Addressing Common Health Conditions in Adults with Down Syndrome

Adult Down Syndrome Center Health Education Series

February 10, 2021 | Brian Chicoine, MD
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.
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.
Adult Down Syndrome Center
Online Resource Library

• Contains videos, articles, and booklets on a variety of topics, including aging, Alzheimer’s disease, and mental health.

• Resources are continually being updated.

adscresources.advocatehealth.com
Objectives

• Provide an overview of common health conditions in adults with Down syndrome, including presentation and prevention.

• Describe guidelines and best practices for addressing common health conditions in adults with Down syndrome.

• Identify resources to learn more about common health conditions in adults with Down syndrome.
What is health?
Health and well-being

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

(World Health Organization)
Health conditions
Common health conditions

• Definition
• Presentation
• Prevention
• Treatment
GLOBAL Medical Care Guidelines

• Evidence-based recommendations intended to offer guidance to healthcare providers who see adults with DS

• Newest set published in October 2020

https://www.globaldownsyndrome.org/global-adult-guidelines/
Overweight and obesity

- Body mass index (BMI)
- More common
  - Estimates vary
  - Review of literature combined results from several studies:
    - 38% of study participants were obese, 34% were overweight
- Associated with other physical, mental, and social health issues

Capone et al. 2018     Tsou et al. 2020
Overweight and obesity

• GLOBAL Guidelines
  – Monitor for weight change and obesity annually
  – Follow a healthy diet, regular exercise, and calorie management

Tsou et al. 2020
Prevention and treatment

Healthy Lifestyle

• 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
  – Make it fun and social
  – Incorporate it throughout the day
  – Get outdoors
Prevention and treatment

• Medications
• Surgery
Vitamin deficiencies

• Vitamin B12
  – Seems to be more common in people with Down syndrome
  – More common in people with digestive disorders such as celiac disease
  – Autoimmune?

• Vitamin D
  – Bone health
  – COVID?
Prevention and treatment

• Healthy diet
• Regular exercise
• Outdoor activities
Nutrition & Exercise Resources

• Hunger and Satiety in People with Down Syndrome
• Low Carb Diets
• Vitamin B12 Deficiency
• Exercise in People with Down Syndrome
Vision and hearing

- Cataracts
- Keratoconus
- Hearing impairment
- Cerumen impaction (ear wax)

Source: American Academy of Ophthalmology
Prevention and treatment

• Consider screening at least every 2 years
Vision and Hearing Resources

• Keratoconus in People with Down Syndrome

• Vision in Adults with Down Syndrome

• Cerumen Impaction
Atlantoaxial instability

- Condition of the vertebrae in the neck

Source: Down's Syndrome Association
Atlantoaxial instability

• GLOBAL Guidelines
  ─ For adults with Down syndrome without symptoms:
    • Routine cervical spine X-rays should not be used to screen for risk of spinal cord injury.
    • Review of signs and symptoms of cervical myelopathy annually. Do an annual screening using targeted history and physical exam.

Tsou et al. 2020
Seizures

• Types
• Alzheimer’s disease
• Treatment

AGE

The onset of seizures is most common in children and older adults.
Neurology Resources

• Atlantoaxial Instability Screening

• Seizures

• Psychogenic Non-Epileptic Seizures (“Fake” Seizures)

• Seizures in People with DS and Alzheimer’s Disease
Mental health disorders

• Behavioral and mental health disorders are common in people with Down syndrome.
  – Depression, anxiety, OCD

• Studies have shown that 25-40% of people with Down syndrome experience a behavioral or mental health disorder during their life.
Common characteristics

• The Groove
• Self-talk
• Strong memory and the concept of time
Mental health disorders

• GLOBAL Guidelines
  – When concern for a mental health disorder in adults with Down syndrome is present:
    • Refer to a clinician knowledgeable about the medical, mental health disorders, and common behavioral characteristics of adults with Down syndrome.
  – Follow guidelines in the:
    • Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and/or
    • Diagnostic Manual – Intellectual Disability (DM-ID-2)

Tsou et al. 2020
Mental health disorders

• GLOBAL Guidelines
  – Clinicians should perform a review of behavioral, functional, adaptive, and psychosocial factors on an annual basis.
  – When concern for a mental health disorder in adults with Down syndrome is present:
    • Medical professionals should evaluate for medical conditions that may present with psychiatric and behavioral symptoms.

Tsou et al. 2020
Prevention and treatment

• Connection between physical, mental, and social health
Prevention and treatment

• Importance of sleep
• Be aware of “empathy radar” or “social sensitivity”
• Social skills
• Work with a mental health provider
  – Consider therapies (e.g., music, art)
• Medications
Mental Health Resources

- Behavior Changes in Adolescents & Adults with DS Webinar
- Down Syndrome and Mental Health
- Mental Wellness and Aging in Adults with DS Webinar
- Social Sensitivity
- “Self-Talk” in Adults with Down Syndrome
Alzheimer’s disease and dementia

• More common in people with Down syndrome
  – Uncommon before age 40.
  – Incidence estimated to be 55% in those between ages 50-59.
  – Incidence estimated to be greater than 75% in those 60 years of age and older.

• Why?
  – One of the genes associated with Alzheimer’s disease is on the 21st chromosome.
    • Amyloid precursor protein (APP)

Coppus et al. 2006  McCarron et al. 2017  Zis & Strydom 2018
Alzheimer’s disease and dementia

• Symptoms
  – Behavioral/psychological/personality changes
  – Memory
  – Loss of skills
  – Incontinence
  – Gait changes
  – Swallowing problems
Alzheimer’s disease and dementia

• GLOBAL Guidelines
  – For adults with Down syndrome younger than age 40, be cautious when diagnosing age-related, Alzheimer’s type dementia.
  – Assess baseline function each year beginning at age 40.
• NTG-EDSD: National Task Group – Early Detection Screen for Dementia

Tsou et al. 2020
Prevention and treatment

- Prevention – possibly exercise and brain stimulation
- Medications
  - Cholinesterase inhibitors (e.g., donepezil / Aricept)
  - NMDA receptor antagonist (memantine / Namenda)
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.
Supporting an individual with AD

• Quality of life
  – Doing what can still be done
  – “Bingo Pace”

• Communication
  – Simple instructions, do not argue, avoid asking them if they remember, get down on their level

• Home safety and adaptive equipment
Alzheimer’s Disease Resources

• **List of resources on Alzheimer’s disease and Down syndrome**
  – [Aging and Alzheimer’s Disease in Adults with Down Syndrome Webinar](#)
  – [Alzheimer’s Disease & Down Syndrome: A Practical Guidebook for Caregivers](#)
  – [Living with Dementia](#)
  – [Alzheimer’s Disease Video Journal](#)
  – [NTG-EDSD - Early Detection and Screen for Dementia](#)
Thyroid conditions

- Hypothyroidism
  - Underactive thyroid
  - Symptoms: fatigue, dry skin, constipation, cognitive impairment, depression, weight gain

- Hyperthyroidism
  - Overactive thyroid
  - Symptoms: fatigue, anxiety, agitation, sweating, tremor, weight loss
Thyroid conditions

• GLOBAL Guidelines
  – Screen for hypothyroidism every 1-2 years beginning at age 21.
    • Serum thyroid-stimulating hormone (TSH) test

Tsou et al. 2020
Treatment

• Hypothyroidism
  – Thyroid replacement medication (levothyroxine, Armour thyroid)

• Hyperthyroidism
  – Medications
  – Radioactive iodine
  – Surgery
Diabetes

• Type 1 diabetes is more common
• Type 2 diabetes is more common (?)
  – Estimates vary
Diabetes

• GLOBAL Guidelines
  – For adults without symptoms:
    • Screen for type 2 diabetes every 3 years beginning at age 30.
  – For adults with comorbid obesity:
    • Screen for type 2 diabetes every 2-3 years beginning at age 21.
  – Hemoglobin A1c (HbA1c) or fasting plasma glucose
Prevention and treatment

• Type 1 diabetes
  – No known prevention
  – Treatment: insulin

• Type 2 diabetes
  – Diet, exercise
  – Metformin?
  – Treatment: oral or injectable medications and sometimes insulin
Endocrine Resources

- Diabetes in Adults with Down Syndrome
- Hypothyroidism
- Thyroid, Weight, and Metabolism
Cardiovascular disease

- Hypertension
- Atherosclerotic disease
- Vasovagal syncope
Cardiovascular disease

- GLOBAL Guidelines
  - For adults with Down syndrome without a history of atherosclerotic cardiovascular disease (ASCVD):
    - Assess the appropriateness of statin therapy every 5 years starting at age 40
    - Use a 10-year risk calculator
      - This is the same recommendation for adults without Down syndrome (U.S. Preventive Services Task Force)

Tsou et al. 2020
Cardiology Resources

- Heart Disease in Adults with DS Between 1996 and 2016
- Vasovagal Syncope
Celiac disease

• More common

• Symptoms
  — Direct symptoms
  — Symptoms secondary to vitamin/mineral deficiencies

Source: Celiac Disease Foundation
Celiac disease

• GLOBAL Guidelines
  – Do an annual assessment for gastrointestinal and non-gastrointestinal signs and symptoms of celiac disease
    • Use targeted history, physical examination, and clinical judgement of good practice.

Tsou et al. 2020
Gastroenterology Resources

• Celiac Disease

• Constipation in Down Syndrome

• Gastroesophageal Reflux Disease

• Treating Gastroesophageal Reflux Disease with Surgery
Skin, hair, and nail conditions

• Dry skin (xerosis)

Source: American Academy of Dermatology
Skin, hair, and nail conditions

• Folliculitis
• Boils
• Athlete’s foot
• Fungal infections of the nails

Source: DermNet NZ
Source: Nemours
Source: NHS
Source: Mayo Clinic
Skin, Hair, & Nail Resources

• Skin, Hair, and Nail Concerns in People with DS Presentation

• Folliculitis and Boils in People with Down Syndrome

• Lotion Options

• Seborrheic Dermatitis

• Ringworm, Athlete’s Foot, and Jock Itch

• Onychomycosis – Toenail Fungal Infection
Cancer

- MORE common – leukemia, testicular cancer
- LESS common – most solid tumor cancers (breast, colon, etc.)
Cancer

• Implications for future guidelines
• How does this affect screening?
• Should my loved one be screened?
  — Discuss with healthcare provider.
Screening

Consider the potential risks and benefits.

Questions to ask

• What does the procedure involve?
• What do follow-up procedures involve?
• Is anesthesia required?
• What is your family history?
Cancer Resources

• **Testicular Cancer**

• **Colon Cancer Screening for People with Down Syndrome**

• **Prostate Cancer Screening in Men with Down Syndrome**

• **Breast Cancer and Breast Cancer Screening for Women with DS**

• **Low Risk of Solid Tumors in Persons with Down Syndrome**
Respiratory infections

• Influenza (flu)
• Pneumonia

• Presentation
  – Confusion or change in mental status

• Prevention
  – Consider earlier vaccination for pneumococcal pneumonia
Respiratory Resources

- Recurrent Pneumonia
- Pneumococcal Vaccine
- Flu Vaccine Information for People with Down Syndrome
COVID-19

• In people with Down syndrome age 40 and older, the risk for severe complications from COVID-19 is increased.

• In people with Down syndrome younger than 40 with co-occurring conditions, the risk is also increased.
Resources

• List of COVID-19 Resources
  – COVID and Down Syndrome Webinar
  – T21RS COVID-19 and Down Syndrome Survey
  – DSMIG-USA IDD COVID-19 Vaccination Position Statement
  – Routines during the Pandemic
Questions?

Resource Library
adscresources.advocatehealth.com

Facebook
www.facebook.com/adultdownsyndromecenter

E-mail Newsletter
http://eepurl.com/c7uV1v
References


References

