

# Promoting Healthy Aging While Stuck at Home

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**Jefferson**

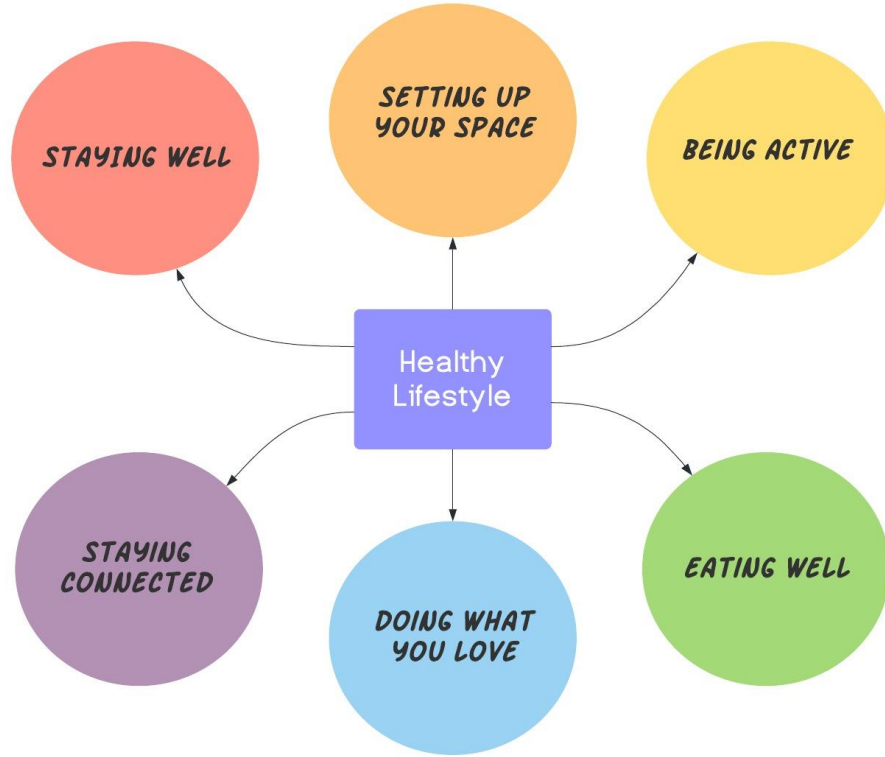
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# Disclosures



# Objectives:

- At the conclusion of this presentation you will be able to:
  - Discuss aspects of healthy aging for individuals with Down syndrome and intellectual disabilities
  - Describe ways to promote healthy aging.
  - Identify strategies to incorporate into your daily routine or the daily routines of individuals with Down syndrome that you support



# Let's look at the literature!

- Down Syndrome Medical Interest Group-USA (DSMIG-USA)
- Adult Health Work Group



RESEARCH REVIEW

**Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines**

George T. Capone , Brian Chicoine, Peter Bulova, Mary Stephens ... [See all author](#)

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RESEARCH REVIEW

**Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines. Part II**

George Capone , Mary Stephens , Stephanie Santoro  ... [See all authors](#) 

First published: 27 April 2020 | <https://doi.org/10.1002/ajmg.a.61604>

# Conditions reviewed

- Thyroid disease
- Cervical spine disease
- Hearing impairment
- Overweight-obesity
- Congenital heart disease
- Sleep apnea
- Osteopenia-osteoporosis
- Hip dysplasia
- Menopause
- Cardiac valve disease
- Type 2 DM
- Hematology
- Dysphagia

# Take home points!

- Screen for thyroid conditions
  - Annually in patients without symptoms, more frequently if symptoms develop
- Spine and hips
  - Think about early arthritis more than instability in adults
- Hearing impairment
  - Probably affects more than 70% of adults with DS
  - Role for testing/treatment/speech therapy
- Osteopenia-osteoporosis
  - Consider screening as early as age 45-50

# Take home points!

- Overweight-obesity
  - We have a lot to learn!
  - ? Role for multidisciplinary approach
  - Judy Kim, MD (Baylor): watch for weight gain in 20's
- Menopause
  - Earlier! Think and talk about it in the early to mid 40's
  - Hormone therapy benefits only shown for relief of symptoms
- Congenital Heart Disease and acquired valvular heart disease
  - Follow established guidelines
  - Make sure the history doesn't get lost!



# Take home points!

- Type 2 Diabetes Mellitus
  - Maybe less common and less severe than the general population
  - Think about side effects of drugs and risk of low blood sugars!
- Blood cells - the numbers and sizes may be different, but what does it mean?
  - May mask things like low iron or B12. . . So look for those things!
- Dysphagia or trouble swallowing
  - It's more common for a few reasons!
  - Report mealtime symptoms, symptoms of reflux (like small spit ups or new tooth grinding/rumination), history of pneumonia

# Are you getting sleepy?

- Hope not!
  - We'll take a look at sleep apnea in more detail a little later

# Approach to the individual - let's think about a patient in DS clinic!

- Recognize how Alzheimer's disease (AD) can present in an adult with DS
- Identify the important co-morbid conditions to consider when evaluating an adult with DS for cognitive decline
- Discuss available treatment options for adults with DS and consider how these patients' support systems may differ from other patients with cognitive decline

# 55 year old male comes to see me in DS clinic

- Past History
  - Seizures as a child, Type 2 Diabetes
  - Aortic valve and hip replaced
- Medications: metformin, warfarin
- Presents for evaluation with his sister who is his primary caretaker
- Concerns for OCD-like symptoms, functional decline, ? memory loss and increased self talk

# Self talk?

- Mental health issues are more common in people with DS
  - Depression, anxiety, OCD
  - Self talk is probably a good thing!
    - As Drs. Chicoine and McGuire would say
      - It should not land you on an anti-psychotic!!
      - But pay attention to the tone and content

# DS and Alzheimer's disease (AD)

- Increased risk of early AD
  - Probable mutations in the APP gene on chromosome 21 are likely the driving force
- AD pathology likely present by age 40 in most adults with DS
  - No longer felt all patients with DS develop clinical AD
- Take home point -
  - It's not AD in a 20 or 30 year old with DS!!!
  
- Sanchez 2012

- Change in gait may be an early marker of cognitive decline
  - Gait dyspraxia: “diminished capacity to correctly use the legs for ambulation” not attributable to other factors
    - Difficulty initiating walking
    - Harder to make turns
    - Shuffling
    - Fear and avoidance of obstacles - including stairs!
- New onset seizures

Anderson-Mooney 2016

- Incontinence
- Decline in occupational and social functioning
  - Preceded by visual memory loss
- Changes in mood and behavior



- Are patients with DS more likely to be depressed than the general population or other people with intellectual disabilities?
  - Probably
  - And may be more likely to have anxiety and phobias as well
- Associated with
  - Increased rates of cognitive decline
  - Poorer quality of life/increased suffering
  - Earlier institutionalization
- Difficulties in quantifying
  - Limitations of available rating skills
  - Reliance on observation vs. patient self-report
  - What's the role of learned behavior?

Dekker 2015, Walker 2011, McGuire and Chicoine 2006

- ? Worse in females vs. males
  - ? Estrogen deficiency/early menopause
- ? Earlier onset and more rapidly progressive
  - Are we missing the mild cognitive impairment stage?
  - What does it look like?
- Early: apathy, social withdrawal, disinhibition, loss of executive functions
- Later: agitation, hyperactivity or slowness, delusions/hallucinations

- Don't lose focus on the differential diagnosis!
- OR. . . The patient's medication list!!!!

# Co-morbid conditions to think about in our patient

- Role of Type 2 DM
- Mental health
- Hypothyroidism
- Constipation
- Pain?
- OSA

# OSA



# Screening for sleep apnea

- 2011 AAP recommendation
  - At least once during the first 6 months of life, discuss with parents symptoms of obstructive sleep apnea, including heavy breathing, snoring, uncommon sleep positions, frequent night awakening, daytime sleepiness, apneic pauses, and behavior problems that could be associated with poor sleep. Refer to a physician with expertise in pediatric sleep disorders for examination and further evaluation of a possible sleep disorder if any of the above-mentioned symptoms occur.

- There is poor correlation between parent report and polysomnogram results. Therefore, referral to a pediatric sleep laboratory for a sleep study or polysomnogram for all children with Down syndrome by 4 years of age is recommended.

# From the DSMIG-USA Review

- Prevalence and severity of OSA in adults with DS is likely greater than the general population
- Ongoing study around other ways to diagnose besides the sleep lab!
- Tension between making the diagnosis and benefits and harms of treatment



# Consequences -or why do we care?

- Breslin 2014
  - Mean Verbal IQ 9 points lower in patients with DS and OSAS
  - Decreased cognitive flexibility
- Chicoine and McGuire 2010
  - Fatigue
  - Poor school/work performance
  - Mood disturbance
  - Muscle pain
  - Reduced ability to focus/attend to tasks
- The big question!
  - Does it contribute to earlier onset AD?

# My approach in DS Clinic

- Talk about it!
- Try to test - lab vs. home
  - Think about the supporting cast
    - Social stories
    - Desensitization
    - Multidisciplinary approach
- If negative, do you believe the result?
- If positive, what do you do now?

# OSA in patients with Down syndrome: current perspectives (Simpson 2018)

- Treatment options
  - CPAP
  - Intranasal steroids
  - Palatal expansion (probably too late in adults) or other oral devices
  - Directed airway surgery based on sleep endoscopy
  - Surgical
  - Hypoglossal nerve stimulation

Sleep Medicine

## Hypoglossal nerve stimulation in three adults with down syndrome and severe obstructive sleep apnea

Carol Li MD, Maurits Boon MD, Stacey L. Ishman MD, MPH, Maria V. Suurna MD 

First published: 13 December 2018 | <https://doi.org/10.1002/lary.27723> | Citations: 1

Presented at the 9th International Surgical Sleep Society Meeting, International Surgical Sleep Society, Munich, Germany, April 5–7, 2018.

The authors have no funding, financial relationships, or conflicts of interest to disclose.

- NTG - Early Detection Screen for Dementia
  - Adapted from DSQIID
    - From the National Task Group on Intellectual Disabilities and Dementia Practices
    - Role is as an “administrative tool” /quick screen
    - ? Begin screening at age 40
    - Signal items
      - Unexpected problems with memory
      - Getting lost
      - Gait changes
      - New seizures
      - Confusion in familiar situations
      - Personality change

# Treatment options

- Cochrane review - 2015
  - 9 studies met inclusion criteria (427 participants)
    - Only 5 focused on adults from 45 to 55
    - Studies focused on donepezil, memantine, simvastatin, antioxidants, acetyl-L-carnitine
  - Bottom line
    - Maybe a benefit to simvastatin
    - Low quality of evidence

- Pharmacologic therapy
  - Medications to slow cognitive decline
  - Medications to treat symptoms and improve quality of life
    - Treat depression and anxiety!!
      - Prasher 2016
- Mental Wellness in Adults with Down Syndrome and The Guide to Good Health for Teens & Adults with Down Syndrome
  - Chicoine and McGuire

- Non-pharmacologic
  - Jenny's Diary
  - Dementia and People with Learning Disabilities
    - The British Psychological Association
  - Other things to think about
    - Who are the caregivers?
    - What about retirement?



# Back to our patient

- Multidisciplinary approach
  - PCP, social work, Memory Center, Adult DS program
  - Treatment of sleep apnea
  - Behavioral strategies
  - Pharmacologic treatment

# Gaps in knowledge and resources

- While there are significant gaps in the current evidence base and in existing resources, there is good working being done!
  - NIH DS Registry: DS Connect
  - Advocacy groups
    - Alzheimer's Association
    - Down Syndrome Association - [www.dsadelaware.org](http://www.dsadelaware.org)
  - Resources at the state level
  - “My Thinker’s Not Working” - from the NTG
  - Down Syndrome Medical Interest Group (DSMIG)

# What to do when your stuck home in a pandemic?

- Think about telehealth
  - Maybe you can access a virtual DS Clinic!
- Practice wearing a mask
  - Overcoming sensory issues
  - What if you just can't do it?!
- Stay organized
  - Visual schedules
  - Time for exercise
  - Make healthy food choices
- Maintain social connections
- Caregiver stress

## Think about when you should travel to the doctor's office, urgent care or ER. . .

- Call your primary care provider if unsure
- If you are going to an ER or urgent care, bring in all your medicines. . . And wear a mask!
- Don't forget immunizations
  - This year it will be especially important to get your flu shot!
  - Individuals with DS may be at higher risk for pneumonia for a number of reasons
    - Talk to your health care provider about a Pneumovax!

# References and resources

## Books:

- Chicoine B, McGuire D. *The Guide to Good Health for Teens & Adults with Down Syndrome*. Bethesda: Woodbine, 2010.
- McGuire D, Chicoine B. *Mental Wellness in Adults with Down Syndrome*. Bethesda: Woodbine, 2006.

## Websites:

- National Task Group on Intellectual Disabilities and Dementia Practice - allows access to NTG-EDSD
- National Down Syndrome Society

# Healthy Aging

## Challenges:

- increased chronic conditions
- high incidence of cardiovascular disorders, obesity, HTN, diabetes
- sedentary lifestyles
- limited social networks
- participation in passive activities

Reppermund & Trollor, 2016



<https://www.pelicanwireless.com/s/helter-in-place/>

# Staying Well

Regular medical care

Primary care screenings

Refer to Mary's slides



<https://www.417mag.com/issues/february-2016/direct-primary-care-in-417-land/>

# Setting up your space

- Establish a routine
  - Create a schedule
  - Include a variety of activities
  - Use visual schedules
  - Keep a log (diary or journal)

## How to Create an Effective Visual Schedule

THEINSPIREDTREEHOUSE.COM



<https://theinspiredtreehouse.com/how-to-make-a-visual-schedule/>



# Setting up your space

- Set up the environment
  - Limit clutter
  - Have enough lighting
  - Make it comfortable
  - Set up a designated space for the activity



<https://www.pinkdesk.org/read/a/Clutter-free-homes-are-beautiful-PDAB20200116065017>

# Setting up the space

- Activities:
  - Replicate valued activities
  - Set up “special events”
  - Schedule fun times



<https://home-blogger.com/top-5-ideas-home-movie-night/>

# Being active

- 150 to 300 minutes of moderate intensity activity per week
  - Walking
  - Swimming
  - Bicycling
  - Dancing
  - Yard work
  - Exercise class (water aerobics)
  - Yoga
  - Tai Chi



<https://www.dadsofarkansas.org/add-a-little-physical-fitness-to-your-weekend/>

# Being active

- Identify an activity the individual likes
- Make it fun
- Add music



# Being active

- Activity ideas
  - Games, dancing, exercise, fun activities, stretches
- Game spinner apps
- Slow down the speed on You tube
- Take “brain breaks”
- Make chores active parts of your day
- Stand during commercials



<https://www.youtube.com/watch?v=HbCJEL55VZc>

# Eating Well

## Eating patterns

- Foods/beverages in combination
- Routines and habits
- Focus on variety, nutritional value and amounts
- Limit calories from sugars, saturated fats
- Reduce sodium intake



<https://wittysparks.com/eating-habits-of-highly-successful-people/>



# Eating well



<https://www.weightwatchers.com/us/blog/food/healthy-snacks-to-support-weight-loss>

# Doing what you love

- Participation in valued activities
  - Promotes health and well being
  - Reinforces our identity and roles
  - Adds value and meaning
  - Enhances quality of life
  - May protect against cognitive decline



<https://dailycaring.com/activities-for-seniors-with-alzheimers-10-inexpensive-diy-ideas/>



# Doing what you love

- Replicate valued activities
- Play games
- Learn something new
  - “relax the rules”
  - It’s the process not the product



<https://www.cambridge-news.co.uk/news/local-news/adults-learning-disabilities-supported-cambridgeshire-18159412>

# Staying Connected

- Social connections are important to health
  - Mental health
  - Physical health
  - Health behavior
  - Mortality risk



<https://www.downs-syndrome.org.uk/for-families-and-carers/growing-up/friendships-and-relationships/>

# Staying connected

- Zoom
- Video calls/video chat
- Audio or video recordings
- Write and receive letters
- Send emails



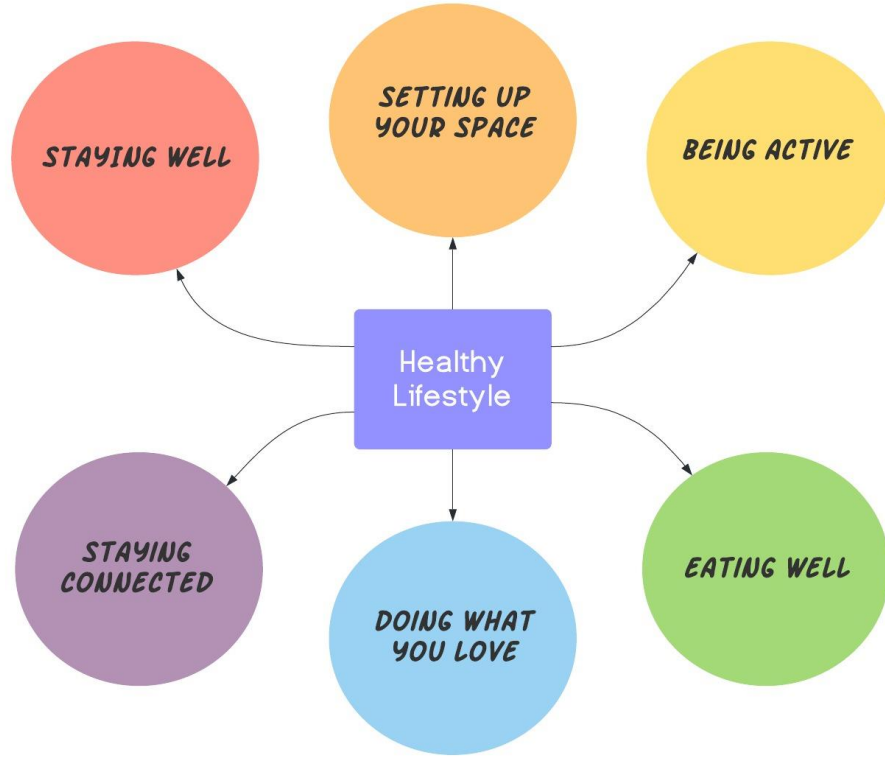
<https://economictimes.indiatimes.com/magazines/panache/stay-in-touch-video-chatting-with-older-adults-may-lower-risk-of-depression/articleshow/66707913.cms>

# Stay connected

- Play games together “on line”
- Celebrate together
- Teach or lead an activity
- Volunteer
- Do projects and share



<https://www.aarp.org/caregiving/life-balance/info-2020/coronavirus-gen-x-caregivers.html>



Thank you for attending!

Questions?



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