Promoting Mental Health in Adolescents & Adults with Down Syndrome

September 28, 2021 – Down Syndrome Association of Delaware
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Adult Down Syndrome Center

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.

Park Ridge, IL
Online Resource Library

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

adscresources.advocatehealth.com

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

Common characteristics
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?

Any and all behavioral change should be viewed as a possible communication tool.
What is health?

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”

World Health Organization
Physical health issues that can affect mental wellness

• Sleep disturbances
• Thyroid disorders
• Dehydration
• Gastrointestinal problems
• And others

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

- Changes in routine
- Grief and loss
- Social isolation
- Family and personal illness
- News overdose
- Changes in diet
- Family stress
- Lack of physical activity

Promoting mental wellness
Mental wellness

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

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
Healthy eating

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

**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.

**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.

[Link to resource]
### Exercise/physical activity

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

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<table>
<thead>
<tr>
<th>Exercise</th>
<th>Sets</th>
<th>Reps</th>
</tr>
</thead>
<tbody>
<tr>
<td>Push-ups</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Sit-ups</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>Squats</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Lunges</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>Plank</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Mountain climbers</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Jumping jacks</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Running</td>
<td>2</td>
<td>10</td>
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</tbody>
</table>
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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.)
Employment, recreation, and social opportunities

• Involvement promotes physical, mental, and social health
• Find options that match interests and skills
• “Safe” reintroduction
Common mental health conditions

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

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Cases (N=6076)</th>
<th>Controls (N=30,326)</th>
<th>Odds Ratio (Cases:Controls)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health conditions</td>
<td></td>
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<tr>
<td>Anxiety</td>
<td>850 (13.98%)</td>
<td>3757 (12.39%)</td>
<td>1.15 (1.06, 1.25)</td>
<td>0.0006*</td>
</tr>
<tr>
<td>Obsessive-compulsive disorder</td>
<td>445 (7.32%)</td>
<td>124 (0.41%)</td>
<td>19.24 (15.74, 23.53)</td>
<td>&lt;0.0001*</td>
</tr>
<tr>
<td>Attention-deficit, conduct, disruptive</td>
<td>233 (3.83%)</td>
<td>1563 (5.15%)</td>
<td>0.73 (0.64, 0.84)</td>
<td>&lt;0.0001*</td>
</tr>
<tr>
<td>behavior disorders</td>
<td></td>
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</tr>
<tr>
<td>Mood disorders</td>
<td>761 (12.52%)</td>
<td>3247 (10.71%)</td>
<td>1.19 (1.10, 1.30)</td>
<td>&lt;0.0001*</td>
</tr>
<tr>
<td>Schizophrenia and other psychoses</td>
<td>99 (1.63%)</td>
<td>176 (0.58%)</td>
<td>2.84 (2.21, 3.63)</td>
<td>&lt;0.0001*</td>
</tr>
<tr>
<td>Impulse control disorders, NEC</td>
<td>27 (0.44%)</td>
<td>34 (0.11%)</td>
<td>3.98 (2.40, 6.59)</td>
<td>&lt;0.0001*</td>
</tr>
<tr>
<td>Catatonia</td>
<td>73 (1.20%)</td>
<td>70 (0.23%)</td>
<td>5.25 (3.78, 7.30)</td>
<td>&lt;0.0001*</td>
</tr>
</tbody>
</table>
A note about diagnosis

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

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)
Anxiety disorder

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

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

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”

**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

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
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

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
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

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

<table>
<thead>
<tr>
<th>Core Features</th>
<th>Variable features</th>
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<tbody>
<tr>
<td>Decline in cognitive (executive) function</td>
<td>Maladaptive behavior</td>
</tr>
<tr>
<td>Social withdrawal</td>
<td>Psychiatric symptoms</td>
</tr>
<tr>
<td>Loss of acquired skills</td>
<td>Failure to acquire new skills</td>
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<tr>
<td>Loss of functional use of language</td>
<td>Inattention – disorganization</td>
</tr>
<tr>
<td>Duration &gt; 3 months **</td>
<td>Motor slowing</td>
</tr>
<tr>
<td>Age: 15-30 years of age</td>
<td>Vegetative symptoms</td>
</tr>
<tr>
<td></td>
<td>• Appetite/weight loss, incontinence</td>
</tr>
<tr>
<td></td>
<td>• Sleep pattern disturbance</td>
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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

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.
Case examples

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

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
Visuals and Videos

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

Articles and Webinars

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

Resources:
adsresources.advocatehealth.com

Facebook:
facebook.com/adultdownsyndromecenter

Email Newsletter:
eepurl.com/c7uV1v