

Strategies to Support Mental Health of Adolescents and Adults with Down Syndrome

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Adult Down
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Please note:

- This presentation is intended for families, caregivers, health care professionals, and service providers of individuals with Down syndrome.
- The information in this presentation is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.
- We recommend that you bring specific questions about an individual with Down syndrome to their medical and/or therapy providers.

Outline

- Discuss the interaction of physical, mental, and functional health.
- Describe common mental health concerns of individuals with Down syndrome.
- Provide practical strategies to promote mental wellness.
- Present case examples.

Resource Library

The screenshot shows the website header with the Advocate Medical Group logo and 'Adult Down Syndrome Center' text. A search bar contains 'I'm looking for...' and a menu icon is in the top right. Below the header is the 'Resource Library | All Resources' section. It features three main categories: 'People with Down Syndrome' (with a photo of a young girl), 'Families & Caregivers' (with a photo of a woman and a man), and 'Health Care Professionals' (with a photo of a woman talking to two men). At the bottom, there are five navigation links: 'Events, Classes & Programs' (with a bell icon), 'Video Gallery' (with a play button icon), 'Related Organizations' (with a sunburst icon), 'Projects' (with a book icon), and 'News' (with a document icon). Each link has a corresponding 'View All' or 'View News Articles' sub-link.

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I'm looking for... MENU

Resource Library | All Resources

People with Down Syndrome

Families & Caregivers

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Events, Classes & Programs
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Projects
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<https://adsresources.advocatehealth.com/>

Common characteristics of most (but not all) people with Down syndrome

Self-talk and imaginary friends

- Developmental stage-appropriate behavior
- Coping strategy
- Boredom
- Change in quality or frequency may be a sign of stress or mental illness

The “groove”

- Tendency towards sameness, repetition
- Functional
- When does it become problematic?

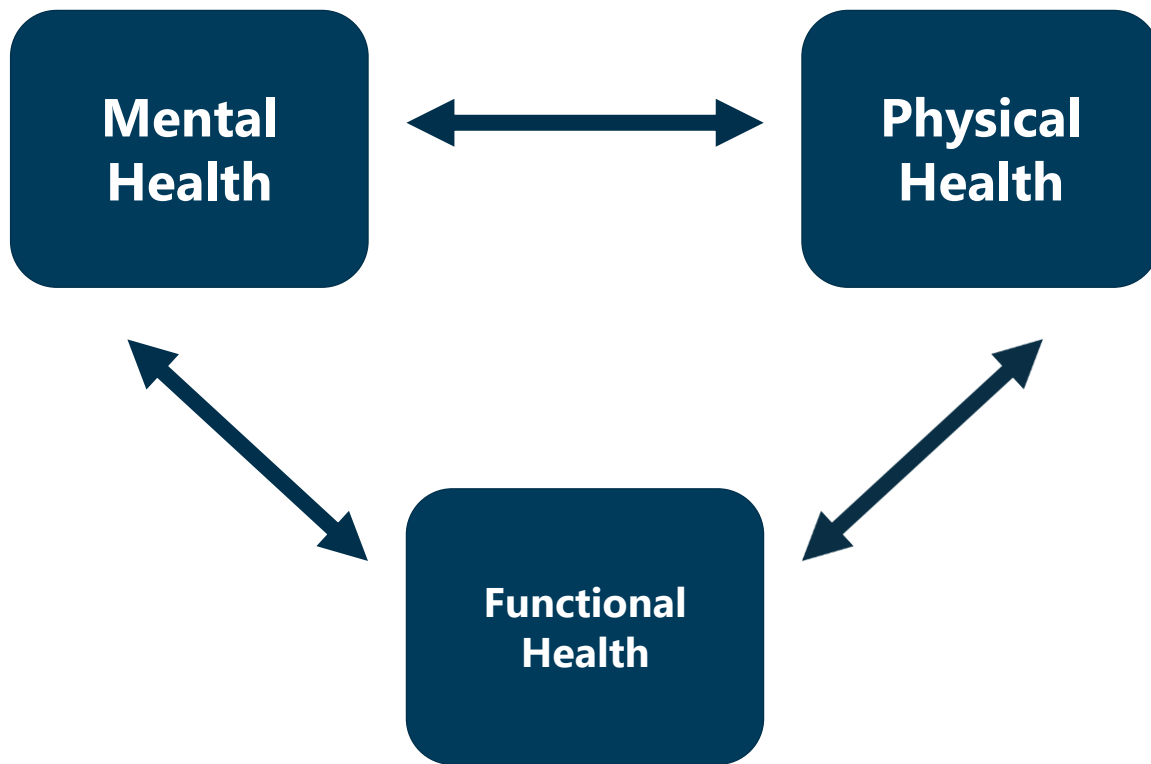
Visual memory

- Better than auditory
- Good at remembering visual data
- “Videographic” memory
- Limited sense of time and chronological order
- Memories experienced as if happening now

Empathy radar

- Sensitive to the emotions and feelings of others

Interaction of physical, mental, and functional health



Physical health

- Being free from injury or illness
- How well your organs and body systems function
- Physical health issues that can affect mental wellness: sleep disturbances, thyroid disorders, dehydration, GI problems, and others

Functional health

- Ability to do what you need to do from the moment you wake up until the moment you fall asleep
- Functional health issues that can affect mental wellness: lack of independence, inability to participate in activities, social engagement

Mental health

- Emotional, psychological, and social well-being
- Mental health issues can affect physical and functional health

Common mental health concerns

Prevalence of Mental Health Conditions Among 6078 Individuals With Down Syndrome in the United States

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Abstract Findings from a recent study of the largest documented cohort of individuals with Down syndrome (DS) in the United States described prevalence of common disease conditions and strongly suggested significant disparity in mental health conditions among these individuals as compared with age- and sex-matched individuals without DS. The retrospective, descriptive study reported herein is a follow-up to document prevalence of 58 mental health conditions across 28 years of data from 6078 individuals with DS and 30,326 age- and sex-matched controls. Patient data were abstracted from electronic medical records within a large integrated health system.

In general, individuals with DS had higher prevalence of mood disorders (including depression); anxiety disorders (including obsessive-compulsive disorder); schizophrenia; psychosis (including hallucinations); personality disorder; dementia (including Alzheimer's disease); mental disorder due to physiologic causes; conduct disorder; tic disorder; and impulse control disorder. Conversely, the DS cohort experienced lower prevalence of bipolar I disorder, generalized anxiety, panic, phobic, and posttraumatic stress disorders; substance use disorders (including alcohol, opioid, cannabis, cocaine, and nicotine disorders); and attention-deficit/hyperactivity disorder. Prevalence of many mental health conditions in the setting of DS vastly differs from comparable individuals without DS. These findings delineate a heretofore unclear jumping-off point for ongoing research. (*J Patient Cent Res Rev.* 2022;9:58-63.)

Keywords Down syndrome, prevalence; mental health; depression; anxiety; dementia; substance use; ADHD

A recent study of the largest documented cohort of individuals with Down syndrome (DS) in the United States described the prevalence of a broad range of disease conditions.¹ Findings strongly suggested significant disparity in mental health conditions, in particular, among individuals with DS as compared with age- and sex-matched individuals without DS.¹ Previous research has shown that, overall, people with DS seem to be more vulnerable to mental health issues and diagnosis;²⁻⁴ however, some experts believe overdiagnosis is common due to deficits in language, communication, cognition, problem-solving, and coping.⁵ Regardless, given that the prevalence of DS itself is increasing⁶ and that the lifespan for individuals with DS has grown in recent decades,^{7,8} a more in-

depth analysis of mental health conditions among this patient population is merited, not only for foundational knowledge but also to facilitate better diagnostics and clinical care.

To explore rates of mental health conditions among individuals with DS, this study utilizes clinical data representing the largest reported DS sample cohort in the United States, treated across a single integrated health system that includes the largest center of care for adolescents and adults with DS. The objective of this follow-up brief report to a broader study¹ was to provide critical information on mental health conditions in individuals with DS in order to better guide general practitioners, enhance specialized care, and inform future research within this unique population.

METHODS

This retrospective, descriptive cohort study utilized 28 years of available encounter data (May 1991–September 2019) abstracted from the electronic medical records of an integrated U.S. Midwest-based nonprofit health

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Prevalence of Mental Health Conditions Among 6078 Individuals with Down Syndrome in the United States

- Advocate Health Care
- 6,078 individuals with Down syndrome
- 30,326 controls (matched on age and sex)

Health Condition	Prevalence (6,078)	More or less common?	Odds Ratio
Depression	571 (9.39%)	More	1.27*
Anxiety disorders	1029 (16.92%)	More	1.09**
Generalized anxiety disorder	24 (0.39%)	Less	0.25*
Posttraumatic stress disorder	25 (0.41%)	Less	0.60***
Obsessive-compulsive disorder	447 (7.35%)	More	20.15*
Psychosis	24 (0.39%)	More	3.87*
Substance use/abuse	76 (1.25%)	Less	0.08*
Mental disorders due to physiologic cause	20 (0.33%)	More	2.94*
Impulse control disorder	73 (1.2%)	More	23.03*

*p<0.001, **p<0.0206, ***p<0.0143

Presentation and diagnosis

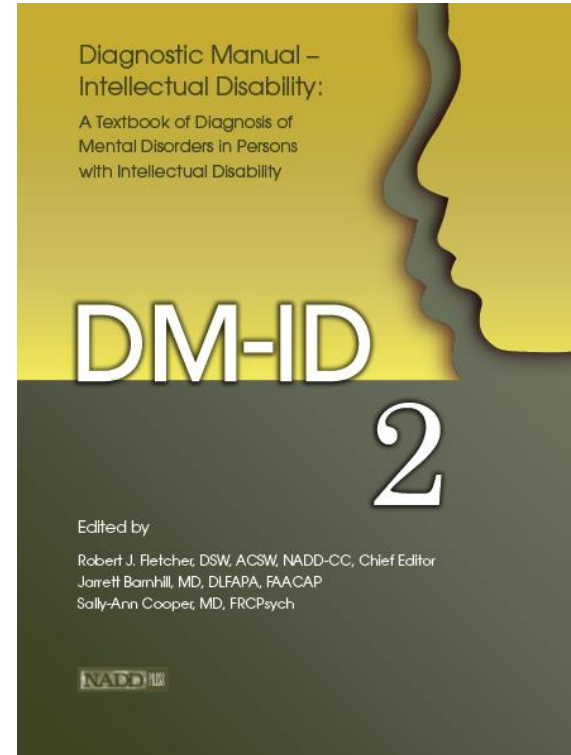
A thorough history and physical exam are important when evaluating for a change in mental health.

Communication issues

- Expressive language limitations
- Intelligibility
- Any and all behavioral change should be viewed as a possible communication tool.

Diagnosis

- More commonly observed as a change in behavior
 - Less often self-report of symptoms



Symptoms

- Change in behavior
- Change in self-talk
- Change in the groove
- Change in sleep patterns
- Change in weight
- Restlessness
- Irritability
- Loss of interest in activities
- Fatigue
- Inappropriate fears or avoidances of people/things
- Strong refusal to leave the home

Treatment approaches

Physician

- Treat co-occurring physical conditions
- Encourage healthy eating, sleeping, and exercise routines
- Encourage participation in affirming social activities
- Referral to other providers

Physician

- Medications
 - Start low, go slow
 - May need more than one medication
 - Medications
 - Antidepressants
 - Benzodiazepines
 - Nonbenzodiazepine anxiolytics
 - Mood stabilizers

Social worker

- Counseling
- Calming strategies/relaxation techniques
- Coping strategies
- Problem solving
- Social skills
- Referral to other therapies i.e., art, music, speech, or OT

Occupational therapist

- Sensory processing strategies
- Calming/relaxation strategies
- Social skills
- Self-care skills
- Referral to other therapies i.e., social work, art, music, speech

Mental health promotion strategies

General tips



- Teach how the individual learns best
 - Visuals, videos, modeling, repetition, practice
- Say what to do instead of what not to do
 - Establish rules/expectations
 - Be concrete
- Help establish a routine
- Provide positive reinforcement for desired behaviors



Use of visual supports

- Pictures, words or other images that are used to...
 - Help communicate
 - Share or manage expectations
 - Provide reminders
 - Teach new information/Maintain skills & independence
 - Facilitate understanding of challenging situations





Sleep

- Sleep hygiene
- Review current medications
- Consider natural products
- Talk with healthcare provider about prescription medications

I should wake up at the same time each day.  




I should go to bed at the same time every night.  

I should create a good sleep space.






   

TV tablet phone


I should have a bedtime routine.

Hygiene   

brush teeth wash face go to bathroom

Relaxation     

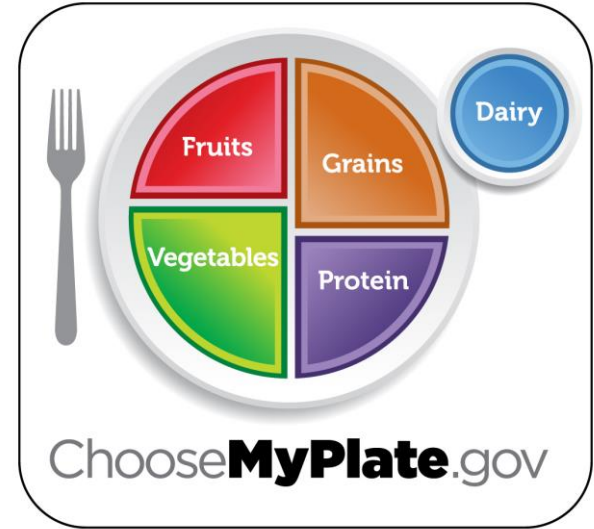
write in journal pray read take deep breaths stretch

Remembering this will help me sleep better and be healthy! 

[Link to resource](#)

Healthy eating

- Hydration
- Balanced meals (all the food groups)
- Portion size
- Limit processed foods and pop/soda
- Small changes add up



Exercise/physical activity

- Find what works for the individual
- Fun and social
- Incorporate it throughout the day
- Go outdoors

ALPHABET WORKOUT

Create a workout by spelling your name, the day of the week, or another word or phrase of your choosing!

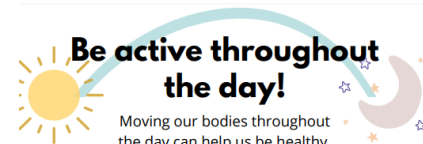
A	10 jumping jacks	N	Run in place for 30 sec.
B	15 crunches	O	10 butt kicks
C	5 squats	P	10 high knees
D	5 push-ups	Q	5 squats
E	Wall sit for 20 sec.	R	10 jumping jacks
F	15 arm circles	S	15 arm punches
G	10 mountain climbers	T	Plank for 20 sec.
H	5 lunges on each leg	U	5 push-ups
I	15 arm punches	V	15 arm circles
J	Plank for 20 sec.	W	10 mountain climbers
K	Wall sit for 20 sec.	X	5 lunges on each leg
L	15 crunches	Y	Run in place for 30 sec.
M	10 high knees	Z	10 butt kicks

The Special Olympics [FIS Cards](#) and [Dynamic Stretches Guide](#) demonstrate these exercises.

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[Link to resource](#)



Be active in the morning



Go for a walk.



Do an exercise video.

Be active in the afternoon



Dance break!



Lift weights.

Be active in the evening



Stretch/do yoga.



Clean.

To be active throughout the day, I can...

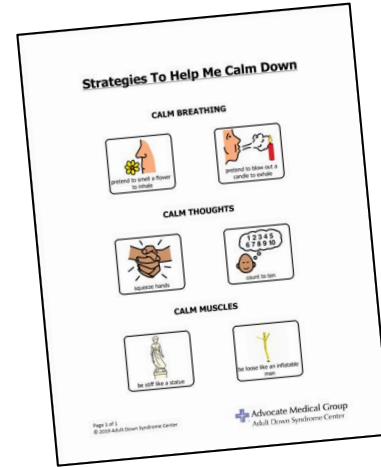
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[Link to resource](#)

Manage emotions

- In the eye of the beholder
- Be aware of empathy radar
- Provide “in the moment” support when possible
- Identifying triggers
- Cautiously avoiding stressful situations



[Link to resource](#)

Close your eyes



Take deep breaths



Talk to family or friends



Use a stress ball



Play with a pet



Spend time outside



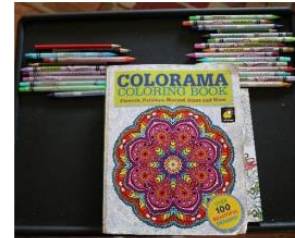
Dance to a favorite song



Listen to music



Color



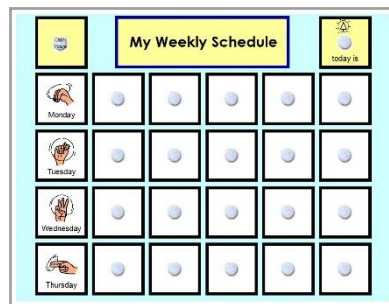
Exercise



[Link to resource](#)

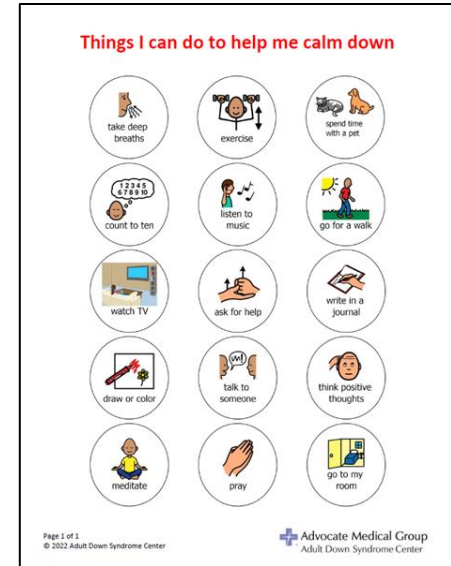
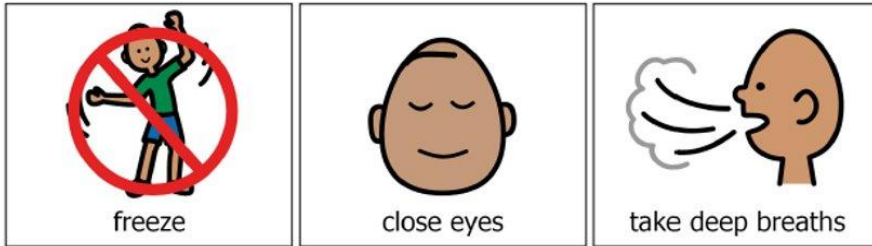
Employment, recreation, and social opportunities

- Involvement promotes overall health
- Find options that match interests and skills
- “Safe” reintroduction



Relaxation/calming strategies

- In the moment calming strategies
- Practice



[Link to resource](#)

Coping strategies

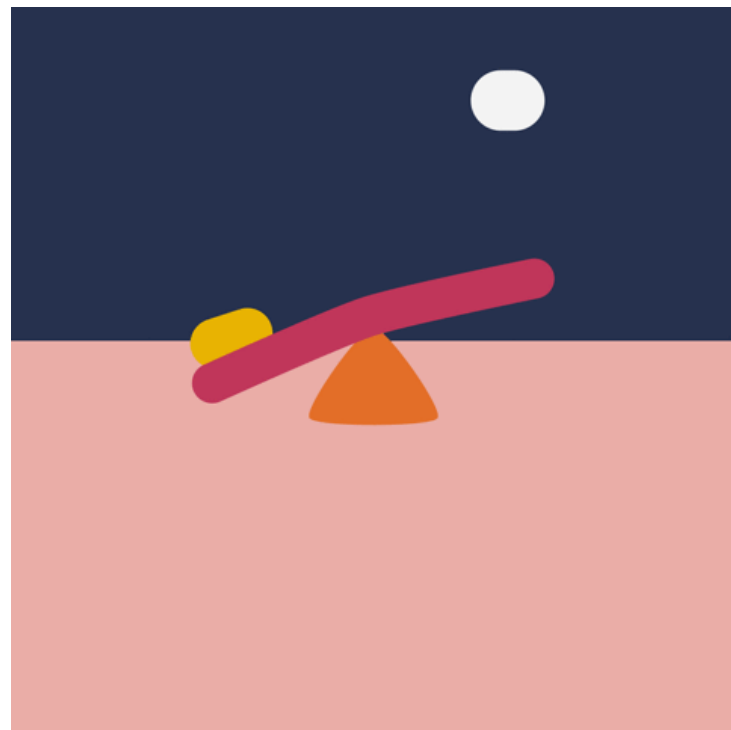
- Short term versus long term
- Examples:
 - Compromise
 - "I" statements
 - Opposite actions
 - Reframing

Sensory strategies

An uneven teeter totter can impact mood and behavior.

We may see...

- verbal outbursts
- physical aggression
- slowing down
- shutting down



Sensory diet

- A planned and scheduled activity program.
- Highly individualized.
- Choosing from a menu rather than following a recipe.
- Helps prevent sensory and emotional overload by satisfying our body's needs.
- Example: Proprioceptive input

Affordable Sensory Equipment Recommendations

Proprioceptive Input

Many individuals with Down syndrome experience difficulty with their proprioceptive sensors in our body are responsible for providing feedback body is in space. When these sensors aren't working like they should difficulty with motor coordination, meaning they appear clumsy. This ability to actually carry out a movement even though they know how planning. They may carry out activities and have difficulty grading the things too hard or too soft. Another feature is the person may have difficulty they often appear slumped over or lethargic.

In order to activate these receptors and improve a person's proprioceptive activities can be encouraged throughout the day to get natural input into activities can be done in preparation for a transition or when you start worked up. For instance, they need to complete a series of self-care require verbal prompts to initiate the activity. Provide proprioceptive input body and prepare to complete the required task. This also goes for transitions leave the house and your loved one with DS doesn't want to go? Try if it helps them transition. These activities may not be effective once they melt-down.

- Animal walking (like bear or crab, even crawling like a cat or dog, or hopping like a bunny)
- Jumping up and down, maybe even on a trampoline
- Dancing
- Jumping Jacks
- Push-ups on the floor or against the wall
- Bouncing on a therapy ball
- Sitting on a sit-disc
- Riding a bike/scooter
- Sports like swimming, yoga, Pilates and martial arts
- Completing an obstacle course
- Carrying a heavy backpack
- Moving furniture
- Pushing a cart/stroller/wagon
- Rolling up in a blanket like a burrito
- Bear hugs or being squeezed between pillows or cushions
- Using play
- Log rolling
- Vibration
- Weighted
- Sitting in a chair
- Rocking in a chair
- Strength training or light weights
- Throwing
- Joint compression
- Massage
- Yard work
- Housework
- Mopping, down the
- Eating chocolate
- Sucking through a straw

Weighted products:

Key points to remember: Please consult with an occupational therapist to help you determine the best size and weight. It is typically recommended to have a blanket be 7-10% of a person's body weight. It is NOT recommended to sleep under weighted blankets.

Weighted blankets and lap pads: Prices vary, but range from \$30- \$100+ depending on size and weight.

Custom weighted blankets and lap pads:

- <http://www.sensacalm.com/weighted-blankets/>
- <http://www.mosaicweightedblankets.com/> (they even offer DIY kits)
- Amazon, Bed Bath & Beyond, and Etsy even carry weighted products

Weighted snake: Prices range from \$25 - \$50+

Amazon has a few versions. They vary in weight.



Alternative ideas to expensive weighted objects

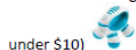
- Door stoppers and neck wraps and warmers (priced \$10 and up)



- Available at drug stores and websites like Amazon, Bed Bath and Beyond and Amazon carry a brand called Bed Buddy.
- Talk with your dentist as you may be able to get an old lead vest used for x-rays.

Vibrating products:

- **Hand held massager:** Amazon as well as drug stores, Target, WalMart etc. (priced



under \$10)

- **Vibrating cushion:** Amazon carries a brand by Dr.Scholl's (priced under \$30)



- **Vibrating neck massager** or **vibrating cushion** (priced \$20-\$50)



Joint Compression-Upper body

Joint compression is a form of proprioceptive input. It occurs when there is compression, push, or weight on a joint. It is important for developing body awareness and body in space, as well as for joint stability. It also promotes self-regulation and can be very calming, regulating, and organizing for the nervous system. This is a technique that seems to be effective for individuals with Down syndrome.

It can be used with transitions as well as to help calm the body. Therefore, complete this quick activity can be stressful for your loved one with Down syndrome. It should only take a few minutes.

For more information, please contact Katie Frank, PhD, OTR/L at 847-318-2331 or kfrank@ocatehealth.com

ocatehealth.com

When a person sits down in a chair or on the floor. If they want or need to stand, joint compression can be used to help them transition.



If it is alright that you touch him/her. Once joint compression becomes part of the routine, just announce that it's time for joint compression.

Use joint compression on either the right or left side and you will plan on doing joint compression to both sides.

Place your hands on top of his/her shoulder and your other hand on his/her upper arm. Gently press towards one another to provide compression at the shoulder joint. Do this 10 times.



Sensory resources

Cases

Case 1

34-year-old man with Down syndrome has an increase in self-talk. He sees a psychiatrist who has diagnosed him with psychosis.

Case 1 – signs and symptoms

- Physical health
 - Weight gain, skin infections, no apparent underlying health conditions
- Functional health
 - Decline in self-care skills
- Mental health
 - Isolation, self-talk, emotional regulation

Case 1 – treatment

- Physical health
 - Healthy diet, exercise, skin care
- Functional health
 - Visual supports and sensory strategies
- Mental health
 - Calming and coping strategies

Case 2

17-year-old woman with Down syndrome is slow to complete morning hygiene routines. She often appears disheveled. Her parents are concerned that she is depressed.

Case 2 – signs and symptoms

- Physical health
 - Dry skin
- Functional health
 - Not completing all tasks, running late, desire to be independent
- Mental health:
 - Self-esteem, relationship conflicts

Case 2 – treatment

- Physical health
 - Encourage skin care
- Functional health
 - Visual supports, fading prompts, modeling, practice
- Mental health
 - Counseling (individual and family), social skills lessons

Case 3

26-year-old man with Down syndrome presents with depressive and psychotic symptoms. He sleeps through the night, doesn't snore, and appears restful while sleeping. He does not appear tired during the day.

Case 3 – signs and symptoms

- Physical health
 - Despite no obvious symptoms, check for sleep apnea
- Functional health
 - Functional health not impacted
- Mental health
 - Depressive and psychotic symptoms

Case 3 – treatment

- Physical health
 - CPAP
- Functional health
 - Visuals and support for using CPAP
- Mental health
 - Discussing barriers and benefits to using CPAP, improve self-esteem, discuss feelings, work with family to support the individual's CPAP use

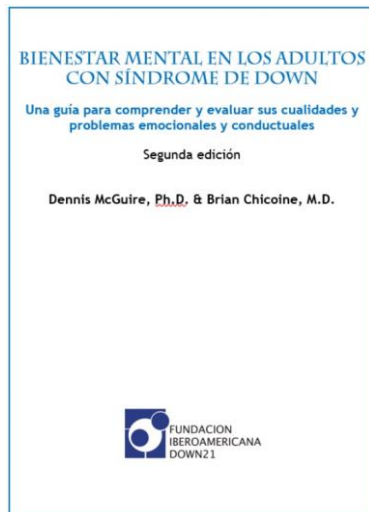
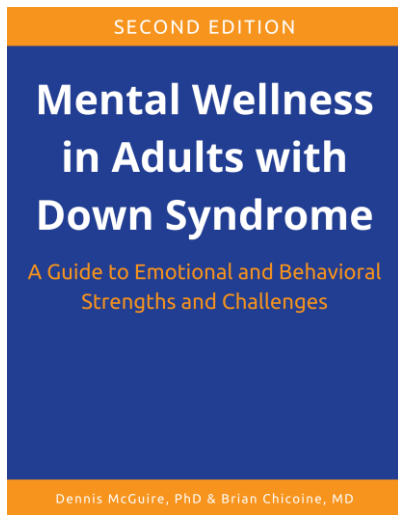
Tips to remember

- Common characteristics are not mental illness.
- Changes in common characteristics/behavior should prompt an investigation into the cause.
- Physical, functional, and mental health are interrelated.
- Successful diagnosis and treatment may require using physical, functional, and/or mental health approaches.

Questions

Resources

Mental Wellness book



**Available as a free
PDF in English
and Spanish**

<https://adsresources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/>

Resources

- All resources
 - <https://adscresources.advocatehealth.com/resources/>
- Decline in skills and regression
 - <https://adscresources.advocatehealth.com/resources/?category=Decline%20in%20Skills%20and%20Regression>
- Exercise and physical activity
 - <https://adscresources.advocatehealth.com/resources/?category=Exercise%20and%20Physical%20Activity>
- Grief and loss
 - <https://adscresources.advocatehealth.com/resources/?category=Grief%20and%20Loss>

Resources

- Mental health
 - <https://adscresources.advocatehealth.com/resources/?category=Mental%20Health>
- Nutrition and weight
 - <https://adscresources.advocatehealth.com/resources/?category=Nutrition%20and%20Weight>
- Self-care and hygiene
 - <https://adscresources.advocatehealth.com/resources/?category=Self-Care%20and%20Hygiene>
- Sensory
 - <https://adscresources.advocatehealth.com/resources/?category=Sensory>
- Sleep
 - <https://adscresources.advocatehealth.com/resources/?category=Sleep>

For health care providers

- Down Syndrome Medical Interest Group – USA
 - <https://www.dsmig-usa.org/>



Down Syndrome Medical Interest Group

FREE RESOURCES

SHARE WITH YOUR HEALTH CARE PROVIDER

- Down Syndrome Project ECHO is a monthly virtual meeting for health care providers to learn and seek input from expert providers.
- The DSMIG Speaker Series consists of webinars and enduring materials designed to share knowledge and experience related to the care of people with Down syndrome and clinical research related to Down syndrome.
- DSMIG vetted resources including articles and important guidelines related to child and adult health issues, and health utilization by people with Down syndrome.

find out more at:

DSMIG-USA.ORG



Resource Library:

adscreources.advocatehealth.com



Facebook:

facebook.com/adultdownsyndromecenter



Email Newsletter:

eepurl.com/c7uV1v

