Promoting Mental Health in Adolescents & Adults with Down Syndrome

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Adult Down Syndrome Center



Park Ridge, IL

Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, community-based health care services.

Online Resource Library

- Contains videos, articles, and booklets on a variety of topics
- Resources are continually being updated.



adscresources.advocatehealth.com

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Disclaimer

This information 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.

Topics

- 1. Common characteristics
- 2. Interaction of physical, mental, and social health
- 3. Promoting mental health
- 4. Common mental health conditions
- 5. Case examples

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Common characteristics

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Strong visual memory

- Better than auditory
- Good at remembering visual data
- "Video-graphic" memory
- Limited sense of time and chronological order
- Memories experienced as if happening now



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?

The Groove in People with Down Syndrome (<u>webinar recording</u>)
The Groove (<u>article</u>)



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Any and all behavioral change should be viewed as a possible communication tool.

Interaction of physical, mental, and social health

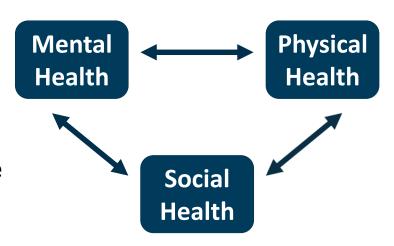
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What is health?

"Health is a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity."

World Health Organization



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Physical health issues that can affect mental wellness

- Sleep disturbances
- · Thyroid disorders
- Dehydration
- Gastrointestinal problems
- And others

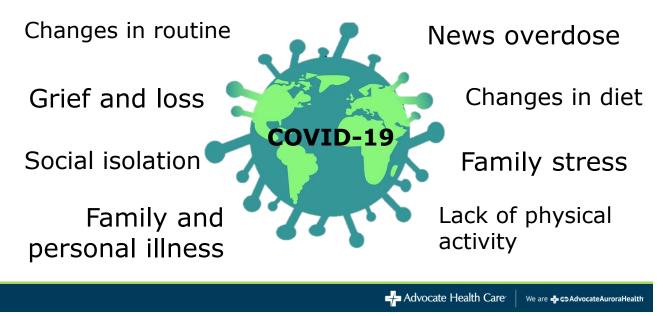


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Social health issues that can affect mental wellness

- Conflicts at school/work
- · Aging out of school
- Leaving a job
- · Sibling moving out
- And others

COVID-19



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Promoting mental wellness

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Mental wellness

- Good sleep
- · Healthy eating
- Exercise/physical activity
- Stress management
- Employment, recreation, and social opportunities



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Good sleep

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

Webinar on Sleep in Adolescents and Adults with Down Syndrome



Link to resource



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Healthy eating

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





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Eat fruits and vegetables with every meal.

Starting your meal with a salad is a good way to do this.



Or fill half your plate with fruits and vegetables.



Choose grilled food instead of fried food.

Eat grilled chicken or fish instead of fried or crispy chicken or fish.





Limit condiments and dressings.

Ask for salad dressing on the side. Only use some of the dressing.



Link to resource

Be aware of how much food you eat.

Eat your meal. Drink some water. Wait a few minutes. Go back for seconds only if you are still hungry.





Eat slowly. Put your fork down between bites of food. Or take a sip of water between bites of food.



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Exercise/physical activity

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



Link to resource

Link to resource

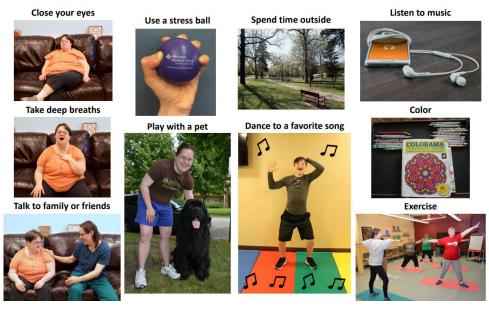
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Manage stress

- Be aware of "empathy radar" or "social sensitivity"
- Provide "in the moment" support when possible
- · Work with a mental health provider
 - Consider therapies (e.g., music, art, etc.)



Link to resource

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Employment, recreation, and social opportunities

- Involvement promotes physical, mental, and social health
- Find options that match interests and skills
- "Safe" reintroduction





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Common mental health conditions



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Prevalence

Prevalence of Common Disease Conditions in a Large Cohort of Individuals with Down Syndrome in the United States

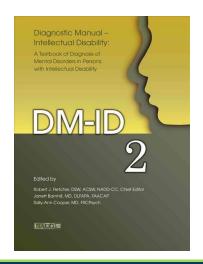
Conditions	Cases (N=6078)	Controls (N=30,326)	Odds Ratio (Cases:Controls)	P
Mental health conditions				
Anxiety	850 (13.98%)	3757 (12.39%)	1.15 (1.06, 1.25)	0.0006*
Obsessive-compulsive disorder	445 (7.32%)	124 (0.41%)	19.24 (15.74, 23.53)	< 0.0001*
Attention-deficit, conduct, disruptive behavior disorders	233 (3.83%)	1563 (5.15%)	0.73 (0.64, 0.84)	<0.0001*
Mood disorders	761 (12.52%)	3247 (10.71%)	1.19 (1.10, 1.30)	< 0.0001*
Schizophrenia and other psychoses	99 (1.63%)	176 (0,58%)	2.84 (2.21, 3.63)	< 0.0001*
Impulse control disorders, NEC	27 (0.44%)	34 (0.11%)	3.98 (2.40, 6.59)	< 0.0001*
Catatonia	73 (1.20%)	70 (0.23%)	5.25 (3.78, 7.30)	< 0.0001*

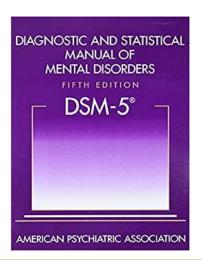
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A note about diagnosis







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Depression

 Persistent feelings of sadness and/or a decreased interest in things that an individual previously enjoyed

Depression

- Symptoms
 - · Depressed or irritable mood
 - Loss of interest or pleasure in activities
 - · Weight loss or gain
 - · Change in sleep patterns
 - Slowing down of physical movement or restlessness
 - Fatigue
 - · Feelings of worthlessness

- Decreased concentration
- · Recurrent thoughts of death
- Psychotic features (extreme withdrawal, hallucinatory self-talk, etc.)
- Inappropriate fears or avoidances of people/things
- Strong refusal to leave the home

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Depression

- Treatment
 - Counseling
 - Identifying and reducing stress
 - Establishing healthy eating, sleeping, and exercising routines
 - Encouraging participation in affirming social activities
 - Medications
 - Antidepressants
 - Selective serotonin reuptake inhibitors (SSRIs)
 - Serotonin-norepinephrine reuptake inhibitors (SNRIs)

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Anxiety disorder

 Anxiety that interferes with day-to-day life on a long-term basis



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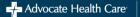
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Anxiety disorder

- Symptoms
 - Feeling worried or anxious most days
 - · Mild self-injurious behavior
 - Being easily fatigued
 - · Difficulty sleeping
 - Restlessness
 - Difficulty concentrating
 - Muscle tension
 - Irritability

Anxiety disorder

- Treatment
 - Treat underlying physical problems
 - Counseling
 - Calming strategies/relaxation techniques
 - Sensory approaches
 - Medications
 - Benzodiazepines
 - Nonbenzodiazepine anxiolytics
 - Antidepressants



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OCD

- Obsessions persistent thoughts or thoughts that preoccupy the mind
- Compulsions repetitive behaviors or acts that one feels compelled to perform
- · Impairs function
- Limits opportunities

OCD

- Individual with Down syndrome often is not upset by the behaviors/thoughts, but family may be
- · Can be problematic when:
 - Individual may get upset if the behaviors/thoughts are blocked or prevented
 - Person cannot participate in usual activities due to being "stuck"

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OCD

- Treatment
 - Non-medicinal strategies
 - Medicinal strategies
 - Start low, go slow
 - May need more than one medication
 - Medications
 - Antidepressants
 - Benzodiazepines
 - Mood stabilizers

Decline in skills/regression

- Decreased ability to perform or use previously mastered skills or abilities
 - Cognition
 - Behavior/psychological changes
 - Ability to perform activities of daily living
 - Motor function
 - Speech



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Medical conditions

- · Medication side effects
- · Sleep apnea
- Seizures
- Vitamin B12 deficiency
- Endocrine disorders
 - Hypothyroidism or hyperthyroidism
 - Adrenal insufficiency
 - Diabetes mellitus
 - Puberty-related

- Cervical myelopathy (subluxation, spinal stenosis)
- Chronic pain
 - Dental
 - Sinus
 - Cervical spine
 - Menstrual
 - Gastrointestinal, severe constipation

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Medical conditions (cont.)

- Cardiovascular disease
 - Uncorrected congenital heart disease with pulmonary hypertension, congestive heart failure
 - Eisenmenger's syndrome
 - Stroke: thrombotic or hemorrhagic

- Neuropsychiatric disorders
 - Catatonia
 - Mood disorder
 - Obsessive compulsive disorder
 - Psychotic disorder
 - Complex tic disorder
 - Post-traumatic stress disorder
 - · Parkinsonism, dystonia



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Medical conditions (cont.)

- · Infectious disease
 - Urinary tract infections
 - Pneumonia
 - Sepsis
 - Viral/bacterial meningitis/encephalitis
 - Lyme's disease
- Toxic-metabolic
 - Numerous etiologies

- Sensory
 - Visual impairment
 - Glaucoma
 - Retinal detachment
 - Cataracts
 - Keratoconus
 - Hearing impairment
 - Hypo- or hyperacusis
 - Tinnitus
 - Vertigo

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Adjustment to life events

- Transitions and relationships
 - Loss of family, friends, pets
 - School graduation
 - Work setting changes
 - Physical relocation
 - Response to hospitalization or medical condition
 - ∘ COVID-19



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Autoimmune disorders

Additional evidence required

- Hashimoto's encephalopathy
- Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS)
- · Central nervous system manifestation of celiac disease
- Central nervous system manifestation of systemic lupus erythematosus (SLE)
- Autoimmune encephalopathy
- · Limbic encephalitis

"Regression syndrome"

Working Definition

Core Features	Variable features
Decline in cognitive (executive) function	Maladaptive behavior
Social withdrawal	Psychiatric symptoms
Loss of acquired skills	Failure to acquire new skills
Loss of functional use of language	Inattention – disorganization
Duration > 3 months **	Motor slowing
Age: 15-30 years of age	Vegetative symptomsAppetite/weight loss, incontinenceSleep pattern disturbance

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Catatonia

- It is an abnormality of movement and behavior
- Can (but may not) be associated with a mental illness
- Various presentations
 - Repetitive or purposeless overactivity
 - Resistance to movement

Treatment

- Treat diagnosable conditions
 - Some specific treatments (e.g., hypothyroidism, catatonia, autoimmune, sleep apnea)
- Treat related signs and symptoms
- Use therapies to help improve function
- Start with "safe" activities

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Treat associated symptoms

- Depression
- Anxiety
- Agitation
- Sleep challenges
 - E.g., day/night reversals

- Medication choices are influenced by a patient's particular symptoms and the particular effects and side effects of the medication.
- Observation and report of symptoms are key to assisting with medication selection.

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Case 1

- 18-year-old man was putting his head on his desk at school and not participating in class activities
- Concerned that he was depressed; scheduled appointment with his physician
- Increased reflexes on physical exam and atlantoaxial subluxation on lateral cervical spine x-ray

Case 2

- 29-year-old woman developed distorted thought processes that involved intertwining real world events with TV shows and movies
- Lost interest in activities she previously enjoyed
- Regression of skills
- Occurred acutely after her sister left for college

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Case 3

- 22-year-old man who aged out of school, started to gain weight, and had a disagreeable mood. Also had difficulty sleeping.
- History, physical exam, labs, sleep study
- Diagnosed with depression and sleep issues

Treatment

- · Established new routine
- Counseling
- Bupropion (Wellbutrin) for depression
- Trazadone for sleep



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Visuals and Videos

- Mental Health
- Sleep
- Exercise and Physical Activity
- Nutrition and Healthy Eating
- Social Skills
- COVID-19



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Articles and Webinars

- Mental Health
- Sleep
- Exercise and Physical Activity
- Nutrition and Healthy Eating
- Social Skills
- Health Promotion
- **COVID-19**

Questions

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facebook.com/adultdownsyndromecenter

Email Newsletter: eepurl.com/c7uV1v

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