALZHEIMER’S DISEASE**

- The individual is more than his or her disease.
- Keep the essence of the individual alive in your mind. What is important to him or her? What have been his or her lifelong preferences?
- Educate yourself – learn about dementia, what to expect, and what resources are available to help you.
- Acknowledge and respect feelings – both your own and those of the individual with dementia.
- Tap into emotions to find a connection - they are powerful communicators if used properly. Gestures like a warm smile, a hand to hold, or a reassuring hug, can say everything without saying a word.
- Be kind...to yourself and to the individual.



- Maintain relationships – for the individual with dementia and for yourself. Stay connected with important long-term relationships and friendships. Keep up social connections with family, friends, and peers.
- In general, provide help only to the extent that it is needed. Resist the urge to just take over and do the entire task because it will take less time or would just be easier.
- Allow the individual to preserve and strengthen existing skills and abilities for as long as possible – this helps him or her preserve their dignity.
- When speaking or interacting, try to maintain a positive tone.
- Maintain a structured, predictable, and familiar daily routine. If most days have a familiar rhythm and flow, this will enhance a sense of safety and security and will reduce anxiety.
- Remain engaged in a variety of mentally stimulating, familiar, and pleasurable activities. Choose activities that use an individual’s existing strengths and abilities, to maximize a sense of capability and healthy self-esteem.
- Aim to make activities as “failure proof” as possible to avoid frustration and agitation. Good options are familiar activities that require only 1 or 2 basic steps, like folding dish towels, watering plants, or sorting coupons.
- Aim to stay physically active on a daily basis. Taking a walk together is good for everyone involved, and movement can help expend extra energy while helping promote circulation.
- Support healthy engagement in daily life. Adults with dementia gradually lose the ability to initiate action on their own, and boredom can increase anxiety, agitation, and distressing behaviors.
- Allow time and space to grieve for the losses that are experienced.
- Enjoy the present moment, celebrate the small victories, and live for the day.

PLANNING FOR A MEANINGFUL DAY

Given the progressive and ever-changing nature of Alzheimer’s disease, caregivers are encouraged to incorporate activities that bring enjoyment, maintain dignity, and foster existing strengths and capabilities. Structure each day around familiar, mentally stimulating, activities to foster a feeling of value, independence, and healthy self-esteem. These activities will shift and simplify over time but should always emphasize enjoyment and minimize frustration which can lead to anger, sadness, or distressing behaviors.

PRACTICAL TIPS IN PLANNING MEANINGFUL ACTIVITIES¹

When planning activities for an individual with dementia, focus on the person, the activity, the approach, and the place.

¹Adapted from the Alzheimer’s Association, www.alz.org

PERSON	• Stick with activities that the person has always enjoyed, adapt as needed to match current abilities. • Pay attention to what activities or settings seem to make the person most happy and relaxed. • Be aware of physical problems, such as arthritis or joint stiffness, vision or hearing loss, and adapt or avoid activities where this would pose a problem or limitation. • Provide choices, offering a few options or visual cues.
ACTIVITY	• Focus on enjoyment, not achievement. • Encourage activities that fit into daily life - wiping down countertops, emptying the trash, etc. • Look for favorites - especially if certain activities were a routine part of a typical day - i.e., looking at the sports section, having a cup of tea, clipping coupons, listening to music, etc. • Change activities as needed. Be flexible based on changing needs. Reduce distractions. • Consider the time of day. Pay attention to what time of day the individual seems the most relaxed or calm. Timing of certain activities may need to be adapted to different times of the day to be more successful, such as the showering routine. • Adjust activities to the disease stage - as dementia progresses, introduce more repetitive tasks. Be prepared for the individual to eventually take a more passive role in activities. • Recognize that some agitation may occur late in the afternoon and plan some diversionary activities or offer a quiet room.
APPROACH	• Offer support, cues, and supervision. • Concentrate on the process, not the result. • Be flexible - don’t force an action or response. • Allow more time to complete activities than previously. • Be realistic. Create a mixture of activity and rest. • Break activities into simple steps and focus on one task at a time. • Let the individual feel useful and helpful. • Relax your expectations. • Don’t criticize or correct. • Encourage self-expression. • Involve the person through conversation. Talk to the individual about what you’re doing. • Try again later. If something isn’t working, it may be the wrong time of day or the activity may be too complicated. Try again some other time, or adapt the activity.
PLACE	• Make activities safe. • Change your surroundings to encourage activities - have scrapbooks, photo albums, or magazines within reach to help the person reminisce. • Minimize distractions that can frighten or confuse. • Look around your home and see if there are features that may disorient or frighten (e.g, shadows, strange images) and increased the lighting or move the features.



Create a fairly predictable daily schedule to help reduce feelings of anxiety and fear. As dementia progresses, daily activities may take much longer and planning for this inevitability can reduce stress for the individual and the caregiver. For example, in late stage dementia, it may take two hours to get dressed and eat breakfast. The routine is always evolving so accomodate adapt to what the individual can handle at the current time.

The Alzheimer’s Association outlines an **Example of a Daily Plan** for early-to middle-stages of the disease. Below is an adapted version which can also be revised based on the routines of the individual’s current daily plan of activities and as strengths and capabilities change over time.

EXAMPLE OF A DAILY PLAN

MORNING	AFTERNOON	EVENING
- Toilet, wash, brush teeth, get dressed - Prepare and eat breakfast - Have tea, make conversation (talk about the weather or the day, using the newspaper or a calendar) - Fold laundry, try a craft project, reminisce over old photos - Take a break, have some quiet time - Do some chores together - Take a walk, play an active game or do an art project	- Prepare and eat lunch, wash dishes - Listen to music, look at magazines or photos, watch TV or a video - Do some gardening, take a walk, visit a friend - Take a short break or nap	- Prepare and eat dinner, clean up the kitchen - Reminisce over dessert, looking at old photos or listening to favorite music - Play a game, watch a movie, give a massage - Wash or take a bath, get ready for bed, incorporate other bedtime routines

Adapted from the Alzheimer’s Association
“Creating a Daily Plan”, www.alz.org

EXAMPLES OF ACTIVITIES APPROPRIATE FOR ADULTS WITH ALZHEIMER’S DISEASE

Adapted from the Alzheimer’s Association
“101 Activities”, www.alz.org

CONVERSATION

- Look at old pictures to prompt reminiscing
- Discuss the weather using the newspaper
- Talk about special date events using a calendar
- Read a book
- Discuss magazine pictures/photos

- Make a greeting card
- Cut/tear pictures for collages
- Color pictures
- Make scrapbook
- Make seasonal decorations

ARTS

- Listen to live music at a community concert
- Use musical instruments (e.g., drum, xylophone, shakers)
- Sing favorite song
- Dance
- Make a family poster
- Knead modeling clay
- Finger paint
- Sand paint
- Sponge paint

USEFUL HOUSEHOLD CHORES

- Fold laundry
- Match socks
- Wash silverware
- Wash windows
- Bake cupcakes or cookies
- Cook a favorite food
- Help make a salad
- Make a sandwich
- Make pudding
- Make a pie from a premade shell

- Arrange flowers
- Help water plants
- Clip coupons
- Make lemonade
- Put out birdseed
- Take out the trash

PHYSICAL ACTIVITIES

- Brush hair
- Massage hands with hand cream
- Toss ball or balloon
- Blow bubbles
- Modified bowling
- Lift small weights
- Chair exercises
- Stretching exercises
- Get manicure
- Ride exercise bike
- Feed ducks
- Rake leaves
- Sweep a patio
- Take a walk in the neighborhood or local park

- Visit a favorite outdoor area
- Walk in the mall
- Plant seeds in pots
- Have a picnic
- Sand a wood block

MISCELLANEOUS

- Look through a clothing catalog or other magazines
- Do puzzles
- Play dominoes
- Play checkers
- Take photos
- Sort coins
- Visit a house of worship
- Have coffee, tea, or ice cream together



COMMUNICATION

Communication is both verbal and nonverbal. As Alzheimer’s disease progresses, processing and understanding verbal communication gradually becomes more difficult and thus responses may take longer. Caregivers can help by simplifying verbal communication - using shorter sentences and smaller words, and pairing words with a gesture, gentle touch, or pointing to help get the message across more easily.

As verbal skills decline, individuals often rely more heavily on emotional cues, tuning into tone of voice, facial expression, or body language as a means of trying to interpret what is being said. For example, if a caregiver is feeling frustrated or angry and is speaking in a loud voice with a tense facial expression, the individual with Alzheimer’s disease may not fully understand the scenario, but may feel a natural instinct to act defensively.

As a general rule, negative tones and negative words like “Stop!”, “No!”, or “Don’t!” are best avoided. The same is true with negative body language or facial expressions. Adapting nonverbal communication to convey a nurturing sense of safety can be quite powerful, especially in times of stress. Keep the vocabulary simple and easy to understand, speak face-to-face at eye level, use short sentences, and use a gentle and relaxed tone of voice.

IMPROVING COMMUNICATION TO IMPROVE CONNECTIONS

In early stage Alzheimer’s disease, an individual may have difficulty finding the right word, telling a story, or keeping up with a conversation. Individuals may become less talkative as a result, or may struggle with answering a question. In middle stage Alzheimer’s disease, vocabulary will become more limited and the ability to express oneself in words will become more of a struggle. The ability to hear and understand spoken language will be further impacted, which can cause additional frustration. In late stage Alzheimer’s disease, communication is significantly affected, as individuals will have little to no verbal expressive abilities and will have very limited ability following even basic verbal instructions. Adapting communication over the course of Alzheimer’s disease is important to avoid the feelings that can arise from feeling misunderstood.

The following tips are recommended for more successful communication:

- Include the individual in conversations with others.
- Take time to listen to how the individual is feeling, what he or she is thinking or may need.

- Talk directly to the individual face-to-face, using clear, simple language.
- It’s okay to laugh. Sometimes humor lightens the mood and makes communication easier.
- Allow time for response so the individual can think about what he or she wants to say.
- Be patient and supportive, offering comfort and reassurance to encourage the individual to express his or her thoughts or feelings.
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what is being said.
- Avoid arguing. You will not win an argument with someone with Alzheimer’s disease. Let it be.
- Offer instructions or provide cues one step at a time.
- Ask one question at a time.
- Ask yes or no questions rather than open-ended questions. For example: “Would you like waffles for breakfast?” rather than “What do you want for breakfast?”
- Give visual clues. Point, touch, or gesture to help enhance understanding of what is being said.
- More often than not, the emotions being expressed are more important than what is being said. Look for the feelings behind the words and sounds.

LEARNING THE LANGUAGE OF ALZHEIMER’S DISEASE

In many respects, learning to effectively communicate with individuals with Alzheimer’s disease can feel like learning a new language. A successful dialogue does largely depend on the caregiver to mold and adapt their language, tone, and message to suit the individual they are talking to. When caregivers “learn the language of dementia” they can anticipate certain barriers and achieve the ultimate shared goal of being heard and understood. The following adaptive strategies can help avoid unnecessary tension or frustration between the caregiver and the individual at times when neither person feels like their needs are being fully understood.

ADAPTIVE STRATEGY: IT'S NOT ANYONE'S FAULT. IT'S A DISEASE.

When accidents happen or frustration arises, caregivers may often revert to communication techniques that feel familiar to parenting – raising his or her voice, expressing disappointment, or repeating a list of certain set rules or expectations. This approach commonly yields the exact opposite of the desired outcome from the individual with Alzheimer's disease, and may increase agitation, irritability, or combativeness. *Remember to avoid correction, use positive body language, as well as listen, observe closely and respond to the feelings or emotion behind the message.*

ADAPTIVE STRATEGY: STAY IN THE MOMENT

Communication in Alzheimer's disease centers on remaining in the present moment. *As a result, you should expect to repeat yourself, offer reminders multiple times, and hear the same question or the same story over and over.*

The concept of staying in the present moment also applies to problem-solving when challenging times arise. Memory loss and confusion frequently can lead to emotions of fear, anxiety, or anger for individuals affected by Alzheimer's disease. To help alleviate the mounting stress or anxiety that the individual may be experiencing, **positive redirection** can be a very powerful strategy to help address and defuse negative feelings and emotions. *You can try gently distracting or redirecting the individual towards a more calming or pleasurable activity as a way of changing focus towards a new positive present moment.*



For example, if an individual is starting to get agitated because he or she is insisting that a sister is coming to visit, rather than verbally correcting them (which will likely only escalate anger or start an argument) try redirecting to another topic or task. i.e.; *"Jimmy, I know you miss your sister. Gosh, the last time she visited you made that special peppermint hot chocolate together. Should we go in the kitchen and see if we still have some? Come with me and we'll see!"*

ADAPTIVE STRATEGY: MAKE SIMPLE REQUESTS.

Bargaining and incentives are common strategies used by many people throughout their lifetime to encourage or reward positive behavior, many times with good success. However, for caregivers of adults with Alzheimer's disease, this strategy is no longer useful or practical. For example, if a caregiver said the following: *"Laura, I'm not going to pick up this mess that you made. Please make your bed and put your art supplies away. If you keep things nice and tidy all day I'll take you swimming tonight."* In this scenario, the promise of a future reward is a concept that requires intact short term memory, which is impaired in individuals with Alzheimer's disease. Using this approach will not be effective in adults with dementia.

Behavior strategies that are designed around future rewards based on current behavior are destined to be a struggle, since this plan requires a working memory. Instead, behavior approaches should be adapted to meet the needs of the individual in the present moment. Effective strategies are those that primarily reinforce a sense of calm, reassurance, safety, and security. You can stay in the present moment, and attempt to positively redirect and negative behavior, and listen and respond to the emotion that the individual is expressing.

BASIC BEHAVIORAL PRINCIPLES

Behavior is a form of communication. As Alzheimer's disease progresses and language skills deteriorate, individuals who previously were very expressive may respond behaviorally rather than struggling with verbally expressing his or her basic needs and wants. In this scenario, one's behavior may become the key form of communication, as vocabulary becomes smaller or abilities to find words and make sentences gets more difficult. For example, an individual who could articulate his or her feelings may say: *"I'm upset. It's not fair that Jenny got to go food shopping with you and I had to stay home!"* However, an individual with dementia may just say *"Hey!"* and ball up their fist and hit Jenny.

Behaviors can ebb and flow and can take various forms - physical aggression, verbal aggression, yelling, vocalizing, combativeness with care, delusional thinking, cursing, paranoia, wandering, self-injury, and so on. For some individuals, old behaviors may re-emerge with Alzheimer's disease, and for others new behaviors may arise which may be surprising and out of character for the way the individual had always acted.

It is beyond the scope of this booklet to address every type of behavior that may be seen throughout the lifespan of dementia. Instead, this booklet emphasizes the common themes of behavior, particularly the concept of behavior as communication. The goal then is to try to understand what it is that the individual is trying to communicate through his or her actions. Problem-solving around behavior often feels like detective work - trying to find patterns, identify triggers, or look for other physical or environmental contributors. From there, the process is typically trial-and-error; attempting an approach to improve or modify the behavior and then observing for the response. This strategy is applied throughout the entire course of dementia, since the features of Alzheimer’s disease are always changing and therefore the response to behaviors will have to adapt and change over time too.

The following **three-step approach** can help identify common dementia-related behaviors and their causes.

- 1. **Examine the behavior**
 - What was the behavior? Was it harmful?
 - Did something trigger it? What happened immediately after?
 - Could something be causing the individual pain?
 - Could this be related to medications or illness?
- 2. **Explore potential solutions**
 - Are the individual’s needs being met?
 - Can adapting the surroundings comfort the individual?
 - Can I change my own reaction or approach?
- 3. **Try different responses**
 - Did my new response help?
 - Do I need to explore other potential causes and solutions? If so, what can I do differently?

COMMON CAUSES OR CONTRIBUTORS TO NEGATIVE BEHAVIORS:

- **Physical pain or discomfort:** illness, medication effects, hunger or thirst
- **Overstimulation:** loud noises or a busy environment
- **Unfamiliar surroundings:** new places or the inability to recognize home
- **Complicated tasks:** frustration stemming from difficulty with activities and chores

*Adapted from the
Alzheimer’s Association
“Behaviors”, www.alz.org*

- **Frustrating interactions:** inability to communicate effectively may cause fear, sadness, or anxiety
- **Personal upheaval:** family illness or poor health in a housemate, grieving over the death of a loved one, loss of a key staff member
- **Boredom:** due to declining ability to occupy unstructured time or to plan or initiate activities. Individuals with dementia become dependent on those around them to help keep them engaged. Boredom can be a major cause of behavioral issues.

A WORD ABOUT PAIN

Pain can frequently be an overlooked key contributor to negative behavior, poor sleep, or agitation. Because pain is subjective and thus dependent on the individual’s personal experience and perception of discomfort, recognition of pain symptoms can be missed by caregivers and healthcare providers.

Many individuals with Down syndrome have different ways of expressing pain throughout their lifetime. When Alzheimer’s disease is present, the expression of pain can be muddled even further. It is not practical to only rely on self-report of pain, since many individuals will not have the means to express their pain symptoms specifically - i.e.; *“the back of my right knee is really throbbing!”* Instead, look carefully for nonverbal clues of pain or discomfort or to look for any signs of potential pain sources when providing care to the individual. Reviewing the individual’s lifelong tendencies around pain reporting can be helpful. Gather information from family about typical facial clues or sounds that have typically correlated with pain symptoms in the past.

Stay mindful of the possibility of pain as a contributing factor when behavior, mobility, or overall demeanor changes. Recall the common conditions that occur with age in adults with Down syndrome: such as osteoporosis and osteoarthritis. These conditions, coupled with increased immobility or risk of skin breakdown or irritation, all raise risk for discomfort or pain. Thus, caregivers and health care providers can together maintain a high suspicion for pain and look for further evidence of pain symptoms or sources so that this important and treatable factor can be properly addressed.

TYING IT ALL TOGETHER: COMMUNICATION AND BEHAVIORAL STRATEGIES

Incorporating certain core principles and ideas into the overall care of an individual with Alzheimer’s disease will help point caregivers in the right direction when trying to problem solve around their own specific challenging scenario.

Key strategies for success with communication and behavior challenges:

- **Validate feelings, empathize.** Remember that actions are often borne out of fear, so reinforce reassuring statements such as “I’m here to help you”, “You’re safe”.
- **Stay in the present moment** when interacting with individuals with Alzheimer’s disease. The present moment is all you have.
- Anticipate certain stressful events or times of day and plan accordingly to **minimize anxiety**.
- Try to **tie a pleasurable or distracting activity to a stressful or unpleasant activity** to make it more manageable. For example: put on headphones and play favorite music when cutting toenails, sing songs while giving a bath, bring a soft blanket or other comfort object on the van ride home from the day program.
- **Do not attempt to reason or rationalize.** You will not win an argument with someone with Alzheimer’s disease.
- **Stay engaged in pleasurable activities.** Individuals will depend more on the guidance and supervision of caregivers to keep busy.
- Get familiar with the “art” of **positive redirection**. Practice shifting focus and redirecting at times of stress or escalating behavior.

CARE FOR THE CAREGIVER

The word “caregiver” encompasses a very diverse group: aging parents, siblings, extended family members, friends, volunteers, paid professional or lay staff, or other individuals in a committed relationship with the individual.

Parents are often lifelong caregivers, but when a son or daughter is diagnosed with Alzheimer’s disease the caregiving role can expand dramatically. This often occurs at a time when parents may be facing their own age-related changes and challenges. Due to the all-encompassing role they play as caregivers over the years, many aging parents may have had fewer opportunities to create and nurture ongoing support through friends



and community. With an Alzheimer’s disease diagnosis, when extensive supports are critically needed, families may find themselves unfamiliar with the network of systems or supports in their communities, which can be challenging and stressful.

With the steady increase in life expectancy among adults with Down syndrome, caregiving responsibilities now commonly shift from one generation to the next. Today, siblings very often find themselves moving into a hands-on caregiving role, sometimes also assuming care for an aging parent at the same time. Stepping into a primary caregiving role in the family while trying to balance his or her family and work responsibilities can be overwhelming for siblings, whether they live locally or are attempting to coordinate care from a distance away.

Paid caregivers, such as community services/support staff, may encounter a different variety of challenges. Alzheimer’s disease impedes an individual’s ability to learn new names and faces, which can mean that even staff who work on a daily basis with an individual may always be regarded as a stranger or may struggle with building trust and developing a rapport. However, working with individuals with Alzheimer’s disease can become more intuitive after learning an individual’s quirks, typical patterns, and preferences.

There can be great variability across community residential settings and among providers in terms of level of experience and familiarity with serving individuals with Alzheimer's disease. Some may have received formal or informal training on dementia, while others may have no required training at all. Education is empowerment in this situation, as a general understanding of Alzheimer's disease can help make working with individuals with dementia feel far more satisfying and rewarding.

Across all settings, caregiving is hard work. It can be a deeply loving, gratifying, and meaningful experience, while also at times being stressful, unpredictable, and mentally and physically depleting. The very nature of Alzheimer's disease, with its incremental and progressive decline, implies that caregiving takes stamina. This process is a marathon, not a sprint. For that reason, it is critical that caregivers find ways to replenish themselves, physically, mentally, socially, emotionally and spiritually.

Taking time for oneself can help reduce stress and allow caregivers to reconnect with who they are and what they need as human beings, so they can return to a role that so often asks/requires them to put their own needs aside.

Replenishment can be accomplished by:

- **Practicing good self-care.** Maintain a healthy diet, get plenty of rest and stay hydrated. See a health care provider for routine visits. Be open about the level of stress experienced.
- **Staying active.** The work of a caregiver can be quite physically taxing, but keep in mind that regular, dedicated physical exercise is excellent for reducing stress, promoting healthy sleep, and maintaining overall wellness. Whether by taking a brisk walk, going swimming, or taking a yoga class – finding an exercise routine that feels good and fits into a typical daily schedule will help increase the chances of sticking with it.
- **Staying mentally stimulated.** Caregivers are encouraged to take time to do something that is mentally engaging - reading the newspaper or a good book, doing a puzzle or a word game with friends.
- **Remaining socially engaged.** As a caregiver, it's often hard to find enough time in a day. However, it is important to stay connected to friends and family and to activities that you love. Even if it's only 30 minutes at a time, make time for friends and family and aim to do something fun or relaxing.

Strive to find joy in the little things.

- **Creating a support network.** Seek help and support from friends, family, volunteers, local organizations, religious groups, support groups, and paid staff. Reach out to other caregivers for support, encouragement, and ideas. It helps to know you are not alone.
- **Being kind to yourself.** Acknowledge and accept that you won't be able to do it all. Allow yourself to be imperfect in this process. Maintaining a kindness towards oneself helps caregivers access the kindness and compassion needed for the individual with Alzheimer's disease that he or she cares for.

CAREGIVER STRESS

Ideally, caregivers would find space and time to practice all of the self-care steps listed above on a regular basis. This is a worthy goal to aim for. However, sometimes caregiving responsibilities can be all-consuming, and achieving even one of these self-care goals seems impossible. As time goes on, the caregiver and the individual with Alzheimer's disease function more and more as a dynamic, interrelated partnership. The health and vitality of that partnership depends on the health and wellbeing of both the caregiver and of the individual.

Sometimes the stress of day-in and day-out caregiving is overwhelming and can lead to more serious symptoms of depression or burn-out. Symptoms of anger or irritability, anxiety, sadness, poor concentration, withdrawal from friends/family/activities, poor sleep, and worsened personal health may indicate that the stress of caregiving is having a negative impact on a caregiver's emotional and physical wellbeing. Caregivers should be mindful of the symptoms of stress or burnout, and pay attention to the feedback or observations that may be offered from trusted family and friends. Don't hesitate to reach out for help or talk to your health care provider or other trusted professional if the stress is overwhelming.

Caregiving is not something that can be done all alone. As Alzheimer's disease is always changing and progressing, it is important to recruit a support system early into the process so that there are people and resources to reach out to as the needs eventually arise.

The general goal in Alzheimer's disease caregiving is to stay at least a few steps ahead of the disease itself so that the caregiver and the caregiving environment can rise up to meet the needs as they come. This takes proactive planning, but this is critically important to avoid having to scramble to find help or additional resources in the setting of a crisis.



PRACTICAL NEEDS OVER THE LIFESPAN

There is no crystal ball that helps predict the future clearly for adults with Alzheimer’s disease. However, the time course and progression of dementia is also not a totally unknowable abyss. There is a typical progression of the features of Alzheimer’s disease as well as certain crossroads that individuals commonly encounter that can be anticipated and prepared for in advance.

Caregivers are encouraged to think proactively about the future, starting with assessing the individual’s current needs, the caregiving arrangement, and the current living environment. Taking these factors into account, consider what needs or concerns one might anticipate arising as memory and personal care skills decline.

For example, an individual living at home with his or her aging mother in a 2-story family home has unique and separate care-planning concerns compared to an individual who was living independently in a supported apartment at the time of his or her Alzheimer’s disease diagnosis. It is important to start a dialogue early and often about the individual’s caregiving needs and the needs of the caregiver, as this will change over time.

As a caregiver, examples of questions to consider include:

- How is the current caregiving situation working?
- Are you capable of meeting his or her current needs?
- What struggles or challenges are being encountered currently?

- What personal or physical limitations do you have?
- What might be a limitation for you in the future? As physical needs grow, what limitations do you see in being able to provide assistance in daily care?
- For how long will this current caregiving situation be sustainable or safe?
- Is this living environment suited for aging-in-place? Are there stairs, an old bathtub, a steep driveway, or other environmental barriers or limitations that would pose a practical or a safety concern for the individual and/or you?
- How much are you or the caregiving team prepared to take on?
- What needs and concerns do you have? Personal health issues? Financial constraints? Access to reliable respite care?
- Are you currently caring for or responsible for other people - children, aging parents, other clients?
- Are you still working full or part time?
- How is my caregiving role affecting my spouse or partner? My children and family?
- Are you willing to accept help in your own home?

With the diagnosis of Alzheimer’s disease, eventually tackling some important decisions is inevitable. Some decisions have to be made more immediately, while other decisions may lie in the future. Eventual changes in cognitive and physical functions require a proactive approach that considers:

Housing and living supports needs. This can be a challenging decision that depends on many factors, including the changing care needs of the individual at the different stages of Alzheimer’s disease, the situational capabilities of the family or caregiver, current housing/living situation, and care options and resources in the community. A person-centered and relationship-centered approach aims to keep the individual safe and cared for throughout all the stages of disease. In planning ahead, an aging-in-place model aims to provide a living setting that would allow for adaptations over time to accommodate the individual’s changing needs, and avoids having to transition to new care environments when

expected changes arise. Despite best efforts, aging in place may not always be possible.

Medical care. Many individuals with Down syndrome may find it challenging enough to find a health care provider with whom they feel understood. A diagnosis of Alzheimer’s disease can lend an additional challenge, although most adult health care providers should have at least a basic familiarity with managing patients with dementia. Finding a trusted health care provider is a very important support to help with concerns as they arise throughout the course of the disease and to help plan for the future and end-of-life.

Medical advocacy. It is important that a companion who knows the individual well accompany him or her to medical appointments or to the emergency room to help share history, current concerns, provide an accurate medication list, and to help assist a medical provider in communicating or interacting with the individual so as to enhance the care they receive. Time spent in preparation for appointments will enable the companion to use time wisely and communicate important issues. Aim to plan appointments based on when the individual is usually most alert and calm.

Legal matters. Many families or other designees may not have explored or planned for the legal, financial and health care planning issues that arise later in life. An Alzheimer’s disease diagnosis makes these issues even more relevant. Identifying a decision-maker such as a health care proxy or guardian is necessary as dementia progresses. Legal and financial options can vary from state to state so it’s important to check local resources proactively. Recording the person’s preferences, their likes and dislikes over his or her lifetime can help keep a person-centered approach to overall decision-making across the disease process. Check with your local Alzheimer’s Association or similar group for legal and financial resources.

Safety. Alzheimer’s disease can be accompanied by other changes that have an impact on the individual’s safety and ability to navigate their environment, such as altered depth perception, hearing loss, unsteady gait, risk of seizures, disorientation and confusion. Safety strategies can encompass home safety (such as removing clutter, improving overall lighting, clearing walkways). This can also include an emergency plan for wandering or getting lost, or if there was an unexpected loss of a caregiver. Organizations such as the Alzheimer’s Association have programs like **Safe Return** that

1 Additional information at www.alz.org

can be of assistance.¹

Cultural considerations. Embracing cultural diversity is important component of person-centered care, and allows for a richer understanding of an individual’s values and beliefs. Awareness, respect, and understanding of cultural diversity must be incorporated into all caregiving considerations. When an individual with Down syndrome and Alzheimer’s disease is entering a new living arrangement or meeting a new caregiver, be sure to provide information about cultural practices that he or she maintains or enjoys.

Overall coordination of care. Coordination, collaboration and communication help foster person-centered care. Involving a team of individuals that are knowledgeable in various aspects of care, and who share information and learn from each other, helps ensure continuity and consistency in the coordination of care for the individual.

PLANNING FOR THE FUTURE

Advance care planning consists of proactively expressing and documenting wishes about how to approach future scenarios that may arise. This is a critical component of Alzheimer’s disease care and should be incorporated into discussions throughout every stage of dementia after the diagnosis is made. Some people may have already accomplished some aspect of advance care planning even prior to their Alzheimer’s disease diagnosis, either by designating a **health care proxy** or naming a **legal guardian**, something that may have been already addressed during adulthood. If no aspect of future planning has yet been accomplished at the time of the Alzheimer’s disease diagnosis, this is important to undertake as soon as possible, making every effort to involve the individual in future planning.

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. Preparing proactively for these decisions protects individuals and their decision-makers from feeling rushed or blindsided by choices that are expected to likely arise in the setting of dementia.

End-of-life discussions generally encompass the following key considerations pertinent to progressive dementia:

Resuscitation. Resuscitation discussions refer to scenarios in which an individual is having a cardiopulmonary emergency (cardio: heart, and pulmonary: lung). When an individual’s breathing stops entirely or when there are severe breathing difficulties, a typical emergency response is to place that individual on a breathing machine called a ventilator.

Similarly, if an individual’s heart stops beating or is in a very dangerous heart rhythm, the typical emergency response is to perform chest compressions (CPR) or possibly deliver electric shocks (defibrillation). As dementia progresses, and especially when an individual is approaching late-stage dementia, decision-makers may outline overall goals of care that may or may not include attempts at resuscitation.

Artificial feeding. These wishes refer to decisions made when an individual’s swallowing worsens to the point that he or she is unable to safely swallow food or fluid without risk of choking. Poor nutrition and weight loss may also commonly arise as a consequence of swallowing difficulties, especially as dementia progresses. When an individual’s ability to safely eat is at risk, decision-makers are often faced with the option of artificial feeding, usually in the form of a feeding tube, either down the nose or directly into the stomach, to provide a means of nutrition. Risks and potential benefits need to be closely weighed in these situations, especially in cases of late stage dementia taking into consideration the overall goals of care for the individual.

Overall goals of care. A discussion about overall goals should take into consideration preferences, priorities, and overall philosophy about quality of life for the individual as he or she progresses towards late stage Alzheimer’s disease. Goals of care discussions often logically lead to further discussion about end-of-life, including a consideration of whether palliative care or hospice care would be desired when late stage disease is present.

It is beyond the scope of this booklet to provide extensive detail about end-of-life decision making, particularly because there are legal issues, terms, rules, and policies that vary from state to state. However, across all scenarios, designation of a health care decision-maker is necessary for an adult with Alzheimer’s disease, as dementia will render impossible any complex decision-making, even if the individual did have this capacity prior to their disease. A health care decision-maker is typically a designated health care proxy or a legal guardian. Again, the details of these roles are best left to further discussion with community supports and medical and legal professionals in the individual’s local area.



ALZHEIMER’S DISEASE AND END-OF-LIFE

Death in late stage Alzheimer’s disease is typically due to medical complications that arise related to progressive dementia, such as: recurrent infections (from skin/wound or bloodstream infections, aspiration pneumonia, or urinary tract infections), inadequate food or fluid intake, weight loss, or progressive failure to thrive.

Advanced/Late stage Alzheimer’s disease has 4 core components, all of which must be present to meet criteria for this stage of disease:

- 1. **Full functional dependency** - including loss of mobility (either primarily wheelchair or bed-bound), dependency for all personal care (bathing, dressing, toileting), and inability to self-feed
- 2. **Profound memory impairment** - including inability to recognize close family members or other important caregivers
- 3. **Loss of meaningful speech** - usually 6 words or fewer, or mainly just vocalizations or sounds

4. **Total incontinence** - including total loss of bowel and bladder function

Late stage dementia does not typically arrive in one pure set of features. For example, some people may show a number of these features but still retain the ability to walk or feed themselves. The natural progression of Alzheimer's disease eventually leads to late stage disease in everyone it affects, provided that they live long enough to manifest all features. Knowing that Alzheimer's disease is terminal, decision-makers may shift overall goals of care in the late stage to primarily emphasizing comfort, preserving dignity and quality of life. Individuals with Alzheimer's disease can qualify to receive palliative care and hospice services to provide additional support to the individual, if this is consistent with the wishes of the health care decision-maker.

Palliative care is a model of care that aims to prioritize the preservation of quality of life by preventing and treating discomfort and suffering. Aspects of palliative care can be offered throughout the continuum of Alzheimer's disease progression, if this is desired by the individual and his or her designated decision-maker. A multidisciplinary palliative care team can help provide input and collaborative physical, emotional and spiritual support, help in symptom management and help in recognizing when referral to hospice care is needed.

Hospice is a service offered by a professional interdisciplinary hospice team and authorized by a health care provider to promote comfort, provide symptom management for the patient, and support the family/caregiving team throughout the end of the individual's life and after his or her death. Adults with late stage Alzheimer's disease are eligible for hospice services, which can further support wishes that prioritize preservation of comfort, dignity, and quality of life. Individuals typically eligible for hospice are those who have all features of late stage dementia and who also are starting to exhibit signs of worsening health due to their disease, such as recent infections, weight loss, skin breakdown or ulceration. Palliative care and hospice services are predominantly home-based, and services and supports can be carried out in the individual's own home.

BEREAVEMENT AND GRIEF

For family, caregivers, and loved ones of an individual with Alzheimer's disease, grief and bereavement may often be an emotion that is interwoven into the progression of dementia. To experience Alzheimer's disease is to experience a slow and progressive loss of abilities and skills, which can be bring about feelings of mourning or loss on an ongoing basis. Caregivers are reminded to attend to these feelings and seek support throughout the process to help cope with feelings of grief, to replenish their spirit and to find strength to keep going. It is important to create these resources and supports throughout the span of the disease so that they can be made available for comfort and solace when death occurs.

Bereavement and grief over loss can also be profoundly experienced by people with an intellectual disability and is important to acknowledge and support housemates, friends, and peers who have been witness to the disease process and all of the visible changes that it may cause. Particularly for housemates or close friends, it is important to provide ample attention to the feelings and emotions that they may be experiencing, knowing that it can be a scary and sad experience that may be difficult to understand. Rituals and other commemoration activities of this individual's life are a part of relationship-centered care and can help console all involved. Validate feelings and allow happy memories or mementos to live on in celebration of the individual's life and the impact of his or her friendship.



AFTERWORD

Reminiscence can be an especially comforting process for family and friends the months and years after the death of a loved one. It is a normal part of the healing process. Enjoying old photos, telling stories, and recalling favorite expressions can bring laughter and joy back into the lives of those who are experiencing loss. The life lost can continue to be celebrated long after an individual’s death, and encouraging such rituals can be helpful for all as they seek peace in the special memories they shared.

For friends, peers, and housemates, a time of sharing can bring comfort and allow for the voicing of memories while providing an opportunity to identify any present concerns or lingering questions.

Lifelong caregivers may find the grieving process particularly painful and challenging. Recognition and commemoration of the special relationship shared over a lifetime can be a source of comfort, gratification, and meaning, as the enduring bond of caregiving can span space and time.

The collaborators of this booklet wish to express gratitude to people with Down syndrome, their families, caregivers, and peers for being our greatest teachers. Your shared wisdom and experience forms an important legacy and we sincerely thank you.

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