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# Health Promotion for Adults with Down Syndrome

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# Introduction

The World Health Organization defines health promotion as “the process of enabling people to increase control over, and to improve, their health.”<sup>1</sup> Individuals with Down syndrome can and should be active participants in promoting their own health. While they may require varying levels of support, they have a desire to be healthy and enjoy the opportunities that life offers. To do this, professionals should include individuals with Down syndrome in their own healthcare instead of assuming they are not capable of such decisions.

It is important to understand how individuals with Down syndrome learn best. This can assist a care professional in providing accurate

health information while using a strategy that facilitates learning for the individual and helps them be active participants in their health. A Down syndrome behavioral phenotype has been described, which explains common characteristics associated with this diagnosis.<sup>2</sup> These characteristics include strengths and weaknesses in motor skills, cognition, language, and social-emotional function. While individuals with Down syndrome are more likely to show these behaviors than other individuals with intellectual disability, not every individual with Down syndrome will display all the behaviors of the phenotype.<sup>3,4</sup> The behavioral phenotype in Down syndrome includes relative strengths in visual-spatial processing, and social skills. Additionally, it identifies relative deficits in auditory and verbal processing expressive language and some motor functioning as well as self-care skills and goal-directed behavior.<sup>3,5-7</sup>

### Hearing impairment

Some 50-70% of adults with Down syndrome experience hearing loss. Sensorineural and conductive hearing loss are common. Will have difficulty listening in noisy environments, processing spoken language, discriminating speech sounds, and learning phonics.

### Verbal memory weakness

Difficulty learning from listening – maintaining attention, retaining instructions, memorizing sequences, and learning new vocabulary and information. Challenges in retaining and consolidating learning into long-term memory.

### Delayed motor skills

Linked to low muscle tone, loose ligaments, and developing motor plans. Affects all physical activities. Delayed self-help skills and handwriting progress but will improve with practice. May have difficulty staying on task and multi-tasking. Easily distracted by other factors. Tires easily.

### Speech & language delay

Limits ability to communicate. Understands more than can express – knowledge may be underestimated. Affects processing of long sentences, learning from listening, understanding new or subject-specific vocabulary, word finding, forming sentences, understanding instructions, reading comprehension skills, and thinking and reasoning.

### Visual learning strengths

Ability to learn and use signs and gestures, to learn to read and use written words. Strengths in learning through imitation, from modeling and demonstration. Learns well from visual resources (pictures, photos, diagrams, symbols, concrete materials, digital technologies, and apps).

### Visual impairment

Common in adults with Down syndrome. Challenges with depth perception. Can experience early onset of age-related vision issues. Bifocals are routinely recommended. Will have difficulties with writing, using a pencil on blue-lined paper, reading <18 point font, coping with text/diagrams/pictures that are too cluttered, detailed, or have little contrast.



This graphic, adapted from *Down Syndrome: Good Practice Guidelines for Inclusive Education*, outlines strengths and challenges associated with the main aspects of the specific learning profile for people with Down syndrome, as well as the unique range of sensory, physical, and cognitive needs of this group of learners.

There are many effective strategies to help individuals with Down syndrome learn. Based on their slower auditory processing but strong visual learning, using pictures and text can enhance instruction. When delivering instructions verbally, speak slowly using simple language, and allow time for the individual to process what is asked of them and to form a response. Avoid using colloquialisms, as they may not be understood due to their abstract nature. For instance, it is better to say, “Please be quiet” than “Bite your tongue”, or “I understand what you are saying” instead of “I am with you.” Individuals with Down syndrome also tend to provide answers to questions that they think others want to hear. Therefore, it is important to ask clarifying questions or even open-ended questions. In addition, individuals with Down syndrome often use scripted speech, repeating phrases from movies or TV shows, or use different narrative timelines when they respond to questions or engage in conversations, which can make gathering accurate information challenging. Families or caregivers can usually provide context for what the individual is reporting. For instance, if an individual is pointing to their abdomen when you ask if they are in pain, the parent may be able to provide context that they had pain around their birthday last year and before the pain question, you were asking about what they did for their birthday last week.

In this article, we will discuss three areas of health – physical, mental, and social – and the impacts if there are deficits in one or more

areas. The physical health section will cover the importance of hydration, healthy eating, physical activity, and sleep. The mental health section will review how to support mental wellness and several important co-occurring mental health diagnoses in the Down syndrome population. Finally, the social health section will discuss the importance of community participation and its impact on well-being.

## Promoting Physical Health in Adults with Down Syndrome

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### Sleep

Good sleep is important for overall health and quality of life, so optimizing sleep for individuals with Down syndrome is a commonly encountered concern. In individuals without Down syndrome, sleep deficiencies have been associated with hypertension, decreased cognitive function, and all-cause mortality.<sup>8,9</sup> In individuals with Down syndrome, restless sleep is associated with executive dysfunction, poor inhibitory control, and worsening episodic memory.<sup>10</sup> There is also growing evidence that sleep disorders can accelerate the development of Alzheimer’s disease.<sup>10</sup> As adults with Down syndrome are already at extremely high risk of developing Alzheimer’s disease, the treatment of sleep disorders in adults with Down syndrome is crucial to prevent co-morbidities.<sup>10</sup>

More information regarding sleep can be found in the [Sleep Disorders in Adults with Down Syndrome](#) article.

There are many reasons for sleep disturbances in individuals with Down syndrome. Between 65-100% of adults with Down syndrome have some degree of sleep apnea, probably related to differences in airway structures and tone.<sup>10</sup> Although snoring is classically associated with sleep apnea, it is not always reported in adults with Down syndrome.<sup>10</sup> Common presentations of sleep apnea in individuals with Down syndrome include waking up in the middle of the night, daytime sleepiness, poor ability to concentrate, and behavioral changes.<sup>10</sup> Most adults with Down syndrome should be screened for sleep apnea at some point in adulthood.

Psychiatric diagnoses like anxiety and depression are also associated with sleep disturbances, and these conditions are more common in individuals with Down syndrome.<sup>11</sup> Evaluating and treating concurrent psychiatric diagnoses may help improve sleep for affected individuals. More information regarding mental health is provided in the second section of this article, and in the article [Mental Health: Diagnosis and Treatment of Adults with Down Syndrome](#).

Gastroesophageal reflux disease (GERD) is common in individuals with Down syndrome, possibly related to lower tone in the gastro-esophageal sphincter. GERD can be worse in the evening if a person lies supine too soon after eating. This can cause discomfort, throat

or chest pain, or cough. Some individuals with Down syndrome have trouble describing these symptoms and may not report them, even if directly asked. However, the discomfort may lead to the person staying awake, having trouble falling asleep, and waking up during the night.

Some adults with Down syndrome report trouble falling asleep and/or trouble staying asleep. Assessing for common medical conditions which may impact sleep, such as depression, anxiety, and GERD, is indicated. In the absence of these diagnoses, creating behavioral supports to encourage good sleep hygiene may be helpful. Using visual supports and timers can help increase compliance with a new bedtime routine, empowering adults with Down syndrome to be in charge of their own sleep schedule. Adults with Down syndrome may also be taught relaxation techniques and calming strategies to help the mind and body prepare for sleep. For adults with trouble staying asleep, creating routines for falling back asleep if awakened may help. If behavioral strategies alone are ineffective, supplements or medications may be considered.

## Exercise

Exercise plays a crucial role in healthy aging and in preventing and managing chronic disease.<sup>12</sup> Physical inactivity is a risk factor for the development of Alzheimer's disease<sup>13</sup> and there is some evidence that, in the non-Down syndrome population, exercise may delay

disease onset.<sup>14</sup> Because individuals with Down syndrome are disproportionately affected by [Alzheimer's disease](#), promoting exercise in individuals with Down syndrome seems reasonable. There is also evidence in adults with Down syndrome that exercise is associated with improved cognition and memory.<sup>15,16</sup> Even after adjusting for differences in body mass index, increased time spent in physical exercise was significantly associated with decreased rates of sleep apnea, decreased rates of metabolic/endocrine disorders, and increased overall physical health.<sup>15</sup> Generally, exercising for at least 30 minutes with a moderate intensity 5 days a week is recommended. However, most adults with Down syndrome do not meet recommended exercise guidelines.<sup>17</sup>

Balance is very important for adults with Down syndrome.<sup>18</sup> Exercise routines involving balance can help reduce the risk of falls in older adults. Additionally, many adults with Down syndrome have trouble with depth perception. This can make maneuvering different surfaces challenging, which makes falls more likely. Working on proprioceptive strength and balance may help preserve mobility in adults with Down syndrome.

Strength and resistance training are also important. Although osteoporosis is reported to be more common in individuals with Down syndrome, there is a growing body of evidence that DEXA scans may underreport bone density in all people of shorter stature. There is also some data that, compared to individuals without Down syndrome,

individuals with Down syndrome may have differences in bone formation pathways.<sup>19</sup> Regardless, adding resistance training can protect bone density and enhance muscular strength.<sup>18</sup>

Many adults with Down syndrome earnestly enjoy physical activity.<sup>20</sup> Others can be encouraged to participate if they are empowered to make their own exercise choices. Offering options (walking, running, biking, swimming, dancing) can help make exercise enjoyable instead of a chore. Note that an individual's preferred type of exercise may change with age. Promoting exercise by making it fun, social, or a game can help improve compliance, as can spreading the exercise throughout the day. There are many organizations that provide opportunities for individuals with Down syndrome to participate in recreational exercise.

## Water

Drinking water and staying hydrated are important components of good health. From clinical experience, many adults with Down syndrome do not drink enough water. Encouraging appropriate water intake can help prevent complications from dehydration such as orthostatic hypotension. One study found that, in individuals without Down syndrome, orthostatic hypotension was associated with early onset of dementia.<sup>21</sup>

Some adults with Down syndrome are averse to drinking water and prefer only flavored beverages. In these cases, working to make the water more tolerable by changing its tempera-

ture (hot or cold) or texture (carbonated or not carbonated) can be helpful. Rather than offering sweetened water, adding natural flavors like fresh fruits or vegetables (cucumber, strawberries, lemon, mint) may make it easier for some individuals with Down syndrome to drink more fluids. Limiting soda or other artificially sweetened beverages can also encourage more water intake. When caretakers model appropriate drink choices, individuals with Down syndrome may follow their lead and drink more water. Finally, [visual supports](#) are available to help individuals be responsible for their own water intake.

## Healthy Eating

Healthy eating is an essential part of preventing and managing disease. Even when compared to other adults with intellectual and developmental disabilities, higher rates of overweight and obesity are reported in children and adults with Down syndrome.<sup>22</sup> Healthy eating is a key strategy to reduce these rates and the associated comorbidities.<sup>23</sup>

No one diet is best. The DASH, Mediterranean, or MIND diets do seem to have some data behind them in individuals without Down syndrome in preventing or delaying Alzheimer's disease.<sup>24</sup> There is currently not enough information about intermittent fasting in preventing or delaying onset of Alzheimer's disease.

Encouraging individuals with Down syndrome to make healthy eating choices, such as limiting processed foods and increasing leafy green

vegetables, can help lead to long-term dietary improvements. Making food swaps can be helpful and using cauliflower pizza crust instead of flour-based crusts, grilled food instead of fried food, or zucchini noodles instead of processed noodles are examples.

Healthy eating habits can benefit everyone in a household. Family involvement in meal planning and weight management has been shown to be key to successful strategies.<sup>22</sup> Rather than assigning the individual with Down syndrome their own diet, having the entire household eat the same or similar foods can help make healthy eating a habit for all. This especially helps adults with dietary needs or restrictions (such as celiac disease, which is more common in individuals with Down syndrome) be more compliant with their diet when all household members are eating the same thing or not eating the restricted food around the individual with Down syndrome.

Many strategies for successful weight management in adolescents with Down syndrome may also be applied to adults. These include specific recommendations for servings of foods from each food group, increasing low energy density foods like fruits and vegetables, limiting high density foods like sweet and fried foods, avoiding dietary restrictions (i.e. providing a wide variety of foods), allowing favorite foods in moderation, and monitoring food intake with simple visual supports.

Empowering adults with Down syndrome to make their own healthy food choices fosters

independence and confidence, as well as greater compliance with healthy eating. If all the foods offered at a meal are healthy, there can be fewer rules about what foods the individual with Down syndrome must eat. Sometimes assisting in food preparation may encourage sampling and enjoying the offered food. It is also helpful to try to avoid using special food as a reward for good behavior. Instead of having preferred food be a reward, consider allowing the food in moderation on a predictable schedule. For example, a person may have their favorite dessert on Friday nights or may drink one of their favorite sodas on Tuesdays and Thursdays. More information can be found in the [Weight Management for Adults with Down Syndrome](#) article.

## Promoting Mental Health in Individuals with Down Syndrome

### The Importance of Emotion Regulation

Emotion regulation—the ability to recognize, understand, and manage one’s emotions—is essential for individuals with Down syndrome. Individuals who develop these skills can better cope with stressors, adapt to changes, and engage in meaningful relationships. Without proper emotion regulation, individuals with Down syndrome may experience behavioral issues, increased anxiety, and depression,

potentially exacerbating existing health conditions.

Building an emotional vocabulary is crucial for a person to articulate their feelings effectively. Regular discussions about emotions using visual aids, stories, and role-playing can make learning interactive and engaging. Teaching relaxation skills such as deep-breathing exercises, muscle relaxation, and mindfulness techniques provides them with tools to manage stress. Simple practices like blowing on a pinwheel or “finger breathing” are easy and accessible.

Encouraging engagement in pleasant activities like hobbies, sports, music, social events, and community involvement enhances mood and provides positive outlets for emotions. Teaching problem-solving and communication skills through structured programs or therapy is also important. In case of distress, create a calming space by designating an area where the person can relax and use coping tools when feeling overwhelmed.

### Impact of Stress and Negative Events

Individuals with Down syndrome often face various stressors that can profoundly affect their mental and physical health. These may include the loss of a family member or loved one, family discord or divorce, bullying or social isolation, and life transitions such as changes in school or living arrangements. Research in

individuals without Down syndrome indicates that stress, depression, and anxiety are associated with cardiovascular diseases, chronic pain, inflammatory conditions, metabolic disorders, and immune dysfunctions. Understanding these connections underscores the importance of addressing emotional well-being in routine care.

## Basic Psychological Needs

Basic psychological needs theory is a well-validated cross-cultural theory of self-determination and well-being. The three basic needs are autonomy, competence, and relatedness.<sup>25</sup> Autonomy is when people can make meaningful choices and have control over their lives, enhancing their sense of independence. Competence refers to skill development and achievement, fostering a sense of mastery and self-efficacy. Relatedness means making meaningful social and emotional connections with others. Studies applying basic psychological needs theory to individuals with intellectual or developmental disabilities (IDD) has shown that autonomy, competence, and relatedness are crucial for their well-being and job satisfaction.<sup>26</sup> Conversely, frustration of these needs is linked to mental health problems in youth with IDD.<sup>27</sup>

Understanding and supporting these needs can lead to improved mental health and resilience in all your patients, including individuals with Down syndrome.<sup>25</sup> Begin by assessing whether the person's environment allows for autonomy and competence and educate caregivers about

the importance of these. Allowing the person to engage in decision-making during healthcare visits is empowering and builds confidence. Where appropriate, encourage social opportunities and the development of meaningful relationships. Be alert for signs of unmet needs, such as behavioral issues or emotional distress, and suggest timely interventions. By actively supporting all three basic needs, caregivers and professionals can help mitigate potential mental health challenges.

## Practical Tools and Techniques

Integrating coping strategies into the person's daily routine makes them a natural part of their behavior. It is essential to practice these strategies during non-stressful times to learn the skills before being expected to use them. Positive reinforcement, through acknowledging and praising their efforts in using emotion regulation strategies, reinforces their use and encourages continued practice. Encouraging caregivers to model healthy emotion regulation in interactions serves as a powerful example for the individual with Down syndrome, demonstrating effective ways to manage emotions. Video modeling is another helpful tool for building emotional skills. Watch TV shows and movies and pause the video to discuss what the people on screen are thinking, feeling, and doing. Ask about the likely consequences of their choices and what else they might do instead.

## Mental Health Screening

The U.S. Preventative Task Force recommends routine screening of anxiety and depression of all children<sup>28,29</sup> and adults.<sup>30,31</sup> To improve diagnostic accuracy, self-report screening instruments should be combined with caregiver-report scales whenever possible. Two specific self-report scales— the Glasgow Depression Scale<sup>32</sup> and the Glasgow Anxiety Scale<sup>33</sup>— have been shown to have good internal consistency and convergent validity for people with mild to moderate intellectual disabilities, supporting their use in this population. Other commonly used caregiver-report scales include the Reiss Screen for Maladaptive Behaviors,<sup>34</sup> developed specifically for youth with intellectual disabilities. One can also use certain parent/teacher rating scales, designed for children without an intellectual disability, to screen for mental health symptoms in children with Down syndrome. These include the Achenbach System of Empirically Based Assessment and the Parent-and-Teacher Forms from the Vanderbilt ADHD Rating Scales.<sup>35</sup>

Individuals with Down syndrome have varying degrees of adaptive functioning, so gathering information about behavioral or functional changes compared to their baseline can provide critical information. Ask caregivers if they have noticed any changes in the person's mood, behavior, or activity level compared to their usual or "best self." Significant changes or regressions in function should be further evaluated. More information is available in the

articles [\*Decline in Skills and Behavioral Change in Adults with Down Syndrome\*](#) and [\*Down Syndrome Regression Disorder: Clinical Features, Diagnosis and Therapeutics\*](#).

## Mental Health Referrals

Individuals with Down syndrome who have mental health concerns, and for whom underlying medical causes have been ruled out, should be referred to mental health professionals for further evaluation and treatment. Unfortunately, the availability of psychiatrists, psychologists, and therapists with expertise in treating adults with Down syndrome is often limited. Finding a professional who can help may require additional advocacy and coordination by the care team to locate someone suitable or willing to expand the scope of their practice. However, this should not preclude you from referring an individual with Down syndrome to specialized services. Multiple research studies have shown that people with intellectual and developmental disabilities benefit from cognitive and behavioral therapies when appropriately adapted to their intellectual level, providing relief from common problems like anxiety and depression.<sup>36</sup> Individuals with Down syndrome and their families may also benefit from increased home- and community-based supports, including in-home behavioral support and social skills groups. More information is available in the article [\*Mental Health: Diagnosis and Treatment of Adults with Down Syndrome\*](#).

# Promoting Social Health in Individuals with Down Syndrome

## The Importance of Social Participation

According to the Occupational Therapy Practice Framework, social participation is an occupation, meaning an everyday activity that brings meaning and purpose to life.<sup>37</sup> More specifically, social participation involves social interactions that support interdependence and make the individual feel valued.<sup>38,39</sup> For individuals with Down syndrome, these interactions may include paid jobs or volunteering, hobbies, relationships, and community building activities like organized sports, theater, art, or religious activities. Through positive social interactions, self-esteem is enhanced and loneliness is prevented. Social engagement stimulates memory and cognition and perhaps slows the onset of Alzheimer's disease in the non-Down syndrome population.<sup>40</sup>

## Improving Social Skills

Individuals with Down syndrome have a desire for social connections with others but many report that their quality of life is reduced by poor health and lack of friendships.<sup>41</sup> Social participation can be impacted by limited social skills, especially since many social skills are abstract in nature and social rules may not apply to all

situations equally. Fortunately, social skills can be learned, such as appropriate touch and conflict management. It is important for caregivers to model appropriate social behaviors and use natural teaching moments to encourage proper social skill development. Using visual supports like videos and picture stories can assist in the teaching of appropriate social skills.

It can be difficult for individuals with Down syndrome to be part of group conversations. This can be due to their poor expressive language skills, but also because conversations may move too quickly for them, or topics being discussed are of little interest. Reciprocal conversation skills are also challenging. It is possible that one person in the conversation will be asking all the questions while the other person answers the questions but does not ask questions of the other person. Additionally, many individuals with Down syndrome appear “egocentric” in that they do well answering questions about themselves but not of topics in general, especially if they are less familiar with them.

## Interactions During Medical Visits

During medical visits it is important to demonstrate good social skills. Knock and wait for permission before entering the exam room. Before starting the medical session, familiarize yourself with the patient and get to know their interests and concerns. This will help you as a clinician get the information you need.

When asking questions of them, use simple language. For instance, do not ask, “Do you sleep well?” or “How do you sleep?” Instead ask about the time they go to sleep and wake up, whether they wake up throughout the night, and if they can fall back to sleep on their own. Allow time for them to process your question and then share their response with you. If additional information is needed, ask their permission before asking a question of the parent or caregiver.

Prior to the physical examination, tell them what you will be doing and then ask if you can touch them. Having pictures of what is going to happen during the exam can also be helpful.

## Resources for Further Support

Several resources have been developed specifically for youth and adults with Down syndrome. Using these resources can enhance your approach and support quality care:

- “Supporting Positive Behavior in Children and Teens with Down Syndrome”<sup>42</sup> is a comprehensive guide that addresses behavioral challenges and provides practical strategies for parents, educators, and caregivers.
- “Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges (2nd Edition)”<sup>43</sup> is a thorough overview of the mental health strengths and

challenges of adults with Down syndrome. It is freely available for download in English and Spanish at the [Advocate Medical Group Adult Down Syndrome Center website](#).

## Conclusion

By actively promoting physical, mental, and social health, primary care professionals can significantly enhance the quality of life for individuals with Down syndrome. Addressing their basic needs and providing tools for emotional coping allow healthcare professionals to make a meaningful difference in the lives of these individuals, fostering an environment where they can thrive.

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