



END-OF-LIFE AND DOWN SYNDROME

A Companion Guidebook to
**AGING AND DOWN SYNDROME:
A HEALTH AND WELL-BEING GUIDEBOOK**

TABLE OF CONTENTS

Introduction	4
Aging and Down Syndrome Overview	5
Promoting Dignity and Choice	7
Thinking Ahead	9
Proactive Planning	11
Advance Directives and Decision-Making	13
Considering Brain Donation	17
Late-Stage End-Of-Life Care	18
Death, Grief, and Coping	20
Conclusion	22

ACKNOWLEDGEMENTS

LEAD AUTHOR, JULIE MORAN, DO

Julie Moran is an internist and geriatrician specializing in older adults with intellectual and developmental disabilities (I/DD). Dr. Moran is an attending physician of a specialty medical unit for adults with intellectual disability at Tewksbury Hospital in Massachusetts and is a statewide physician consultant for the Massachusetts Department of Developmental Services (DDS). She is a Clinical Instructor of Medicine at Harvard Medical School.

ADDITIONAL CONTRIBUTORS

Dr. Moran and the National Down Syndrome Society (NDSS) extend their thanks and gratitude to the dedicated working group who helped make this guidebook possible: Anna Esbensen PhD, FAPA, FAAIDD; Elizabeth Head PhD; Beth Kallmyer, MSW; Jeanne Kerwin, DMH, HEC-C; Leigh Ann Kingsbury, MPA, Kathy Service, NP; Anne Tournay, MD.; the Alzheimer's Association; and the National Task Group on Intellectual and Developmental Disabilities and Dementia Practices (NTG).

INTRODUCTION

This guidebook aims to provide guidance for the crossroads and decisions that arise in later life and at the end of life. The information in this guidebook is best approached proactively and ideally not at a time of crisis or emergency. However, for those readers who do find themselves reaching for this guidebook in a crisis, the information provided aims to be practical and supportive, with guidance and resources to help. Through the information in this guidebook, readers will recognize and understand the reasons that planning for your own future and having a backup plan for care of your loved one with Down syndrome are so important.



AGING AND DOWN SYNDROME OVERVIEW

The life expectancy for individuals with Down syndrome has changed significantly in recent decades and now averages around age 60.

LONGER LIFE can hold a wide range of experiences, including some exhilarating and triumphant moments like celebrating a milestone birthday, being honored for years of service at a job or in a community activity, or discovering new relationships and friendships as an adult.

However, growing older can also present an array of challenges for individuals with Down

syndrome, especially when general, cognitive, or physical health starts to decline. Adults with Down syndrome commonly present premature characteristics of growing old, often referred to as accelerated aging. As a result, many adults may appear to have a mismatch between their chronological or actual age and their apparent physical or functional age. In other words, individuals with Down syndrome

in their 50s can commonly exhibit features and challenges that are usually encountered in the general population by adults in their 70s or 80s. Therefore, references to 'old age' for adults with Down syndrome can apply to an individual in their late 50s, especially if they are showing signs of physical frailty and worsening physical or cognitive health.

The aging-related problems seen at earlier ages for individuals with Down syndrome include changes in physical functioning, mobility, cognition, and memory.

Common conditions experienced by older adults include:

- Diminished balance and/or sensory issues
- General movement/mobility difficulties from joint stiffness and discomfort
- Memory loss and declining skills due to the emergence of Alzheimer's disease/dementia
- Progression of hearing loss and low vision
- Osteoarthritis
- Osteoporosis





The features associated with these conditions, either alone or in combination, can contribute to an overall frailty and vulnerability that occurs with older age. More information about common conditions in adults with Down syndrome can be found in *NDSS Aging and Down Syndrome: A Health and Well-being Guidebook*, and in the resources section of this guidebook.

As adults with Down syndrome grow older, it can be increasingly challenging to manage illnesses and cope with health setbacks



or changes in physical abilities. This is especially true for individuals who develop dementia due to Alzheimer's disease, as the increased difficulty with thinking and memory can make once ordinary daily tasks seem confusing and unfamiliar. It can be challenging for aging adults who experience poor physical health to adapt to new health symptoms that affect overall energy or stamina and impact engagement in daily life.

For many individuals, their own experience of the aging process may be mirrored in the world around them as their peers and loved ones also grow old. Adults with Down syndrome will also more commonly witness the declining health, debility, and death of family members, friends, colleagues, and peers as they age.

Adults with Down syndrome can be quite emotionally perceptive and are often sensitive to the shifting health and well-being of those around them. This can bring up questions or concerns about their own health needs as time goes on and can cause fears around their own mortality. Further, as individuals experience their own medical or physical challenges, they may begin to ask questions about end of life and death. Materials about how to talk about death with your loved one with Down syndrome can be found in the resources section of this guidebook

Change is a common and recurring theme throughout the aging process. Some changes are slow and gradual, but others can feel unexpected or sudden and cause feelings of worry and confusion.

For people with Down syndrome, their families, or caregivers, feeling unprepared, overwhelmed, or ill-equipped to face aging-associated changes can contribute to stress at an already difficult and sad time.

While individuals with Down syndrome are living longer, death still occurs at younger ages compared to their same-aged peers without Down syndrome, with risk of death increasing after age 40. The most common causes of mortality change with aging, and older adults more commonly experience death as a complication of respiratory illnesses and infections, complications related to choking or swallowing dysfunction, and the progressive worsening of underlying dementia.



PROMOTING DIGNITY AND CHOICE



Respectfully supporting an individual with Down syndrome as they age includes helping them maintain their individuality and autonomy in all aspects of care and services.

BUILDING A SOLID foundation of healthy living throughout adulthood is important for optimizing physical, emotional, spiritual, and social health and minimizing illness and conditions that can affect adults with Down syndrome at a younger age than typical adults. These conditions include obesity, sleep disorders, and mental health issues. Adults with Down syndrome are entitled to the same human dignity and respect as any adult facing a life-limiting illness or end of life.

The basic principle of dignity honors an individual's personhood and the importance of considering their unique life experiences and

values. Person-centered care practices and promoting choice for adults with Down syndrome aim to uphold the important ethical principle and basic human right of self-determination. Incorporating an individual's voice and autonomy into decision-making is a priority wherever possible. For individuals who have designated decision-makers such as guardians, activated health care proxies, or medical powers of attorney, these principles are still important to include in discussions so that an individual's values and wishes are considered in complex decisions.

Unfortunately, many adults with Down syndrome are not included in

discussions about preferences and wishes about their own end-of-life care. Further, many adults are not directly included in key discussions about their overall health or when new, serious, or life-limiting diagnoses are made.

Common barriers to these discussions include:

- discomfort of health care providers and caregivers
- lack of specialized training or education
- perceived communication difficulties
- incorrect assumptions about an individual's ability to grasp certain information or concepts

Discussions about aging and the end of life are important to explore throughout adulthood, as the preferences, wishes, and choices that are made in later life are often informed deeply by the way one lives their life each day. These conversations can evolve over the lifespan, occurring at natural opportunities to discuss topics as they arise when a friend or family member becomes ill or passes away. Individuals with Down syndrome may welcome the opportunity to help process what they are experiencing by also talking about what they would or would not want if they were in a similar situation.

The often-unpredictable nature of aging can make life feel out of control and may add to distress and worry with age. Individuals who take an active role in expressing preferences and choices about their own body, health, and future may feel some relief and ownership by taking some control over shaping these challenging decisions.

IMPORTANT NOTE: Discussions about wishes and preferences do not only need to be centered on medical decisions and death.

Person-centered care, individual personhood, and personal choices are strongly reflected in how one chooses to spend their time—making a nightly phone call to a

sibling before bed, going out for coffee, spending time with friends, listening to a favorite band, going swimming, or sitting out on the front porch at sunset.

The scope of these experiences and what is seen as most important and integral to joy and pleasure are all expressions of individual priorities that make up a quality of life.



THINKING AHEAD

It's never too late, or too early, to think ahead and plan for what the future will look like for an individual with Down syndrome."



WITH THE TRANSITION into adulthood, many individuals with Down syndrome may understandably focus their future planning on goals of early adulthood. They may seek employment, education and training, or community programming services. They may wish to make new friendships, start romantic relationships, and build independence in the community.

A positive and enjoyable activity to build throughout all of adulthood is a diary, memoir, or life story. This can be in a journal or scrapbook format highlighting favorite activities, accomplishments, hobbies, skills, and memories. This can be a treasured item for an individual with Down syndrome to reflect on happy memories, see familiar faces, and build healthy self-esteem.

A diary, memoir, or life story is also an extremely valuable means of expressing one's

unique personhood and can provide a much richer and more vivid picture of a lifetime of stories and experiences. This is especially valuable as time goes on and changes take place with age, as it provides a much more meaningful introduction to people who are getting to know an individual later in life — either new caregivers, peers, or health care providers. These scrapbooks can help highlight lifelong priorities or preferences when having conversations about goals of care and future planning. They are also a wonderful means of commemorating a life well lived and valued — through pictures, journal entries, memorabilia, video clips, or favorite objects that were important to the individual with Down syndrome.

In addition to ongoing projects like a life story or a scrapbook, it is important to start discussions early in adulthood about future planning. When planning for the

future, a lifespan perspective is encouraged to anticipate what aging and accelerated aging can look like. A plan for the future requires flexibility and adaptability to account for any changing needs of adults with Down syndrome as well as the needs of those who make up their network of supports such as aging parents, siblings, and caregivers.

Over time, older individuals with Down syndrome will notice that they need to adapt and adjust their routines to better suit their changing needs, capabilities, or preferences. Similarly, the changing and evolving needs and circumstances of families and caregivers will often require plans to be reframed and revised. It is important to keep future planning a topic of discussion that is actively revisited and updated on an ongoing basis.

PROACTIVE PLANNING



While supporting an individual with Down syndrome with planning, stay a few steps ahead in anticipating needs and supports so there are minimal disruptions or upheavals for everyone involved.

PROACTIVE PLANNING allows individuals, their families, and caregivers to feel a greater sense of control and comfort when times feel unpredictable. It is in proactive planning that caregivers can help their loved one with Down syndrome plan for a life that is going to be well lived. To start, ask yourself these questions:

- What are your goals for your loved one?
- What do you wish for them if you are no longer able to be in their life?
- What shared values do you have with the person you are caring for?

- Does your care recipient want the same things for themselves that you want for them?

There is no way to perfectly predict the future and all the barriers and challenges that might arise. However, there are numerous factors that can be considered to help make more informed plans and decisions.

One key factor that weighs heavily in understanding current and future needs is an individual's health and health care needs. Multiple medical problems or recurring, worsening, or chronic medical illnesses can have a very distinct impact on all

aspects of daily life. Many health conditions have gradual and progressive changes over time and can be incorporated into an overall plan that considers present-day needs and future possibilities.

Some common health care scenarios are addressed below.

Alzheimer's Disease

Adults with Down syndrome are at increased risk of developing dementia due to Alzheimer's disease, especially after the age of 50. This topic is covered in detail in the NDSS guidebook, *Alzheimer's Disease and Down Syndrome: A Practical Guide for Caregivers*. Readers are urged to review this topic in depth, as Alzheimer's disease is a common diagnosis for older adults with Down syndrome but also one that can be misdiagnosed or inadequately evaluated.

There are many serious implications for future planning and expectations any time a person with Down syndrome receives a diagnosis of dementia due to Alzheimer's disease. Alzheimer's disease is a terminal diagnosis, meaning that the disease causes a persistent decline in function over time which makes individuals vulnerable to medical setbacks that eventually lead to death.

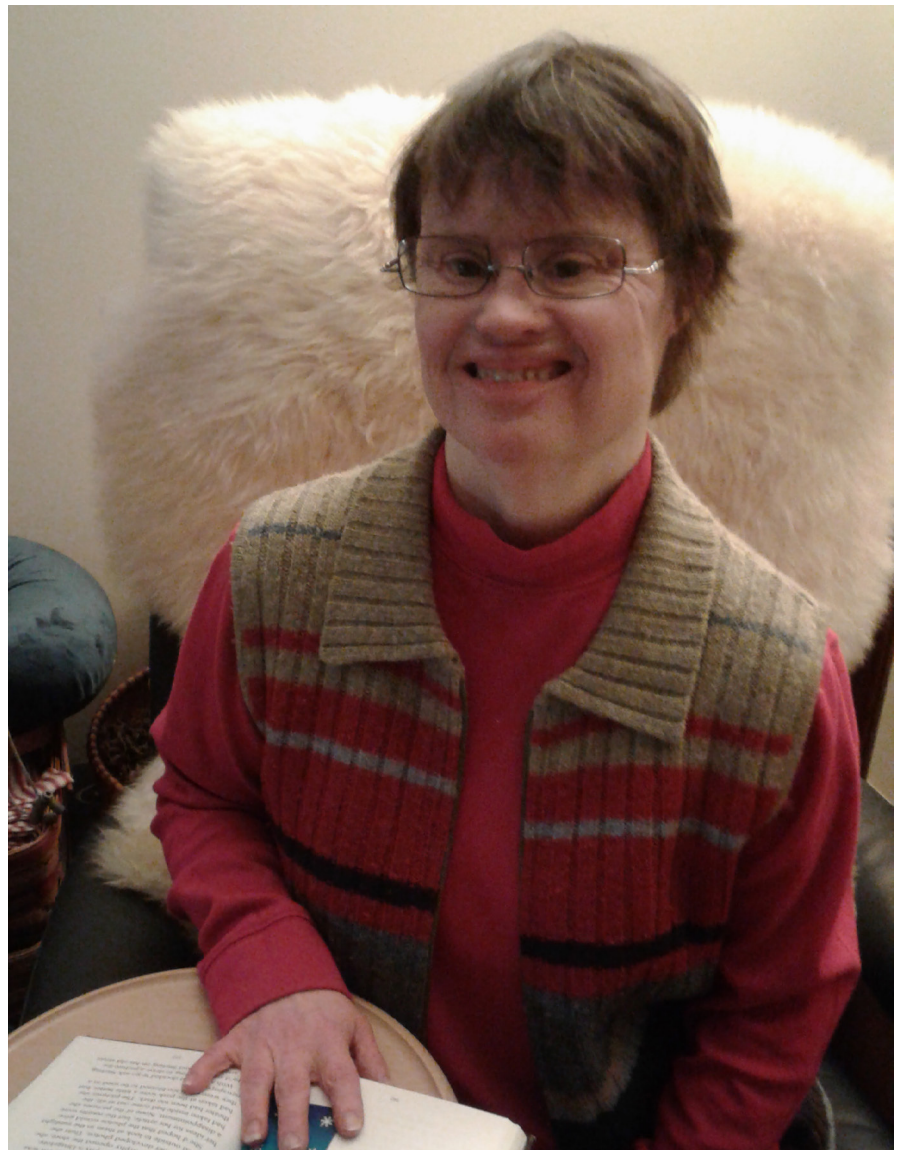
Caring for an individual with dementia due to Alzheimer's disease can be very physically and emotionally demanding. Often the caregiving tasks can eventually be too all-consuming or overwhelming for just one or a few caregivers to safely provide. It is important to be proactive in planning so that resources are acquired to reinforce support for the individual and the caregiver team.

Physical decline

Many individuals with Down syndrome start to become more physically slow and less independent in their mobility as time goes on. This can occur for a variety of reasons, including worsening arthritis, wear-and-tear of large joints like knees and hips, or aging-related stiffness and discomfort with walking and standing. Sensory processing problems can worsen with age, and several factors can contribute

to difficulty with overall function, such as diminished sense of balance, worsening vision and hearing, increased difficulty with depth perception, or tendency to be overwhelmed or overstimulated by certain environments (even when previously fine in those environments).

Proactive planning is important for adults who are experiencing physical decline so they avoid fall risks and safety hazards that can arise in environments no



longer suited to their abilities. Individuals who are physically struggling within their living environment can pose a safety risk to themselves and to the caregivers around them. It is important to anticipate concerns early so that decisions can be made to keep everyone safe and well.

Chronic illness and chronic symptom management

Similar to symptom management in the general population, individuals with Down syndrome who have chronic illnesses will experience an increase in a range of symptoms that impact their daily life. For example, individuals with diabetes may need more frequent blood sugar checks and experience the effects of fluctuations in their blood sugar,

IMPORTANT NOTE: When a diagnosis of Alzheimer's disease is made prematurely for an individual with Down syndrome, it can result in muddled expectations for the future and missed opportunities to discover and address other treatable conditions that might be playing causing a change in an adult with Down syndrome. It is critically important to seek out a thorough evaluation of memory concerns so that diagnoses are made carefully and accurately.

and those with heart failure or other chronic heart conditions may experience shortness of breath or fatigue with exertion.



Symptom management related to aging and chronic illness is important to consider when planning proactively for the future care of older adults with Down syndrome and optimizing their quality of life. Partnering closely with an individual's health care team can help with understanding, anticipating, and managing symptoms as time goes on.

Living environment and caregiver supports

As individuals with Down syndrome grow older, it is important to continually assess the living arrangements and caregiver supports to ensure that barriers or gaps in care are anticipated. If an individual with Down syndrome is aging at home with an elderly parent or other aging relative, a proactive discussion about the future is necessary for the wellbeing of everyone involved to avoid having to find supports in a time of unexpected illness or crisis.

It is important to consider all aspects of supports for an individual who is growing older. If an individual with Down syndrome is at home, in a group home, or another type of group residence, are the staffing and supports adequate to allow an individual to age in place? In other words, is there enough flexibility in the physical environment and the caregiving team to meet needs safely as they occur?

Thinking and acting proactively is encouraged for all future planning discussions about living environment and caregiving needs. Certainly, the reality of these discussions depends highly on the specific state or local agencies and resources available, so making connections to recruit help and gather additional guidance and information is a key priority.

ADVANCE DIRECTIVES AND DECISION-MAKING



Family, loved ones, and caregivers of adults with Down syndrome are strongly encouraged to seek help early to understand the specific legal framework around health care decisions for a loved one with Down syndrome.

DISCUSSIONS ABOUT advance directives, medical orders, and any decisions about medical care have legal implications that need to be carefully explained and considered. Specific legal guidelines, regulations, and protections vary from state to state for adults with intellectual disabilities.

Under normal circumstances, individuals with Down syndrome who become sick or injured and need emergency treatment are expected to receive standard medical care in an urgent care clinic, emergency room, or hospital

just like anyone else. Depending on the severity of illness, this could include the highest level of life-saving measures such as CPR (cardiopulmonary resuscitation) or intubation (placing a breathing tube in the airway to support respiration). Health care facilities and providers follow this standard of care when it is appropriate for the situation unless there are specific instructions that indicate a preference or order to avoid certain interventions.

These specific instructions or directions are referred to as advance directives and are made

to be exactly that—an expression of wishes made in advance of any life-limiting or catastrophic illness to help guide care decisions. These directives also specify any wishes an individual or their decision-maker has outlined that would be different from a standard medical response to an emergency.

Advance directives are legal documents that officially communicate valuable information that would be used if an individual became ill or was unable to speak for themselves. Advance directives can include the designation of health care power of attorney or health care proxy. This document designates who is authorized to make medical decisions for an individual if they are unable to communicate for themselves. Health care proxies/powers of attorney make medical decisions based on the individual's known wishes and beliefs. The health care proxy can be named only by an individual who has the capacity to make these decisions.

Advance directives can also include an instruction directive or living will. These are written documents that outline what medical treatments or interventions an individual would or would not want under specified medical circumstances.

Some of the specific interventions outlined in an advance directive can include the following.

Do Not Resuscitate [DNR] or Do Not Intubate [DNI] directives indicate an individual's wish to avoid the emergency interventions that occur when an individual's heart stops beating effectively (cardiac arrest)

or when an individual's breathing stops or becomes dangerously weak (respiratory arrest).

"Resuscitation" refers to emergency efforts to restart the heart, either through CPR (chest compressions) or electric shocks (defibrillation) that are needed if the heart is in a dangerous heart rhythm.

"Intubation" refers to a procedure where a tube is inserted into the airway to help support breathing when an individual is too ill to safely breathe on their own. Intubation requires being placed on a ventilator machine which is managed in an intensive care unit with additional medications to help keep a person partially or fully sedated to be able to tolerate the breathing tube.

Advance directives can be translated into official medical orders that are signed by a health care provider. This is official guidance outlining which procedures or interventions can be used or attempted in the event of a serious illness. DNR orders and DNI orders can be implemented by a health care provider after a discussion with an individual competent to make their own decisions or with a health care proxy.

Medical Orders for Life Sustaining Treatment [MOLST] (also referred to in some states as "portable" orders **[POLST]**) is a comprehensive set of medical orders for interventions and decisions for patients who are seriously ill or facing a limited life expectancy. Orders may direct the refusal or acceptance of

resuscitation for cardiopulmonary arrest, intubation and airway management for respiratory distress, artificial nutrition and hydration, IV medications and antibiotics, hospitalizations and intensive care treatments, and the overall level of care that is desired.

The language surrounding advance directives and medical orders at end of life tends to center around what things an individual would like to not happen to them. In these discussions it is important to focus not only on what not to do but to also think about what to do to help guide the actions or experiences that an individual would like prioritized. Conversations about overall goals of care can help uncover what matters most to an individual at the end of life. Engaging an adult with Down syndrome in a goals-of-care discussion allows them to openly express their priorities and their fears and have their needs and core values heard.

IMPORTANT NOTE:

Advance care planning can be a layered discussion and can also have variations from state to state that are important to explore further. More detailed information about advance directives and advance care planning is available on a variety of excellent online groups that can be found in the resources section of this guidebook.



HEALTH CARE PROXY VS. GUARDIANSHIP

These two terms are not the same. An important distinction exists between health care proxy and guardianship.

Guardianship is a legal designation. A legal guardian is a person who has been appointed by a court and has the legal authority to act on behalf of an adult who is deemed unable to make some or most decisions for themselves.

Health care proxies serve as a voice of the individual when they are unable to speak for themselves. A proxy is named by the individual, not by a judge in court.

The authority to make medical decisions and end-of-life decisions differs in guardianships versus health care proxies. The specifics vary from state to state, and there are legal differences between these two entities. Readers are advised to proactively seek guidance about the legal options available to an individual and to clarify if a guardianship is already established or if the individual has the ability to name a health care proxy.

This table of comparisons demonstrates the differences in tools, documents, treatments, and resources that can be used for advance care planning.

TABLE OF COMPARISONS

ABBREVIATIONS USED:

AD = Advance Directive

APN = Advanced Practice Nurse

ANH = Artificial Nutrition and Hydration (PEG tube, NG tube, TPN, IV fluids)

DMC = Decision Making Capacity

DNR = Do Not Resuscitate or DNAR = Do Not Attempt Resuscitation

EMS = Emergency Medical Services

HC = Health Care

MD = Medical Doctor (Physician)

PA = Physician Assistant

POLST = Portable Orders for Life-Sustaining Treatments

OOH DNR = Out of Hospital Do Not Resuscitate order

CATEGORIES	ADVANCE DIRECTIVES	MOLST/POLST	DNR
Appropriate population	Adults with DMC	Any age with serious illness and limited life expectancy	Any age with serious illness and limited life expectancy
Treatments covered	Any described in document	Levels of care; resuscitation status, airway management, ANH, hospitalization, ICU, care, and goals of care	Cardiopulmonary Resuscitation (CPR)
Instruction time frame	Future health care needs	Current	Current
Who completes	Individual adult with DMC	Medical practitioner (MD, APN, PA) with patient or surrogate	Medical Practitioner (MD, APN, PA)
Need for consent	Yes	Yes - from patient or surrogate	Yes, unless CPR is deemed medically inappropriate or futile
When operational	Used only when an individual has lost their DMC as determined by an MD. Used for diagnosis, prognosis, and evaluation of instructions according to AD	Upon presentation to HC provider (includes EMS)	Upon presentation to HC provider (includes EMS)
Legal designation of HC proxy/agent/representative	Yes (optional)	No - HC proxy/surrogate may be listed	No
Portable	Yes	Yes	See state AD statute
Legal penalties for not following	No (may require POLST or OOH DNR for community setting)	See state POLST statute	

CONSIDERING BRAIN DONATION

Helping future generations of people with Down syndrome

Another decision to consider when weighing options for advance directives is to consider brain donation to help researchers further the understanding of aging and Alzheimer's disease in people with Down syndrome.

Brain donation is a gift that is valued for decades beyond the life of the donor and helps make discoveries that may lead to new ways to treat or prevent Alzheimer's disease and improve quality of life for older adults. There are several routes by which this can occur

and in all situations the teams that help families with brain donation prioritize respect, kindness, and dignity and make every effort to minimize burden and cost to the family. Brain donation is compatible with many religious guidelines and can accommodate funeral arrangements.

A discussion of this gift within the family and with the person with Down syndrome should occur early in the planning process, as making arrangements in advance will make the process smoother and less burdensome during a challenging time.

In many brain donation scenarios, the family may request a final neuropathology report that will describe brain changes that had developed prior to death. Families that have participated in brain donation have noted that this opportunity provided another sense of closure that was appreciated.

More information about brain donation and how it can be arranged can be found in the resources section of this guidebook.



LATE-STAGE END-OF-LIFE CARE

For some people, the end of life can be quick and intense, especially if a serious illness comes suddenly. For many others, the process may feel more prolonged with chronic illness, patterns of calm stability followed by illness or setbacks and then further slow decline until death.

CAREGIVERS, family, and friends are encouraged to be aware and mindful of the changing course of an individual's health and wellbeing and the symptoms they are experiencing over time. Staying connected with health care providers and discussing symptoms can provide further insight and guidance about when the end of life is approaching.

In terminal conditions, death is an expected outcome since there is no cure or any means of reversing the underlying condition. When there is no expectation for cure, then the treatment approach typically is supportive and focused on symptom management. In the setting of a terminal condition, any interventions should be evaluated to weigh the burdens versus the benefits of the treatment and must consider the individual's personal preferences. In the absence of a distinctly terminal diagnosis, end of life can also arise when illnesses do not improve or when they

recur frequently or intensely enough to cause significant medical and functional setbacks. Common examples include recurrent pneumonias and other infections requiring frequent emergency attention and frequent hospitalizations. While treatment options are available in each recurrent encounter, some older or more vulnerable individuals may struggle to recover or rebound back to their baseline health. In these scenarios, often there comes a time where these interventions feel increasingly burdensome or do not seem to provide any significant lasting benefit, and this may indicate a time to reassess and reconsider an individual's overall goals of care.

When an adult with Down syndrome expresses goals of care that emphasize relief from pain or painful/burdensome symptoms, involvement of palliative care and hospice can be considered. Both palliative care and hospice are underutilized services for adults

with Down syndrome for a variety of reasons, including poor or inadequate discussions of future planning and lack of experienced providers comfortable with serving adults with disabilities.

Palliative care

This care approach is defined by the World Health Organization as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual." Palliative care can be incorporated into a continuum of care for an individual with Down syndrome over the course of a lengthy illness to reduce suffering and to manage symptoms. Palliative care specialists and palliative care teams can be involved at any time in disease progression,



and early involvement of a palliative care team can help bring comfort and support even while other active treatments are taking place. Referrals to palliative care can come from a primary care provider, and support can typically be arranged to take place in a community-based setting, skilled nursing facility, or home setting.

Hospice

Hospice service focuses primarily on maximizing quality of life and reducing suffering for people with advanced, life-limiting illnesses.

As described by the National Institute on Aging, “hospice provides comprehensive comfort care as well as support for the family, but, in hospice, attempts to cure the person’s illness are stopped. Hospice is provided for a person with a terminal illness whose doctor believes he or she has six months or less to live if the illness runs its natural course.” Hospice focuses on the end of life, although many individuals who use these services do so quite late in the disease progression and are therefore unable to take full advantage of all the help hospice could provide to

the individual and to their family and care team. Therefore, it is important to consider options about hospice proactively so that the individual and team can involve these support services in a timely fashion when needed. Like palliative care, hospice services typically involve a team of individuals and can take place in a variety of settings, including community-based settings, skilled nursing facilities, and home settings. In addition to symptom management, they can also be helpful in the emotional support of family, caregivers, and friends in the death and bereavement process.

Comfort care

Comfort care is commonly used for end of life and is similar in many respects to hospice care. Comfort care means that the primary focus and goal of care is to make an individual comfortable and to provide relief from any uncomfortable or painful symptoms related to dying.

End-of-life doula

Dying is not just a medical event; it is a human one. Doulas have been known to accompany the community through the significant events of birth and death since the beginning of time and are used in many cultures as a guide to ease physical and spiritual pain. End-of-life doulas care for the dying and those close to them with compassion and aim to create a comfortable environment for all involved.

** More information about late-stage end-of-life care can be found in the resources section of this guidebook*

DEATH, GRIEF, AND COPING

Witnessing the various changes that occur as a loved one with Down syndrome ages can bring up feelings of grief. Loved ones and caregivers may feel sadness when physical changes cause a decrease in stamina or energy in their loved one or when they stop finding enjoyment in activities that they used to do with skill and vigor. Grief can be especially profound when individuals with Down syndrome experience more debilitating changes towards the end of life, especially those who develop the progressive changes of dementia. The feelings that arise watching a loved one experience a gradual loss of baseline skills and abilities can be devastating.

END OF LIFE AND DEATH can be a deeply emotional, erratic, and challenging time for everyone. No matter how much preparation and planning has taken place leading up to the time of death, the actual experience of witnessing a loved one pass away can take a heavy emotional toll. This is entirely normal. Some people may also feel a sense of relief if they believe their loved one was suffering prior to dying. This sense of relief may compound feelings of sadness or guilt.

Throughout the entire process leading up to death, it is important that families and caregivers be kind and gentle to themselves. No one is perfect and no one can do it all alone.

Grief and bereavement are expected and natural parts of the process of death. They are also highly unique to each person, and each person may demonstrate their grief differently. There is no right or wrong way to grieve. Families and friends might find support in one another, but it is important to include all people who were deeply involved in the support of an individual with Down syndrome. Attending to the emotional and spiritual needs of the individual and the caregiving team can provide comfort and can help with finding peace at a challenging time. Providing bereavement support to professional support persons and caregiving teams is especially important as many caregivers become like family to

individuals over the years and can feel deep grief and loss of a dear friend. Most individuals will need time and support over time to help with their grief.

Involvement of peers and friends with Down syndrome and other forms of intellectual disability is extremely important as well, allowing them time to process their grief in their own way and providing emotional support and comfort during the grieving period, in whatever way it shows up for them. Each individual situation is different, but friend and peer relationships and bonds can be extremely special and deep, so gentle and honest support is a priority throughout the end of life and after death. Encouraging and supporting individuals to



share memories and to express their feelings is a healthy part of healing and can bring comfort to the individual and to the caregiving team.

Memorial services and other religious or spiritual ceremonies can offer a space to positively remember and memorialize an individual with Down syndrome and a life richly lived. Reaching back into memories, in the life story or a memoir scrapbook that was built over time, can provide a time to find laughter, gratitude, and joy in the memories of the individual with Down syndrome.

There are many resources available for individuals with Down syndrome and other forms of intellectual disability to review concepts of death and dying as well as other common diagnoses seen in old age. These are recommended for review with peers and friends and are also recommended as a resource to be used for an adult with Down syndrome throughout adulthood whenever these subjects arise. Several sources can be found in the resources section of this guidebook.

CONCLUSION

AN INDIVIDUAL with Down syndrome's end-of-life experiences, and how you care for someone through these experiences, is not one-size-fits-all. There are many ways in which one individual with Down syndrome's life story can vary from another, so comparison with other individuals serves no purpose. As a caregiver, prioritizing person-centered care, dignity, and choice for your care recipient with Down syndrome is helpful in ensuring they have ownership over how they age. Promoting self-advocacy and autonomous decision-making can create a healthy environment for an individual with Down syndrome as they near the end of their life. Document their amazing lives using videos, photographs, or a written journal, and share these documents with new care professionals.

It is important to seek out professionals in your state who are well versed in providing resources for the disability community, such as your local Down syndrome affiliate group, the Arc, or your state developmental disabilities (DD) council.

Make plans with and for your loved one with Down syndrome with the anticipation that they are going to live a long, healthy life. Recognize that death is part of the continuum of life and that at the end of life there is an opportunity to celebrate and honor the life of the individual who passed away.

This guidebook is written in gratitude to people with Down syndrome who have passed away and the families and caregivers who loved them and carry their memories with them today.



RESOURCES

NATIONAL DOWN SYNDROME SOCIETY (NDSS)

<https://www.ndss.org>

<https://www.ndss.org/publications>

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

321GO!

<https://ndss.org/321go>

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

AARP

<https://www.aarp.org>

AARP is doing amazing things to make life better for today's 50-plus population and generations that follow. In the face of constantly changing realities, AARP is a champion for social change. They help people navigate ageless realities — financial well-being, health, how to contribute to society and local communities, and how to fully enjoy life.

THE ARC OF THE UNITED STATES

<https://www.thearc.org>

The Arc of the United States is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.

ADVOCATE MEDICAL GROUP: ADULT DOWN SYNDROME CENTER

<https://adsresources.advocatehealth.com/search/people-with-down-syndrome/>

The Adult Down Syndrome Center at Advocate Medical Group has a great library of videos and pamphlets that discuss a variety of health and wellness topics, such as *Taking Charge of My Appointment*.

CANADIAN DOWN SYNDROME SOCIETY (CDSS)

<https://www.cdss.ca>

CDSS provides reliable information and connections to people with Down syndrome and those who support them, while positively shaping the social and policy contexts in which they live.

CAREGIVER ACTION NETWORK (CAN)

<https://www.caregiveraction.org>

CAN is the nation's leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age.

DOWN SYNDROME CLINIC TO YOU (DSC2U)

<https://www.dsc2u.org/>

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

COMPASSION & CHOICES

<https://www.compassionandchoices.org/>

Compassion & Choices envisions a society that affirms life and accepts the inevitability of death, embraces expanded options for compassionate dying, and empowers everyone to choose end-of-life care that reflects their values, priorities, and beliefs.

DOWN SYNDROME MEDICAL INTEREST GROUP (DSMIG-USA)

<https://www.dsmig-usa.org/clinic-directory-map>

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

FAMILY CAREGIVER ALLIANCE (FCA)

FCA CareNav: <https://fca.cacrc.org/login>

Services by State: <https://www.caregiver.org/connecting-caregivers/services-by-state/>

FCA seeks to improve the quality of life for caregivers through education, services, research, and advocacy.

GLOBAL DOWN SYNDROME FOUNDATION

<https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/>

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

MY HEALTH PASSPORT

http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

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

NATIONAL DOWN SYNDROME CONGRESS (NDSC)

<https://www.ndsc.org>

The purpose of the NDSC is to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information.

NATIONAL INSTITUTE OF HEALTH (NIH)

<https://www.nih.gov>

The mission of NIH is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

NATIONAL INSTITUTE ON AGING—LONG-TERM CARE

<https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes>

At some point, support from family, friends, and local programs may not be enough. People who require full-time help might move to a residential facility that provides many or all the long-term care services they need.

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

<https://www.the-ntg.org/ntg-edsd>

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

SPECIAL NEEDS ALLIANCE (SNA)—LETTER OF INTENT

<https://www.specialneedsalliance.org>

<https://www.specialneedsalliance.org/the-voice/letter-of-intent-3/>

SNA is a national organization comprised of attorneys committed to the practice of disability and public benefits law. Individuals with disabilities, their families, and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena.

BRAIN DONATION RESOURCES

THE INTERNATIONAL DOWN SYNDROME BIOBANK CONSORTIUM

<https://devdownsbio.wpengine.com/>

The focus of this project is to develop a strong collaborative network between six different research groups focused on providing much-needed information about the intersection between Down syndrome and Alzheimer's disease.

THE BRAIN DONOR PROJECT

<https://braindonorproject.org/>

The Brain Donor Project connects potential donors with a brain bank in the NeuroBioBank, a network of brain banks that make brain tissue available to neurologic researchers. The NeuroBioBank is part of the NIH, which is the primary U.S. agency responsible for biomedical and public health research.

THE BRAIN SUPPORT NETWORK

<https://www.brainsupportnetwork.org/>

BSN's first mission is to make brain donation easy for families (in the United States and Canada) that want to donate a loved one's brain. Research for a cure of any neurological disorder needs brain tissue from persons with that disorder.

THE NIH NEUROBIOBANK

<https://neurobiobank.nih.gov/>

The NIH-funded NeuroBioBank (NBB) was established in September 2013 as a national resource for investigators utilizing human post-mortem brain tissue and related biospecimens for their research to understand conditions of the nervous system.

ADVANCED DIRECTIVES AND DECISION-MAKING RESOURCES

CARINGINFO

<https://www.Caringinfo.org>

Understanding and discussing topics like advance directives, palliative care, caregiving, and hospice care may feel overwhelming on top of dealing with a serious or life-limiting illness. CaringInfo's guides and resources are here to help you through the journey you are on and to aid you in understanding the choices you have.

HEALTH IN AGING

<https://www.HealthinAging.org>

Health in Aging is a trusted source for up-to-date information and advice on health and aging, created by the American Geriatrics Society's Health in Aging Foundation.

NATIONAL POLST

<https://www.POLST.org>

<https://polst.org/program-names/>

POLST has different names in different states. At the national level, it is simply called POLST: Portable Medical Orders, or POLST for short. Portable means that the order is valid outside the clinic or doctor's office, like a drug prescription. POLST is many things, including a process, a conversation, and/or a medical order form.

PREPARE FOR YOUR CARE

<https://www.PrepareforyourCare.org>

Prepare for Your Care grew out of a desire to help make medical decisions easier for people and caregivers. It is the result of ongoing research, collaboration, and generous funding.

THE CONVERSATION PROJECT

<https://www.ConversationProject.org>

The Conversation Project® is a public engagement initiative of the Institute for Healthcare Improvement (IHI). Their goal is both simple and transformative: to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected.

THE FIVE WISHES

<https://www.FiveWishes.org>

Five Wishes is an easy-to-use legal advance directive document written in everyday language. It helps all adults, regardless of age or health, to consider and document how they want to be cared for at the end of life.

LATE-STAGE END-OF-LIFE CARE

INTERNATIONAL END-OF-LIFE DOULA ASSOCIATION (INELDA)

<https://inelda.org/>

INELDA encourages the presence of end-of-life doulas by normalizing death, dying, and grief through conscientious education, and stewardship, and by fostering community and advocacy.

DISCUSSING DEATH AND DYING

BEYOND WORDS

<https://booksbeyondwords.co.uk/bookshop>

Books Beyond Words are award-winning wordless picture stories covering topics including physical and mental health, lifestyle and relationships, abuse and trauma, grief and bereavement, employment, and criminal justice.

DOWN'S SYNDROME SCOTLAND

<https://www.dsscotland.org.uk/resources/publications/for-parents-of-adults/>

Down's Syndrome Scotland has several resources for parents of adults with Down syndrome on a variety of issues including diet, weight, exercise, and dementia.

I HAVE A QUESTION BOOK SERIES

<https://www.ihaveaquestionbook.com/>

This book series allows children and their caregivers to grapple with difficult topics in ways that are straight-forward, reducing fear and anxiety. Designed initially for children with autism spectrum disorder and other special needs who are often under-represented in children's literature, these books have become a go-to resource for helping ALL children understand challenging life transitions.

End of Life & Down Syndrome

A Practical Guidebook for Caregivers

Copyright © 2023 National Down Syndrome Society
All Rights Reserved
