CAREGIVING AND DOWN SYNDROME

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

National Alliance for Caregiving

national down syndrome society ndss

ntg National Task Group on Intellectual Disabilities and Dementia Practices

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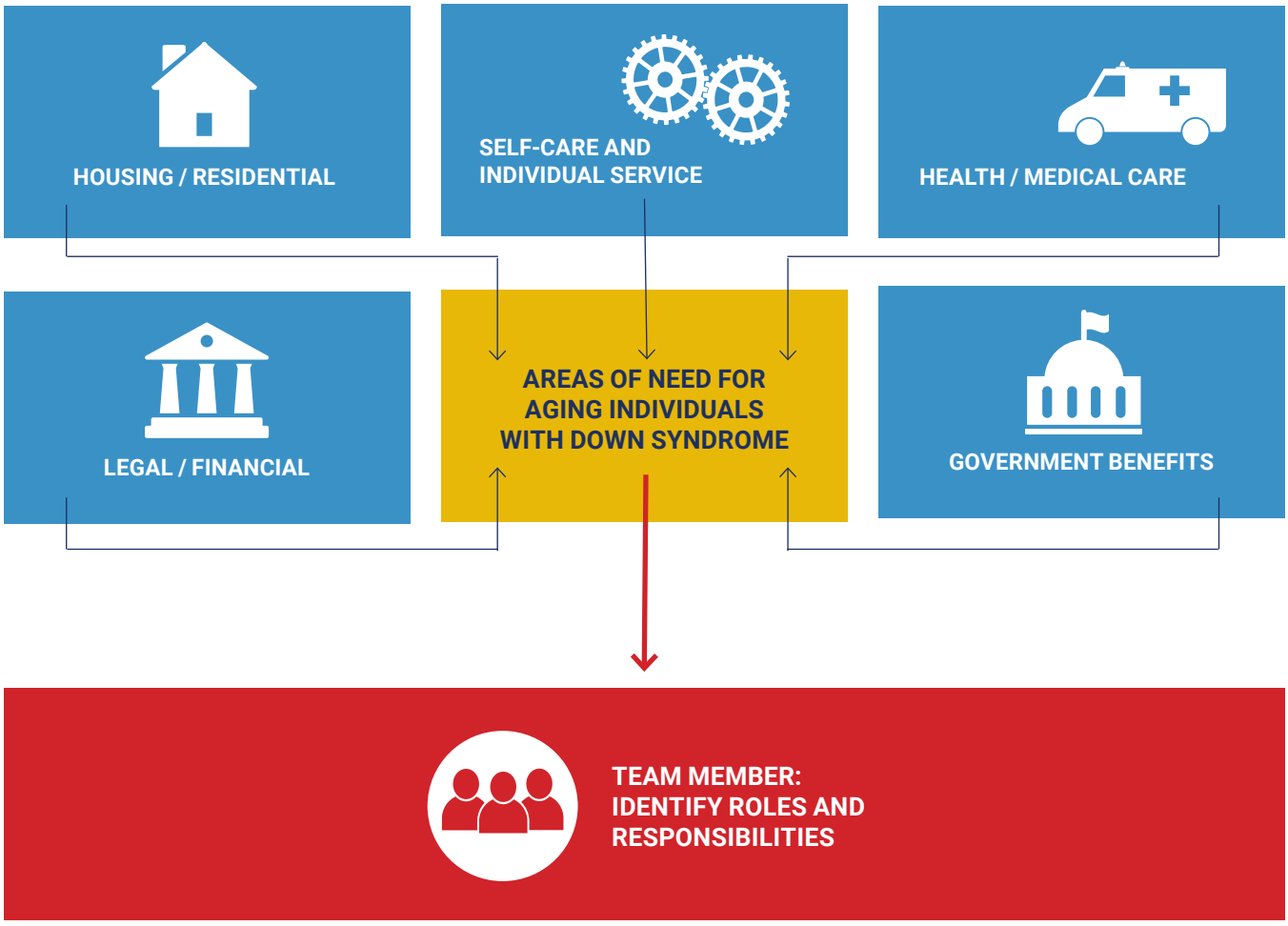
INTRODUCTION

As adults with Down syndrome are commonly living into their 50s, 60s, and 70s, their caregivers play a critical role in providing support for a good quality of life. The purpose of this guidebook is to offer information on how to navigate caregiving for an individual with Down syndrome as they age.

WE RECOMMEND YOU START preparing for the future of your care recipient with Down syndrome before the age of 18. However, it is never too late to begin the process.

NOTE: Stories and quotes throughout this guidebook are shared directly from caregivers in the Down syndrome community and are used to illustrate examples of the realities that some families face.



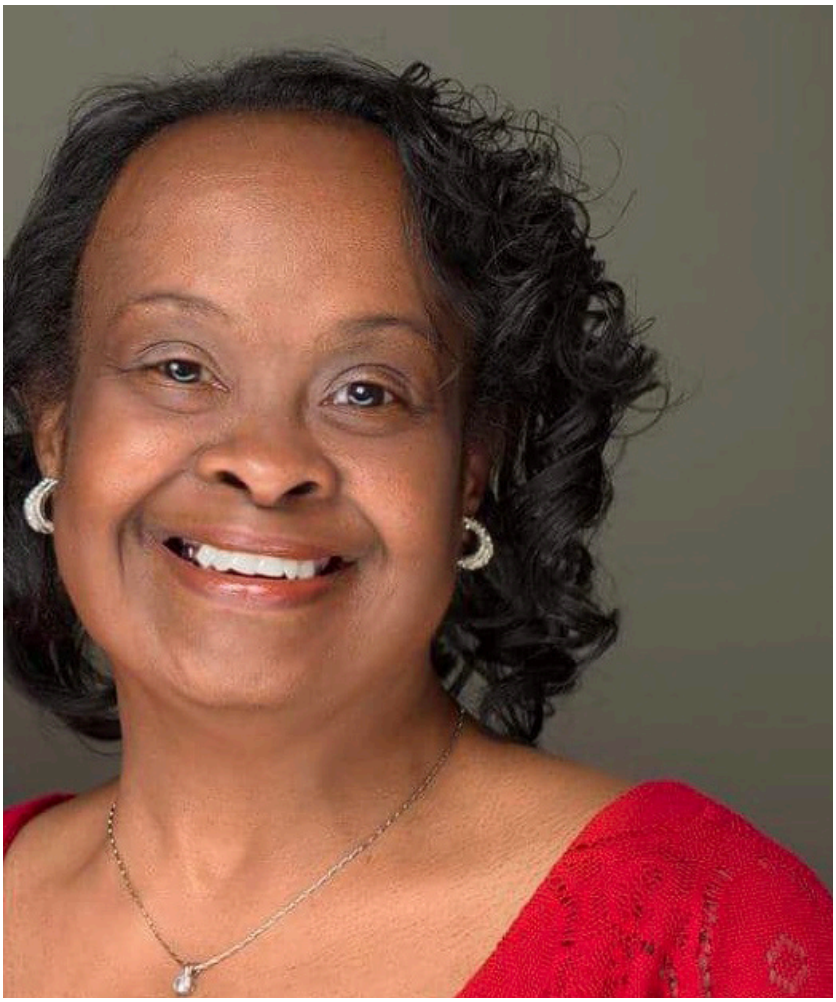
THE GOALS OF THIS GUIDEBOOK:

- **Provide guidance, information, and support to families and caregivers of older adults with Down syndrome**

- **Prepare families and caregivers with the key areas of support needed to navigate adult life and aging for individuals with Down syndrome**

- **Empower families and caregivers with information and resources to take proactive, team-based steps to address the needs of an adult with Down syndrome over the course of their lifespan**

- **Provide advocacy and self-care tips for families and caregivers**



SUPPORT PLAN

A support plan can be described as a blueprint for how to care for an adult with Down syndrome as their needs become more complex. This process-oriented approach can include person-centered plans, navigating daily routines, and identifying future guardians and health advocates for the individual with Down syndrome.

A. Letter of Intent

The letter of intent is a tool to guide guardians, trustees, siblings, and others to care for the care recipient in the way both you and the care recipient desire. It contains detailed information that only a parent/sibling/caregiver would know about their care recipient's history and personal preferences, and it paints a picture of the individual's life today, as well as desires for their future.

PERSONAL PROFILE

In January of 2020, my sister, Margaret was showing signs of significant decline due to dementia. She had been living with me for five years, so I was able to track these changes very closely.

Over the previous two years, I had noticed gradual changes, mostly in her short-term memory, performing tasks of daily living, and her personality. However, now it seemed that everything became accelerated all at once. All the behaviors she had been exhibiting increased in frequency as well as intensity. What had once been occasional incontinence became an everyday occurrence. What started out as her refusal to get out of the car or get ready for bed had become full-fledged oppositional, defiant, and combative behaviors. She soon started experiencing hallucinations (both happy and fearful) and she began trying to leave the house on her own. By June of 2020, I knew that I could no longer care for her at home, and I made the difficult decision to move her to a memory care facility.

Now the question was, will they know how to take care of her the way that I do? How will I be able to tell them all the things about her that make her the unique and wonderful person she is? How will they know how to take care of her when she isn't able to communicate her wants and needs like she was once able to do?

Having a tool for creating her personal information that I would send with her to the memory care facility was a lifesaver. I used the "My Health Passport" created by Liz Perkins at UCF (which we will include here in the guide). Even though it didn't tell the staff everything about my sister, it gave them a good picture of who she is, how she communicates, her likes and dislikes, and most importantly, what to do if she is in pain or upset. A tool such as this will prove to be invaluable to you and your loved one as you navigate your journey as a caregiver.

— Embry B.

Although it may seem intimidating, completing a letter of intent is a crucial step in ensuring the care and future wellbeing of your loved one.

As a family member, it can be difficult to think about what can happen if you suddenly become unable to provide your loved one with the support they need. With the right preparation, your child or loved one will be safe with the caregiver of your choosing who will be prepared with personal knowledge you have provided ahead of time. There are steps you can take now to minimize the natural disruption and disorientation that will occur if you become unable to care for your child or loved one during your lifetime.

You can prepare a letter of intent to help loved ones or potential future caregivers manage a difficult transition when you are no longer the primary caregiver. A letter of intent is an important planning tool for parents of children with intellectual and developmental disabilities (IDD), including adult children, and may also be useful when planning for minor children who do not have a disability.

Although a letter of intent is one of the most important estate planning documents a parent can prepare, it is not a formal legal document that must be created by an attorney. The goal of a letter of intent is to guide future caregivers, guardians, and trustees in providing the best possible care for your child or loved one. It is important to re-evaluate and update this letter as things change over time.

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

PERSONAL PROFILE

It can be a tough road, and everyone is unique. Services for our loved ones are often hard to come by. As a caregiver, you must be diligent, follow each step, and stay in touch with agencies providing services and work opportunities. We have found value in volunteering, and the two of us are a dynamic duo! I think it is important to give back, and my daughter feels good about herself in the process.

— Jackie R.

PERSONAL PROFILE

My sister worked at Goodwill Industries for two years back in the 1980s. At this time, she was extremely independent and had excellent communication skills. There wasn't a need for our mother to intervene on her behalf because Margaret was dedicated to her work, extremely compliant, and wanted to please her supervisors. However, as a caregiver, you may be called upon to advocate for your loved one with Down syndrome regarding issues with employment. It is imperative that someone at the place of employment is willing to maintain contact with you and update you on any problems or challenges that may arise.

— Embry B.

B. Daily Routine

Often, we require calendars or electronic devices to remind us of our daily or weekly schedule. As much as possible, we like for life to be predictable, and our routine is what provides a way for us to be prepared. People with Down syndrome are no different, and having a written schedule of their daily routine is important. For most people with Down syndrome, a routine is what provides comfort and structure to their days, weeks, and months.

Many adults with Down syndrome attend day programs that provide structure, but for others, just having a routine at home is vital. Make sure that anyone who is providing care has access to their daily or weekly schedule and that they understand the importance of sticking to this schedule for the comfort and security of the individual with Down syndrome.

Schedules can be written out on a dry erase board, typed out as notes, or created with visual pictures and Picture Exchange Communication System (PECS) icons. The daily routine may evolve as the individual ages, but having written and visual schedules are important, especially as caregivers may change.

C. Employment/Day Program

Many individuals with Down syndrome obtain employment. If you are caring for a person with Down syndrome who is employed, it is important their boss or supervisor understands that their caregiving needs may change as they age.

Whether the care recipient is employed or attending a day program, it is wise to initiate communication with employers and day program staff on a regular basis. Make sure the supervisor and staff workers understand why it is important to observe for and report any changes in performance, loss of skills, or memory concerns.

D. Aging and Medical Issues in Down Syndrome

New possibilities are continuously emerging from research on aging to help people with Down syndrome live longer, more fulfilling lives. Adults with Down syndrome can enjoy a future that includes education, employment, recreational activities, meaningful relationships, and many other things that in the past seemed out of reach.

It is important to remember, however, that people with Down syndrome experience accelerated aging, meaning they will age faster than the general population. It is expected that adults with Down syndrome will show physical, medical, and cognitive signs of aging much earlier than what is expected for their chronological age. These signs and symptoms can include difficulties with vision, hearing, lack of energy, gait instability, and other health concerns.

These general signs of aging may start to appear as early as 40 years of age for people with Down syndrome. It is important to be aware of this acceleration in aging so you can better understand what to expect and what is normal. It is also a good idea to develop a baseline assessment, no later than 35 years of age, to closely keep track of any changes in mood, personality, or behavior. The National Task Group (NTG) Early Detection Screen for Dementia (NTG-EDSD) tool is used for individuals with IDD who are suspected of having changes in thinking, behavior, or adaptive skills, suggestive of mild cognitive impairment, or dementia.

Establishing a baseline level of abilities will be very helpful in monitoring any changes that take place as the person with Down syndrome ages over 35 years. It will prove to be essential not only to you, the family member or legal guardian, but also to anyone who will be involved in the care recipient's life going forward. More information on the NTG-EDSD screening is in the Resource page at the end of this guide.

As we begin to age, it is important to be active, live a healthy lifestyle, and stay involved (to the greatest extent possible) in things we enjoy. This is also true for individuals with Down syndrome. The accelerated aging process may cause them to slow down and lose interest in some of the activities they once enjoyed. If this happens, attempt to find other activities that may spark their interest as their abilities change over time. Continued involvement in outings and activities such as going to movies, family gatherings, sporting events, or a supportive day program are important to maintain healthy social connections.

Medical issues

Please refer to NDSS' *Aging and Down Syndrome: A Health and Wellbeing Guidebook* for more in-depth information about the medical concerns for individuals with Down syndrome as they age. For the purposes of this guidebook, below is a list of common medical conditions you should be aware of and brief recommendations.

Sensory Loss (Vision and Hearing) — Get yearly hearing and vision screenings.

Hypothyroidism — Test for thyroid abnormalities periodically through screenings and blood tests.

Obstructive Sleep Apnea — Monitor sleep patterns, especially if there is a change in mood, behavior, or ability to concentrate.

Osteoarthritis — Pay attention to changes in walking and activity level, and watch for signs of stiffness or discomfort.

Atlantoaxial Instability and Cervical Spine Concerns — When chronic changes occur in the cervical spine, symptoms include weakness in arms or hands, walking abnormalities, and incontinence. A screening cervical spine x-ray is generally recommended at least once during adulthood.

Osteoporosis — Talk to the primary care doctor about bone density screenings; this can be treated through medication as well as exercise and lifestyle modifications.

Celiac Disease — A screening blood test can identify celiac disease. Consider the possibility of celiac when there is weight loss, poor nutrition, or persistent changes in bowel habits.

Alzheimer's Disease — Early onset Alzheimer's disease is more common in adults with Down syndrome than in the general population. Consult NDSS' *Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers* for additional information on Alzheimer's in adults with Down syndrome.

My Health Passport

My Health Passport is a document that is filled out by individuals with disabilities and their caregivers with the intention to share the information when you visit or stay at a hospital or clinic. In addition to the common medical conditions listed above, there may be deficits in communication and daily living skills as individuals with Down syndrome begin to decline. Below are some questions you may want to address and include in the personal section of the My Health Passport document found in the resource page of this guidebook:

• How do I show pain?

• What are some things that can cause me distress?

• How can someone help me when I'm in distress?

• How do I cope with medical procedures?

• How can someone assist me with eating, drinking, and personal grooming?

TIP In addition to **My Health Passport**, another helpful way to keep record of personal information about your loved one is to create an "about me" document, via journal and/or video. You can take videos of them engaged in a favorite activity or talking about something they enjoy. It is so important to document and track any changes in behavior, and videotaping or writing down these behaviors will be helpful as you describe new behaviors to professionals. This can also be helpful for a rotating staff to understand who their care recipient is, what works, and some of the struggles they might be experiencing.

E. Identify Advocates and Legal Guardians

Every person with Down syndrome benefits from having others who can advocate for them in all areas of life. Advocacy is acting with or on behalf of an individual to resolve an issue, obtain needed support, or promote a change in practices and policies. Advocacy is essential for promoting and protecting the civil and human rights of people with Down syndrome, and for establishing, maintaining, or improving their quality of life.

Each state varies in how they view guardianship. There can also be a lot of overlap in how the terms guardianship and conservatorship are used and how they are defined under state law. It is important to be aware of what the laws are in your state and consult with an attorney regarding these matters.

Laws regarding legal guardianship and conservatorship can be different depending on the state that you live in; it is important to check what the guidelines are in your state to ensure you are following the correct protocol. The legal guardian/conservator is the person who not only advocates for the individual with Down syndrome but is also there to sort through the paperwork of legal issues such as wills, trusts, financial transactions, and government subsidies such as disability benefits. This person is usually the point of contact for medical information, appointments, and any decisions that must be made regarding medications, procedures, or surgeries.

The advocate/legal guardian/ conservator should be responsible for the following:

- Yearly update of individual's medical history
- List of physicians, therapists, and caseworkers who provide care
- List of current medications (dosage, delivery, name of pharmacy, and what the medication is used for)

GUARDIANSHIP

"Because guardianship is governed by state law, incapacity guidelines, application processes, and defined responsibilities differ somewhat across the U.S. In some states, it's referred to as "conservatorship." Depending on the state and individual circumstances, the process can take several weeks or months to complete. Full guardianship typically involves responsibility for making decisions regarding basic needs, personal property, finances, and medical treatment. In many states, though, limited guardianship is also recognized, based upon the ward's capabilities. In such cases, the court will stipulate which decisions a guardian should handle."

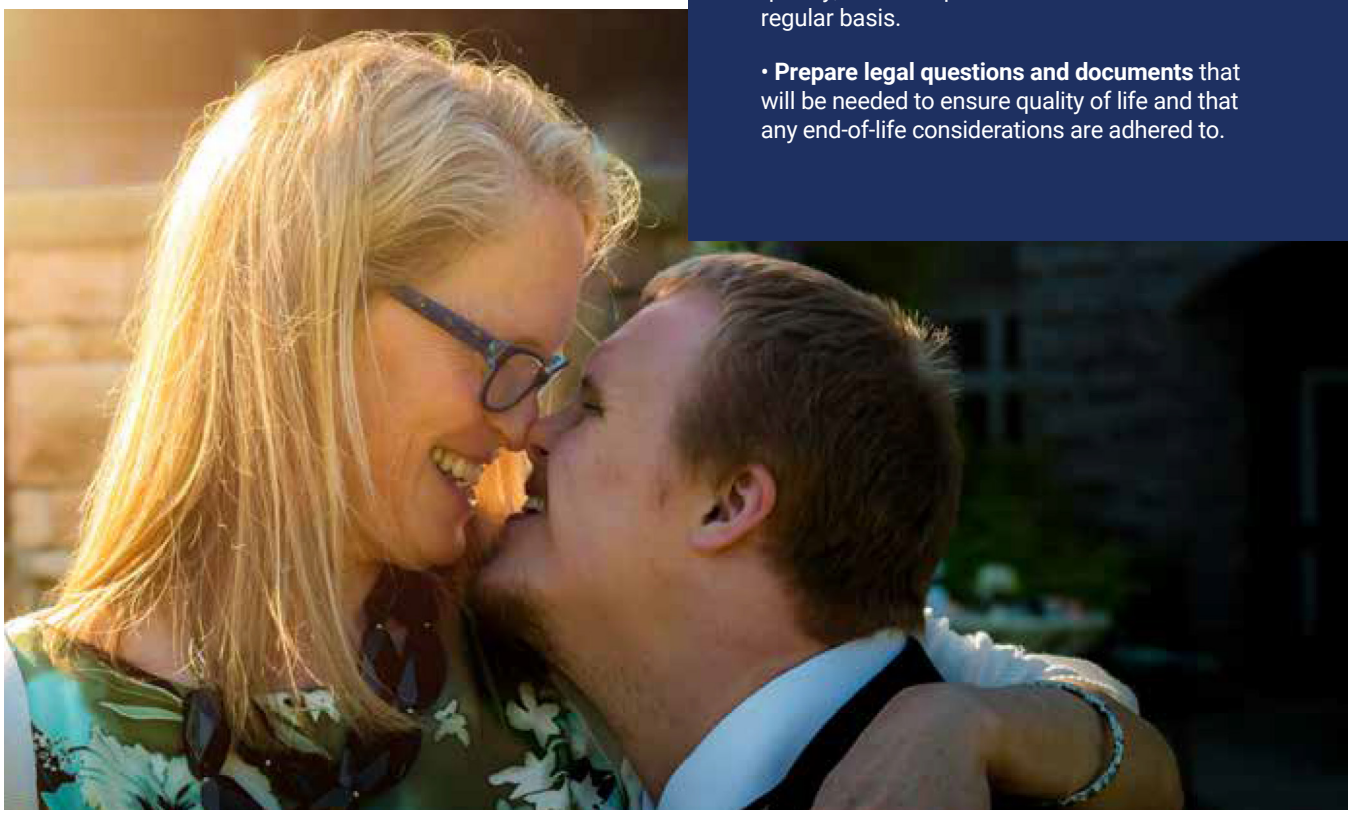
—Special Needs Alliance

TIP It is important to monitor for signs of change indicating a medical condition and to assess what legal considerations need to be in place for the care recipient. Below are some questions that can serve as a guide to navigating a challenging time for the care recipient with Down syndrome:

- **Does the care recipient have a medical directive and/or living will?**
- **Has a healthcare proxy been designated? If so, who is it?**
- **Has a HIPAA release been signed?**
- **Are there any designated beneficiaries?** Are they up to date?
- **Is there a current and complete will?**
- **Does the care recipient have a power of attorney?**
- **Can you access these documents?**
- **Do you know who helped them complete these documents?**
- **Do you have contact information for your loved one's healthcare providers?**

TAKEAWAYS
SUPPORT PLAN

- **Creating a personal profile/My Health Passport** can help all caregivers, family, and friends be on the same page regarding your loved one's needs, likes, and wants, while documenting what works and doesn't work for them.
- **Take steps to ensure proper care and wellbeing** of your loved one with Down syndrome. A letter of intent of wishes for medical care and end-of-life care can help family members understand the needs and wishes of your loved one so all families and caregivers involved are on the same page.
- **Caregivers should be prepared to advocate** for the personal needs of their loved one in the areas of medical care, work opportunities, daily living, and end-of-life care.
- **Be aware of and monitor any changes, signs, and symptoms** as the care recipient with Down syndrome ages. Subtle changes may occur quickly, so it is important to monitor these on a regular basis.
- **Prepare legal questions and documents** that will be needed to ensure quality of life and that any end-of-life considerations are adhered to.



LEGAL AND FINANCIAL

The legal and financial matters of planning for the future can be a huge responsibility for a caregiver. This is a critical area of future planning for individuals with Down syndrome so you can ensure their wishes are respected as they age. Consider creating a family plan to appoint specific caregiver roles, such as choosing a power of attorney and a healthcare power of attorney.

BEGIN TO INVESTIGATE government benefits that are available for your care recipient to see if they are being utilized. Benefits may include:

- Supplemental Security Income (SSI)
- Social Security Disability Insurance (SSDI)
- Local and state disability
- Adult developmental day training/job programs
- Transportation assistance

Be cognizant of federal, state, and local laws when managing all legal and financial affairs, and be aware of additional information regarding maintaining an ABLE account in your state. Please refer to the NDSS resource *Financial Wellness: A guide for individuals with disabilities, their families, and caregivers* for more helpful information on financial management.

To keep things organized, family members and caregivers can create a system to manage important personal documents so they can be utilized in a time of need. It will make things easier if you can access these documents before a crisis occurs. Keep in mind that not all documents listed below may be applicable to the individual you are caring for. All documents should be stored together and secured in a fireproof safe.

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

ABLE ACCOUNTS

Achieving a Better Life Experience (ABLE) accounts (also known as 529As) allow those with disabilities and their families to invest money and withdraw it later, tax-free, for expenses such as housing, education, transportation, health care, and employment training. A key component: having the money won't disqualify the beneficiary from valuable federal benefits, such as Medicaid.

Contributions to the account, which can be made by any person (the account beneficiary, family, friends, Special Needs Trust, or Pooled Trust), must be made using post-tax dollars and will not be tax deductible for purposes of federal taxes; however, some states may allow for state income tax deductions for contributions made to an ABLE account.

List of Important Documents

• **Identification documents:** Birth certificate, Social Security card, healthcare/insurance card, Medicaid and Medicare cards and policies, passport, citizenship papers, and marriage certificate

• **Legal documents:** Guardianship papers, power of attorney for financial and medical care, advance directives, wills, trusts, estate planning, deeds to property, cemetery plot, and funeral arrangement documents

• **Banking and financial documents:** Credit and debit cards, bank accounts and contact person, safety deposit boxes, tax returns (federal, state, and local), financial planner contact information, accountant contact information, car title and insurance, and investment information

• **Other documents:** Waiver information if applicable, copy of individual service plan (ISP), and medical records/psychological evaluation

PERSONAL PROFILE

Several years before our mother died, my sister inherited a large sum of money from one of our mother's cousins. Because of the amount of money, we thought we should contact an attorney to find out the best way to protect these assets. As my brother, mother, and I sat around the large conference table with a financial advisor and the attorney, someone asked the question, "Does Margaret have a legal guardian?" The answer was, no, she didn't — we just assumed that our mother was Margaret's legal guardian, since she was her mother.

This was not the case — a person with Down syndrome over the age of 21 is not a minor any longer. According to the law (and each state may be different), a 21-year-old is an adult with the same rights as anyone else.

After the meeting was over, we began the process of establishing my mother as Margaret's legal guardian. Thankfully, our family had never faced any challenges that would have kept our mother from deciding on Margaret's behalf, however it could certainly happen. It's important that every family with a loved one with Down syndrome understands that legal guardianship is important.

— Embry B.

TAKEAWAYS

LEGAL AND FINANCIAL

• **Gather all legal papers,** organize, and keep them in one safe place. Get these together including a power of attorney before you encounter a crisis.

• **Make a family plan** to determine who will assume each caregiving role.

• **Make sure that the individual** you are caring for with Down syndrome is getting every available benefit, including Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), local and state disability, adult developmental day training/job programs, and transportation assistance.

• **Be cognizant of federal, state, and local laws** when managing all legal and financial affairs.

• **Find an attorney that specializes in special needs law**. Check with your local Down syndrome support group to see if they have recommendations and other resources related to legal and financial matters. When applicable, seek a financial consultant regarding special needs trusts and funding restrictions. Extended family should consult with the care recipient's guardian when considering gifting to a special needs trust.

GOVERNMENT BENEFITS

Many adults with Down syndrome are employed and living independently. However, some adults with Down syndrome may never be able to work or live without supportive care.

GIVEN EITHER circumstance, adults with Down syndrome will need financial assistance. The Social Security Administration (SSA) allows a third party to apply on behalf of a disabled individual for Social Security disability benefits. These include SSDI and SSI.

Applying for Social Security Disability Benefits

You can make an appointment to apply in person or by phone by calling 1-800-772-1213 (TTY 1-800-325-0778)

OR

Complete the application online with the SSA's website.

Be sure to gather all the required medical documentation before submitting your claim to avoid delays in the processing of your application.

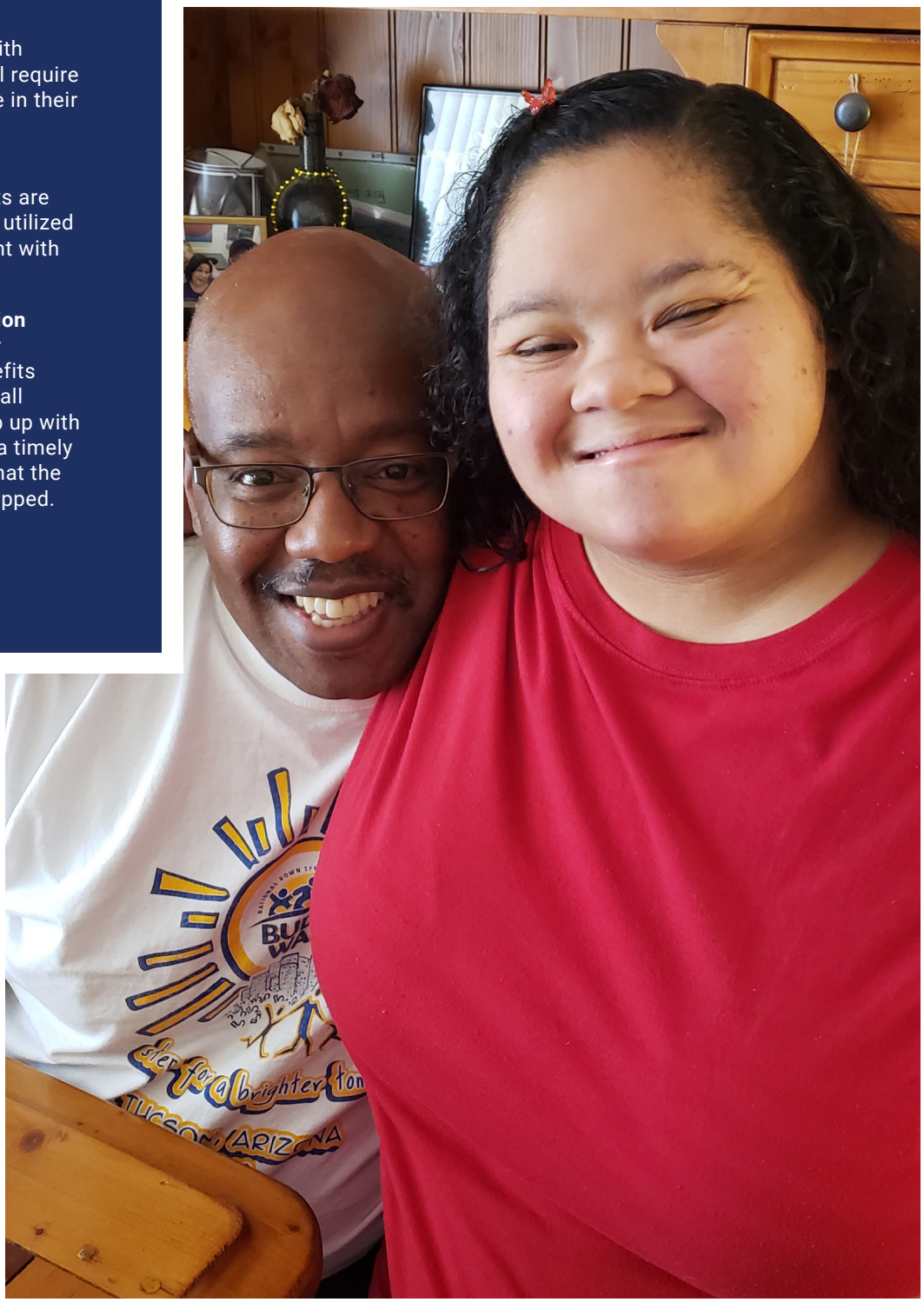
State Medicaid Waivers

Medicaid Waiver programs provide money that can pay for services for people with disabilities. These services can take place in the person's home or in the community. Each state Medicaid program is unique, reflecting how states implement options and use waivers to design programs that meet their needs and priorities. Please note that there are often waiting lists for these waiver programs; we recommend you apply for these benefits as early as possible. In addition, if the individual is on a waiver program and plans to move to another state it is important to see if this waiver will transfer.

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

TAKEAWAYS
GOVERNMENT BENEFITS

- **Many individuals** with Down syndrome will require financial assistance in their adult life.
- **Inquire about what government** benefits are available and being utilized for the care recipient with Down syndrome.
- **Gather all information** prior to applying for benefits. Once benefits are secured, follow all guidelines and keep up with correspondence in a timely manner to ensure that the benefits are not dropped.



HOUSING/ RESIDENTIAL

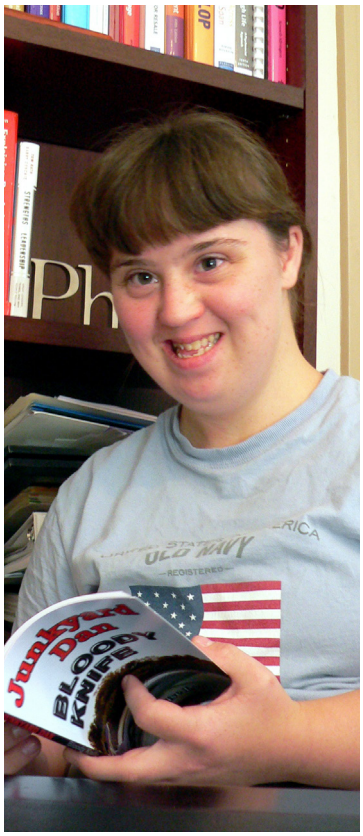
Housing options for individuals with Down syndrome include living in the home using in-home support, living in the community in group homes, assisted living, and other options depending on the location.

MAKING THE transition outside the home and into the community can be a daunting task for individuals with Down syndrome along with their guardians, family members, and friends. The key is to have a supportive care and coordination team in place to navigate the system and advocate for the individual with Down syndrome. The team should start with an assessment tool to determine the needs and level of care. Some questions to consider are the individual's preferences, options, and funding that is available. The goal should be to find the right fit and make the transition to a new living arrangement both seamless and comfortable.

Before transitioning to living away from the family home, consider which additional activities of daily living (ADLs) require extra support.

- Cooking and preparing meals
- Budgeting
- Paying bills
- Shopping
- Cleaning and tidying
- Personal grooming and care
- Transportation
- Social environment and activities
- Organizing and getting ready for work or school
- Routinely taking medication

Please see the National Institutes of Health (NIH) link on the resources page at the end of this document for more information on the various types of housing options.



TIP As a caregiver, being prepared is vital to success. The clock is ticking. We cannot roll the dice in middle age without a plan. Do not wait to look for housing/residential placement in crisis mode.

—Jeanne D.

PERSONAL PROFILE

Finding the right housing fit comes with many challenges. It is a waiting game. I am a parent of a child with disabilities. My son Nick has a dual diagnosis of Down syndrome and autism (DS-ASD); he is mostly non-verbal and requires constant care. Like many parents, I am convinced that there is no one who can take care of my child, understand his needs, and love him like I can. Here is the thing — I know that this is not sustainable.

Recently, I turned 60 years old. So, the question begs, how long should I wait to put my child on the list for a group home? As caregivers, we tend to hold off because we know that we are their everything. Our loved ones need something more, and they can get this by being out of the home and with peers their own age.

Being tethered to your adult child can be draining and is not sustainable over the long haul. I understand this now, and since this realization, I have met some amazing personal support workers who also work in group homes locally. My uncertainties and fears have relaxed to some degree as I have witnessed the love, care, dedication, and compassion they have shown to my son. This gave me a sense of peace and confidence to commit and put Nick's name on the waiting list.

Now we wait, and I look back and ask myself if I should have started sooner. Could we cast a wider net further than an hour away where there are potential openings? I am not ready to do that yet. For now, I will continue to stay as healthy as possible and be patient in this waiting game. My goal is for my son to find a home where he feels cared for, supported, happy, valued, and loved.

— Teresa U.

Living Arrangements and Options: When is it time to look at long-term care options?

There are several different options for placement outside of the home if the time comes when your care recipient needs the type of attention and care that you can no longer provide. These types of facilities vary based on the level of care needed. For example:

- Group home
- Assisted living
- Memory care
- Continual care
- Nursing home (skilled nursing facility)

PERSONAL PROFILE

Even though we hope that our loved ones never have to face challenges, sometimes life events are out of our control. A home care option or a residential option may soon not work out or may not meet the needs of our loved one. It is at this time that unexpected changes may be necessary. For example, I am now being tasked with finding a nursing home for my sister, because the memory care facility she has lived in for the past 22 months is no longer able to meet her needs due to progression of her dementia. Residents must remain ambulatory, and she has gotten to the point that she does not want to walk anymore. In addition, she has developed chronic UTIs and simply needs more skilled nursing care than this facility can provide.

I was able to find a room for her in a nursing home close to my home and had completed all the necessary paperwork to move her into the facility. However, the admissions director told me that she could not be admitted until they received medical information from her physician. A few days later, the admissions director called to say they received the necessary paperwork from the doctor; however, upon entering my sister's diagnosis of Down syndrome into their computer system, it triggered a "flag" from the state regulators, and now we must wait for a social worker from the state office of mental health to evaluate her. Everything was put on hold, and now we play the waiting game…again. Yet another hurdle that I had not planned for.

— Embry B.

TAKEAWAYS
HOUSING/RESIDENTIAL

• **Assemble a care team to assess housing needs** to determine the levels of support needed and what type of residence setting is most appropriate.

• **Do a few overnight trial runs** to make sure the housing placement is the right fit. Adjust as needed to ensure a smooth transition.

• **Plan ahead, weigh housing options, and make decisions before there is an urgent crisis.** Regarding the decision-making process, be sensitive to all family members who may want to weigh in on housing placement so the plan is something that everyone can agree on.

• **Get a plan B in place** in case there is a crisis, or in case the current caregiver is unable to assume the role. Check with your state, regional, and local agencies to get a list of homes that take in individuals in crisis. Arrange for tours to determine which would be the best fit for a plan B.

• **Be aware of changes and signs of decline** that may make it necessary to investigate a long-term care facility. There are several long-term care options for when the caregiver can no longer meet the needs at home for the individual with Down syndrome. It is wise to research these living options ahead of time to be prepared before any decline in health.

TIP Discussing housing options for your loved one or care recipient may bring forward a lot of unexpected emotions. It is not only a big logistical change, but it is also an emotional one. Take the time to map out what you and your care recipient want for their future, teach them autonomous decision-making and how to advocate for themselves, and most importantly, express that you will do your best to always advocate alongside them.

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

SELF-CARE FOR THE CAREGIVER

Being a caregiver involves love, great joy, a myriad of challenges, and sometimes even heartbreak. It is not a vocation so much as it is a labor of love; a commitment to ensuring the well-being of another. Due to the stressful and continuous nature of caregiving, those of us who provide care for someone with Down syndrome as they age need to practice self-care.

UNFORTUNATELY, SELF-CARE AND RESTING are not rewarded in our society. In fact, we are encouraged to “take things as they come” or to simply “put our heads down and keep going” when things in our lives become challenging or overwhelming. When this is the case, our own health and well-being can, and will, suffer. Our society does not place value on self-care, and as a result, many of us are conditioned to sacrifice our own health for the sake of another. Self-care can be anything that benefits your own well-being. Enjoy a hobby, exercise, get a spa treatment, have lunch with a friend, go shopping, take a nap, etc. Do whatever activity gives you a sense of peace and keeps you centered. If you do not prioritize your own health and well-being, you will be unable to care for someone else, especially someone who will need the type of care an individual with Down syndrome will require as they age. Be kind and patient with yourself as you make decisions on behalf of your care recipient. Recognize that as things change in both of your lives, the choices you are making for your well-being will help them as well. Two forms of self-care that are often overlooked include incorporating small changes into your daily routine or saying "no" to plans or an obligation when you want your alone time.

PERSONAL PROFILE

In-home personal support workers are valuable for providing respite care for individuals with Down syndrome. But just as important, they give caregivers an opportunity to take time to take care of themselves. Sometimes I just go for a walk, work in my garden, shop at my favorite stores, or have a lunch date with girlfriends. I always feel restored carving out time for these activities and more energized to take care of the complex challenges of being a caregiver to my son with Down syndrome and autism. My advice to caregivers is to find support workers to take some of the workload off your shoulders, so you can take time to do what feeds your soul.

— Teresa U.

Pillars of health

If you are having difficulty implementing self-care practices, you may be able to begin by focusing on improving one or more of the five pillars of health. You will usually see the pillars described in four categories; however, according to Reita Clanton and Ford Dyke who designed and teach a stress reduction class in the School of Kinesiology at Auburn University, "breath" should also be added to the basic four pillars, which are listed below:

1. **Nutrition**
2. **Hydration**
3. **Movement**
4. **Sleep**
5. **Breath**

Improving even one of these areas will begin to have a positive effect on your overall health and well-being. Most people walk around in a state of dehydration, which can have several negative effects on your body and mind. If you can make a commitment to increasing the amount of water you drink each day, you will notice the benefits almost immediately.

We all know that healthy eating will improve energy and decrease the likelihood of developing chronic disease; however, it can also improve your mood and your sleep. Giving yourself foods that nourish your brain and body will help you feel better, both physically and mentally.

The United States Department of Agriculture encourages you to "walk in the woods for wellness", and if you live in a part of the country where you can take a walk outdoors in the grass or dirt with just your bare feet, this is an even greater immune booster. Being in nature and connecting with the earth is a powerful way to improve your mood and calm your nervous system. Take your loved one outside with you, if possible. Both of you will feel the benefits of being in the sunshine and connecting with nature!

Caregiver exercise tips

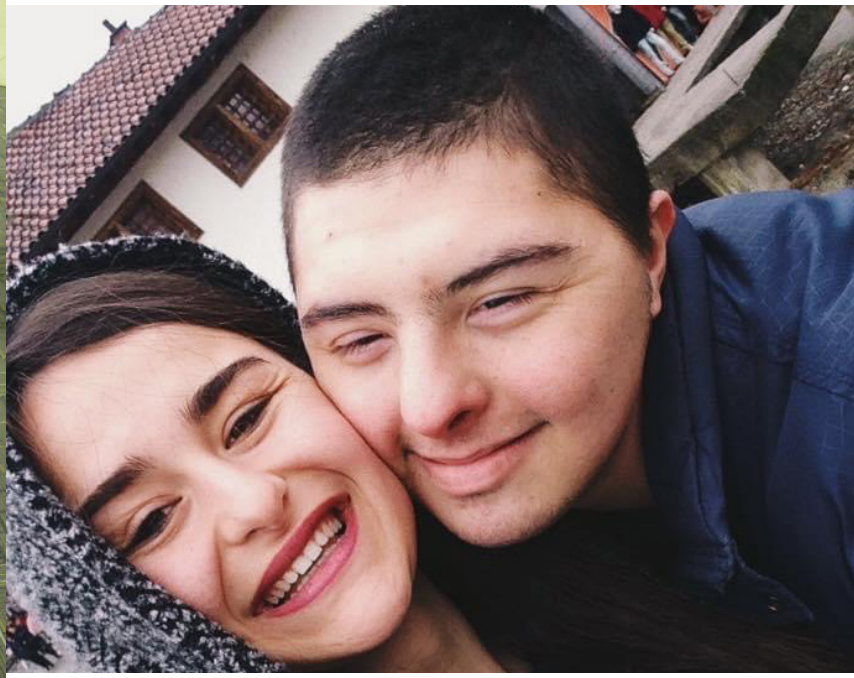
Exercise provides physical benefits, keeps stress in check, gives you more energy, helps you sleep better, and improves your overall health and mood. Caregivers may feel that taking time to exercise is a luxury, but remember, your well-being means their well-being. Studies show the benefits of taking walks and short 10-15-minute workouts are beneficial to overall health.

The NDSS *321go!* program can be used to add these healthy habits into a routine. The *321go!* program promotes healthy lifestyle choices in physical activity, balanced nutrition, and emotional wellness among individuals with Down syndrome and their families.

TIPS THAT WILL KEEP YOU MOTIVATED, STRONG, AND REFRESHED:

- Keep goals simple and realistic.
- Consider working out with your care recipient. Take walks or do exercise videos together. There are many videos available on YouTube or on-demand TV such as chair workouts, yoga, and dancing for all fitness levels.
- Be consistent with your workouts; it all adds up. Results happen over time not overnight.
- Whether you work out at a gym or home, incorporate cardio, strength, and flexibility exercises in your routine.
- Be accountable. There are many apps that track fitness routines and help to keep you motivated. Work out with a friend; they can be your accountability partner.
- Check with your physician before starting a new fitness routine.
- Have fun and pick activities that you enjoy!

**For more information about NDSS 321go! and how to obtain a kit, please see the Resources page.*



Healthy sleep habits

Healthy sleep habits are imperative for a healthy lifestyle. It is only during deep sleep that your brain's lymphatic system can do its "housecleaning" and get rid of metabolic waste in your brain. So, not only does a good night's sleep help you feel more rested and able to focus, but it is also a time when your body performs a critical waste removal process. Sometimes finding time to sleep may feel like a luxury, especially if your care recipient does not sleep well. If possible, take time to nap or sleep when they do.

TIPS FOR HEALTHY SLEEP HABITS:

- Limit exposure to blue light (TV, cell phone, tablets) for at least an hour before bedtime. Blue light signals your brain that it is time to be awake, which is why it is difficult to prepare yourself for sleep if you leave a television on or lay in bed staring at your phone. Most devices have a blue light filter that you can turn on if you like to read in bed.
- Try not to eat or drink anything (other than water) for at least three hours before you go to bed.
- If you have anxious thoughts or your mind wants to replay the events of the day when you go to bed, try using some type of guided meditation or soothing sound to prepare yourself for sleep. There are numerous apps that are available (some free and others for a small fee) that have wonderful guided meditations for sleep, soothing sounds, and sleep stories that are a great way to take your mind off the problems of the day.
- Make sure your room is cool or a comfortable temperature. Also, making the room as dark as possible will enable your body to tune into its circadian rhythm.

Mindful breathing practice

Even though our breath is something that happens without our thought, it is the only involuntary process over which we can gain conscious control. In most cases, humans can go two weeks without food, three days without water, but only three minutes without our breath. When thought of in these terms, it is important that we pay attention to our breath and use it to our advantage. Deep breathing is one of the most restorative practices we can use throughout the day. Remind yourself that every cell of your body responds when you take a deep breath. There are many breathing practices used in yoga and meditation; however, you do not have to learn all of them. You can simply pause throughout the day and take a few deep breaths, which will help to reset your nervous system, slow your heart rate, and let your body and your mind know that everything is okay.

TIPS FOR HELPFUL BREATHING:

Incorporate *NDSS 321go!* Breathing into your routine.

- Inhale slowly while thinking "3-2-1."
- Hold while thinking "3-2-1."
- Exhale slowly while thinking "3-2-1."

Practice 3-2-1 breathing for at least one minute to immediately feel more relaxed!

Asking for and accepting help

Sometimes caregivers feel that they are the most qualified person to take care of their care recipient. After all, who knows them better than we do?

One of the hardest things to realize is that at some point, things can become overwhelming, and you must reach out and ask for help. Caregiver support group facilitators often notice their participants find it hard to accept help because they feel the help will not be given to the care recipient in the way that they usually provide it. Bottom line, this is not something that can be done alone. Asking for and accepting help from family members or others in your support network or hiring additional personnel can ease the burden on a caregiver. In some areas, respite facilities are available, either for you or for your loved one, so that you can practice one of the most important aspects of self-care: taking time for yourself.

If there is not a respite facility near you, you can consider contacting an agency that provides care workers for all types of needs. Many agencies have staff who will come and sit with someone for just a few hours a day. Even if it is only one day a week, allow yourself to have that break – you deserve it, and it is okay to take this time for yourself. Your loved one may need a break from you as well, so it is a win-win.

You may also find that joining a support group is helpful; not only will you make connections with other caregivers, but you may also receive valuable recommendations, referrals, and other information from group members. Check for your local Down syndrome support group on the NDSS Local Support page, Easter Seals, or online search to find a caregiver group for people who are caring for someone with Down syndrome. For example, Facebook has a group specifically for caregivers of individuals with Down syndrome who are experiencing regression. Caregiver support groups can help caregivers feel less alone, less isolated, and less guilty, and they will add a wealth of support and encouragement.

Being a caregiver is one of the most selfless acts of compassion and love. The experience can be rewarding and positive, but also stressful and draining. Give yourself grace when the days are challenging and do not go the way you expected. Go easy on yourself when you are too tired or lack the energy to exercise self-care. Rest when you need to; that is also an act of self-care. Cut yourself some slack and lower your standards of perfectionism and expectations from yourself and others. Be aware of how you are feeling and listen to that voice, then ask for and accept help so you can do the best job of helping the care recipient.

TAKEAWAYS

SELF-CARE FOR THE CAREGIVER

- **Caregiving can be rewarding**, but it comes with challenges and stress. For these reasons it is important to make self-care a priority.
- **Being mindful and practicing** the principles of the five pillars of health each day will have a positive effect on overall health and well-being.
- **Carving out time to exercise** or enjoy hobbies and other activities will provide many health benefits, reduce stress, and give caregivers an overall mood booster.
- **Healthy sleep habits** and mindful breathing practices have been shown to contribute to overall wellness. Individuals with Down syndrome and dementia may have sleep issues that can affect the caregivers. Try to take nap breaks alongside them to avoid sleep deprivation.
- **Part of self-care** is recognizing that you cannot do it alone. Seek help and support groups that will provide respite, offer information, and enable connections on your caregiver journey.
- **What you can do each day** is enough, even if that changes day-to-day. If you miss or skip a day of self-care, or if your self-care looks different from what has been described in this book, what is important is that you are aware of your needs, your limitations, and when to ask for help.

CONCLUSION

BEING A CAREGIVER for an individual with Down syndrome as they age can be rewarding and filled with many positive experiences; however, it also comes with challenges and stressors. This guidebook outlines the key areas that need to be managed on a regular basis. The responsibilities associated with the affairs of adults with Down syndrome as they enter adulthood and mature are extensive. For this reason, it is important to be organized and build a team to help. Even more crucial is the willingness to ask for and accept help from family members, friends, and outside personnel.

Making self-care a priority is not always easy, but it is essential to avoid burnout. It will also ensure that the care recipient with Down syndrome receives optimal attention and the best version of you.

Whether you are living separately or under the same roof with the care recipient, there can be many feelings of guilt that arise if you are not able to fulfill a promise to a parent or yourself. At whatever stage you find yourself in the caregiver journey, take solace in knowing that you are still looking out for the care recipient with Down syndrome and have their best interests at heart.

It is important to remember you are not alone on this journey. What you can accomplish each day, for yourself and your loved one, is enough. As much as possible, continue to seek out support groups, additional help, and respite services. Remember that your empathy, compassion, advocacy, and effort do not go unnoticed.

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

321GO!

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 wellbeing, 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://adscresources.advocatehealth.com/search/people-with-down-syndrome/

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

BENEFITS WEBSITE OF THE U.S. GOVERNMENT

https://www.benefits.gov/

The mission of the official benefits website of the U.S. government is to increase citizen access to benefit information, while reducing the expense and difficulty of interacting with the government.

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.

CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

www.cms.gov

CMS serves the public as a trusted partner and steward, dedicated to advancing health equity, expanding coverage, and improving health outcomes.

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.

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.

EASTER SEALS

https://www.easterseals.com

The Easter Seals mission is to provide exceptional services to ensure that all people with disabilities and their families have equal opportunities to live, learn, work, and play in their communities.

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

MEDICARE.GOV

http://www.medicaidwaiver.org/

Medicare is health insurance for people 65 or older. You are first eligible to sign up for Medicare three months before you turn 65. You may be eligible to get Medicare earlier if you have a disability.

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 very familiar with providing care to individuals with intellectual and developmental disabilities.

NATIONAL DOWN SYNDROME CONGRESS (NDSC)

https://ndsccenter.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.

RESOURCES

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 help full-time help might move to a residential facility that provides many or all of the long-term care services they need.

NATIONAL INSTITUTE ON AGING - SLEEP INFORMATION

https://www.nia.nih.gov/health/infographics/getting-good-nights-sleep

Not getting enough sleep can affect all areas of your life and cause health problems. Learn how to develop healthy habits at bedtime as you age to help you get a good night's sleep.

NATIONAL RESOURCE CENTER – ACHIEVING A BETTER LIFE EXPERIENCE ACT (ABLE NRC)

https://www.ablenrc.org/

The mission of ABLE NRC is to educate and promote the positive impact of ABLE on lives of millions of Americans with disabilities and their families.

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 mild cognitive impairment (MCI) or dementia or—alternatively—signal behaviors that may be amenable to intervention and remediation.

PALLIATIVE CARE NETWORK OF WISCONSIN

https://www.mypcnow.org/fast-fact/palliative-care-for-patients-with-down-syndrome/

The Palliative Care Network of Wisconsin supports the growth of palliative care services in Wisconsin through education, system change, and advocacy. Fast facts are provided on Palliative care for patients with Down syndrome, written by Jane E Loitman, MD, and Gail Gazelle, MD.

SOCIAL SECURITY ADMINISTRATION

www.ssa.gov
https://secure.ssa.gov/iClaim/dib?URL=/apps6z/radr/radr-fe

The Social Security Administration assigns Social Security numbers and administers the Social Security retirement, survivors, and disability insurance programs. They also administer the Supplemental Security Income program for the aged, blind, and disabled.

(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.

STANFORD DOWN SYNDROME RESEARCH CENTER (SDSRC)

https://dsresearch.stanford.edu/family-resources/adults-down-syndrome

The goal of SDSRC is to become a center of excellence creating a synergistic, cross-disciplinary research community and leveraging the academic excellence at Stanford University to support innovative, rigorous research that will lead to improvements in the lives of individuals with Down syndrome.

STATE MEDICAID DISABILITY SERVICES AND WAIVERS

http://www.medicaidwaiver.org/

Medicaid Waivers help provide services to people who would otherwise be in a nursing home or hospital to receive long-term care in the community. Although there are waivers for many conditions, this focus is towards waivers for people who have intellectual disabilities, developmental disabilities, and autism.

SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (SNAP)

www.fns.usda.gov/snap

SNAP provides nutrition benefits to supplement the food budget of families in need so they can purchase healthy food and move towards self-sufficiency.

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Caregiving & Down Syndrome

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

National Alliance for Caregiving
www.caregiving.org

national down syndrome society
ndss
www.ndss.org

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