

Aging in Adults with Down Syndrome

Brian Chicoine, MD and Hannah Graham, MD

Advocate Medical Group Adult Down Syndrome Center

October 24, 2024





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Please note:

- This webinar is intended for families, caregivers, health care professionals, and service providers of individuals with Down syndrome.
- The information in this webinar 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.



Brian Chicoine, MD



Hannah Graham, MD

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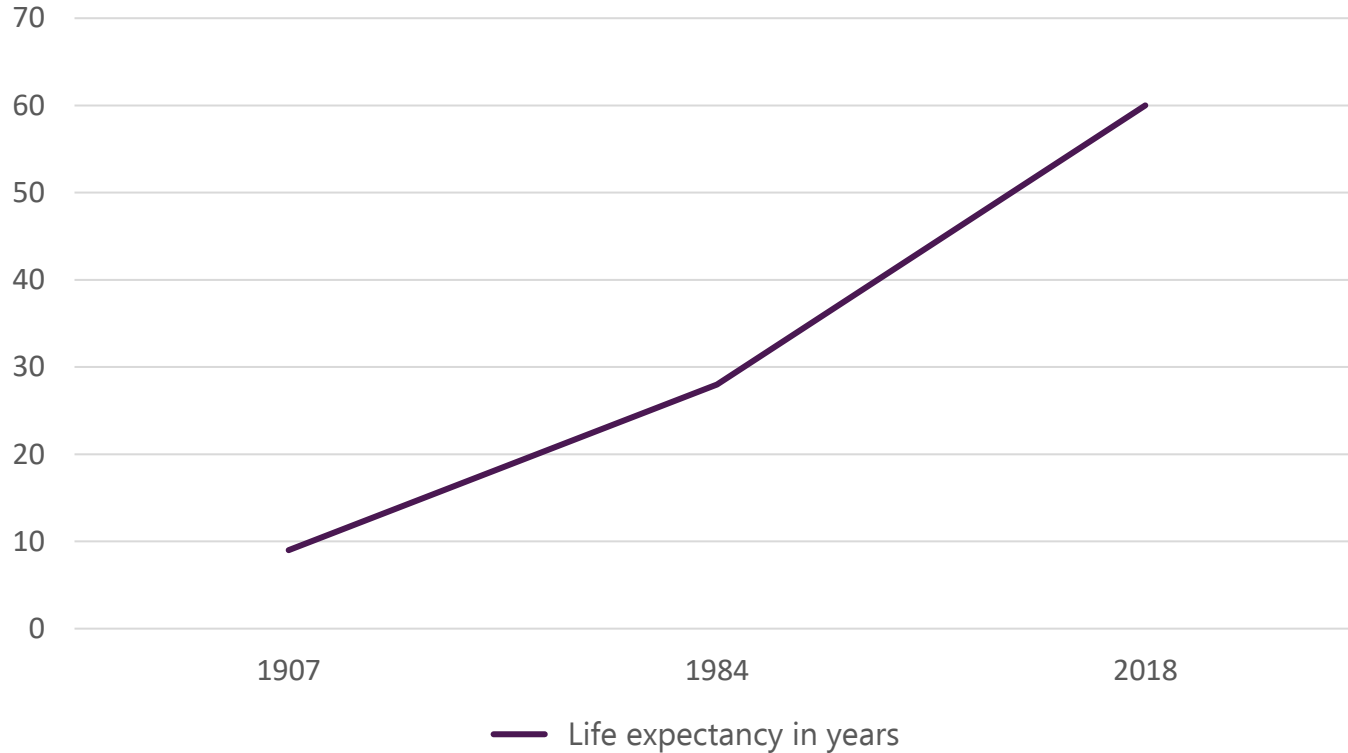


Objectives

- Identify similarities and differences in aging of adults with Down syndrome compared to adults without Down syndrome.
- Discuss common conditions associated with aging of adults with Down syndrome (including Alzheimer's disease).
- Describe strategies for supporting adults with Down syndrome in promoting their health as they age.

Today, people with Down syndrome are living *longer* and *healthier* than any other time in the past.

Life expectancy in years



There are more **adults** with Down syndrome living now than ever before.

People with DS in the United States

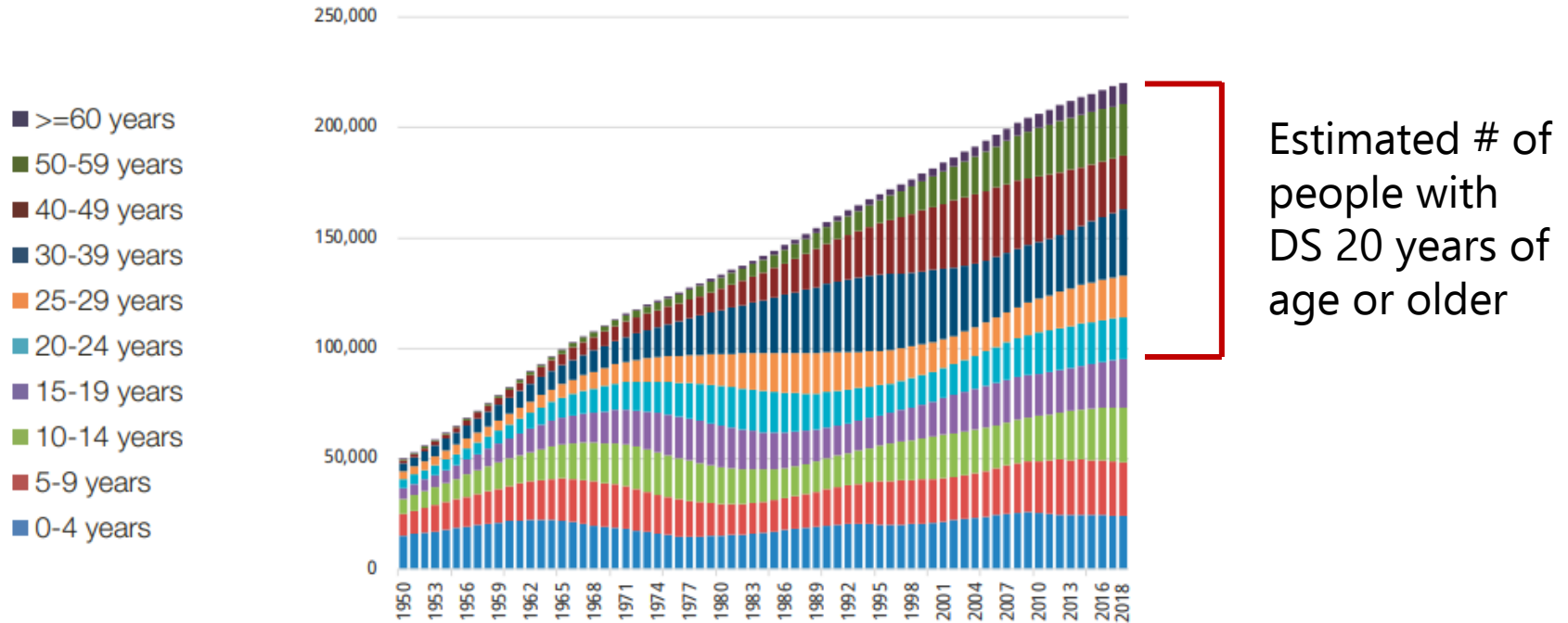


Figure 5. Population of people with Down syndrome in the USA, 1950-2018

Aging

Similarities

- Becoming more set in one's ways
- Slowing down
- Different activity preferences

Differences

- Earlier aging
- Living arrangements
- Health conditions

Common Conditions

Cataracts

- More common in people with Down syndrome
- Treatment
 - Monitored until it affects vision
 - Surgery
 - May require general anesthesia
 - Eyes drops post-surgery

Hearing loss

- Occurs at a younger age?
- Person with Down syndrome may not be able to explain their hearing difficulties
 - Behavior change
 - Loss of skills
- Hearing aids

Osteoarthritis

- Is it more common?
- Does it occur at a younger age?
- Is it underreported?
- How does it present?

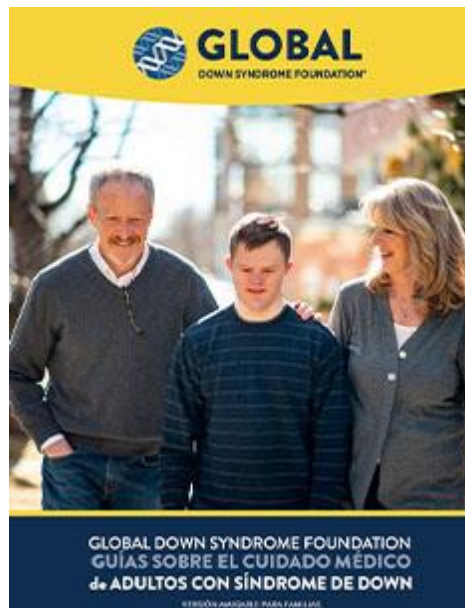
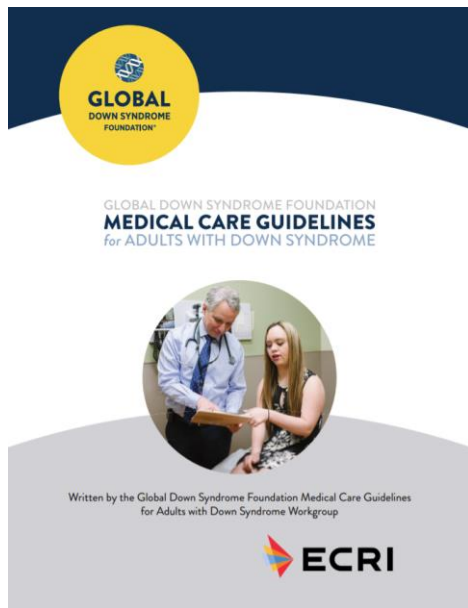
Osteoporosis

- Is it more common?
- Are DEXA scans accurate?
- Is the pathophysiology different indicating treatment should be different?

Menopause

- Occurs at a slightly younger age in women with Down syndrome
- Same treatment options for women with and without Down syndrome
- Association with memory

GLOBAL Medical Care Guidelines



[Link to GLOBAL website](#)

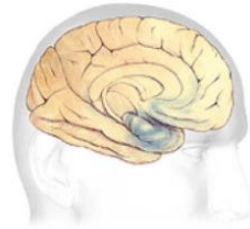
Alzheimer's Disease

What is Alzheimer's disease?

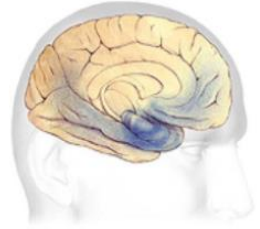
- Progressive neurological condition
- Affects the brain
- Is a type of dementia
- Plaques and tangles = the microscopic changes of the brain consistent with Alzheimer's disease

Alzheimer's and Down syndrome

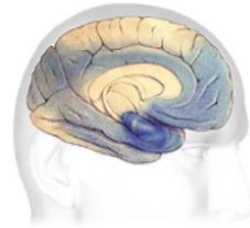
- By age 40, nearly all people with Down syndrome have the **brain pathology** of Alzheimer's disease.



Earliest Alzheimer's



Mild to moderate Alzheimer's



Severe Alzheimer's

Why?

- Amyloid precursor protein (APP)
- Chronic inflammation?
- Metabolic abnormalities?

Alzheimer's and Down syndrome

- By age 40, nearly all people with Down syndrome have the **brain pathology** of Alzheimer's disease.
- **HOWEVER**, *symptoms* of Alzheimer's disease are uncommon before age 40.

Alzheimer's and Down syndrome

- Prevalence of clinical Alzheimer's disease
 - Estimates vary
 - 55% in those ages 50-59
 - Greater than 75% in those ages 60 and older
- Average age at diagnosis
 - 54 to 55 years old
- Average age at death
 - 59 to 60 years old


Symptoms

- Changes in self-talk, adherence to routines
- Psychological changes
- Memory impairment
- Loss of previously mastered skills
- Incontinence
- Weight loss
- Seizures
 - Higher rate
- Unsteady gait
- Swallowing difficulties

Screening

- National Task Group on Intellectual Disabilities and Dementia Practices – Early Detection Screen for Dementia

[NTG-EDSD](#)



ntg
National Task Group
on Intellectual Disabilities
and Dementia Practices

NTG-EDSD

v.1/2020.1

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

⁽¹⁾ File #: _____ ⁽²⁾ Date: _____

Name of person: ⁽³⁾ First _____ ⁽⁴⁾ Last: _____

⁽⁵⁾ Date of birth: _____ ⁽⁶⁾ Age: _____

⁽⁷⁾ Sex:

	Female
	Male

⁽⁸⁾ Best description of level of intellectual disability

No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

⁽⁹⁾ Diagnosed condition (check all that apply)

Autism
Cerebral palsy
Down syndrome
Fragile X syndrome
Intellectual disability
Prader-Willi syndrome
Other: _____

Instructions:

For each question block, **check the item that best applies to the individual or situation.**

Current living arrangement of person:

- Lives alone
- Lives with spouse or friends
- Lives with parents or other family members
- Lives with paid caregiver
- Lives in community group home, apartment, supervised housing, etc.
- Lives in senior housing
- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other: _____

Diagnosis

History and physical exam

- Rule out other causes

Neuro-psychological testing

- Limitations

Blood testing and Imaging

- MRI? CT?

Treatment

Associated symptoms

Alzheimer's disease

Depression

Agitation

Seizures

Anxiety

Sleep challenges

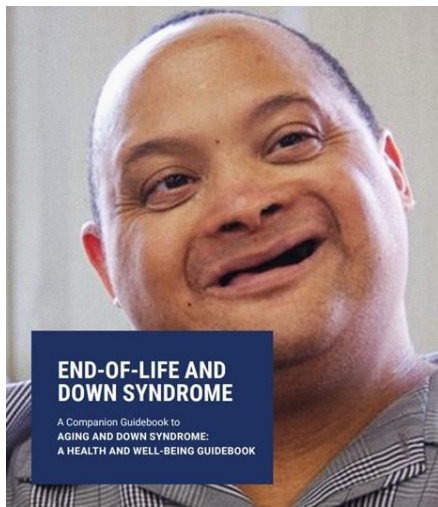
Pain

Cholinesterase inhibitors

NMDA receptor antagonist

Amyloid-beta therapies

Advance directives



[End-of-Life Guidebook from National Down Syndrome Society](#)

The poster is for a workshop titled 'Workshop END OF LIFE DIRECTIVES' organized by 'THE Inclusion INSTITUTE'. It is for 'DOWN SYNDROME NEW SOUTH WALES'. The event details are: Date: Wednesday 14th August, 2024; Time: 9:00am - 10:30am (AEST); Format: Online; Cost: Free. Two speakers are featured: Dr. Brian Chicoine MD, Adult Down Syndrome Centre Illinois, and Dr. Mary Stephens MD, Family & Community Medicine, Jefferson. The poster has a blue background with white and dark blue text and circular graphics.

End-of-Life Directives Presentation

*recording will be posted to [DS NSW's YouTube page](#)

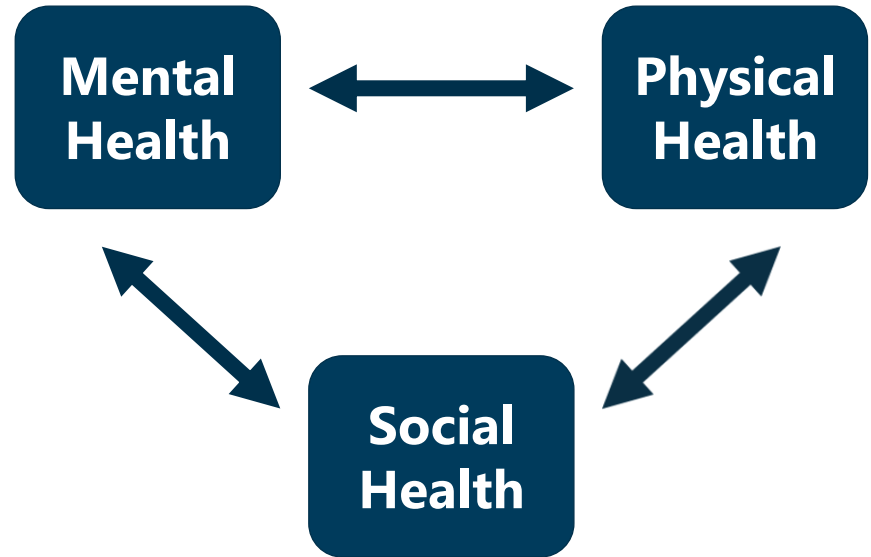
How other people with DS are affected

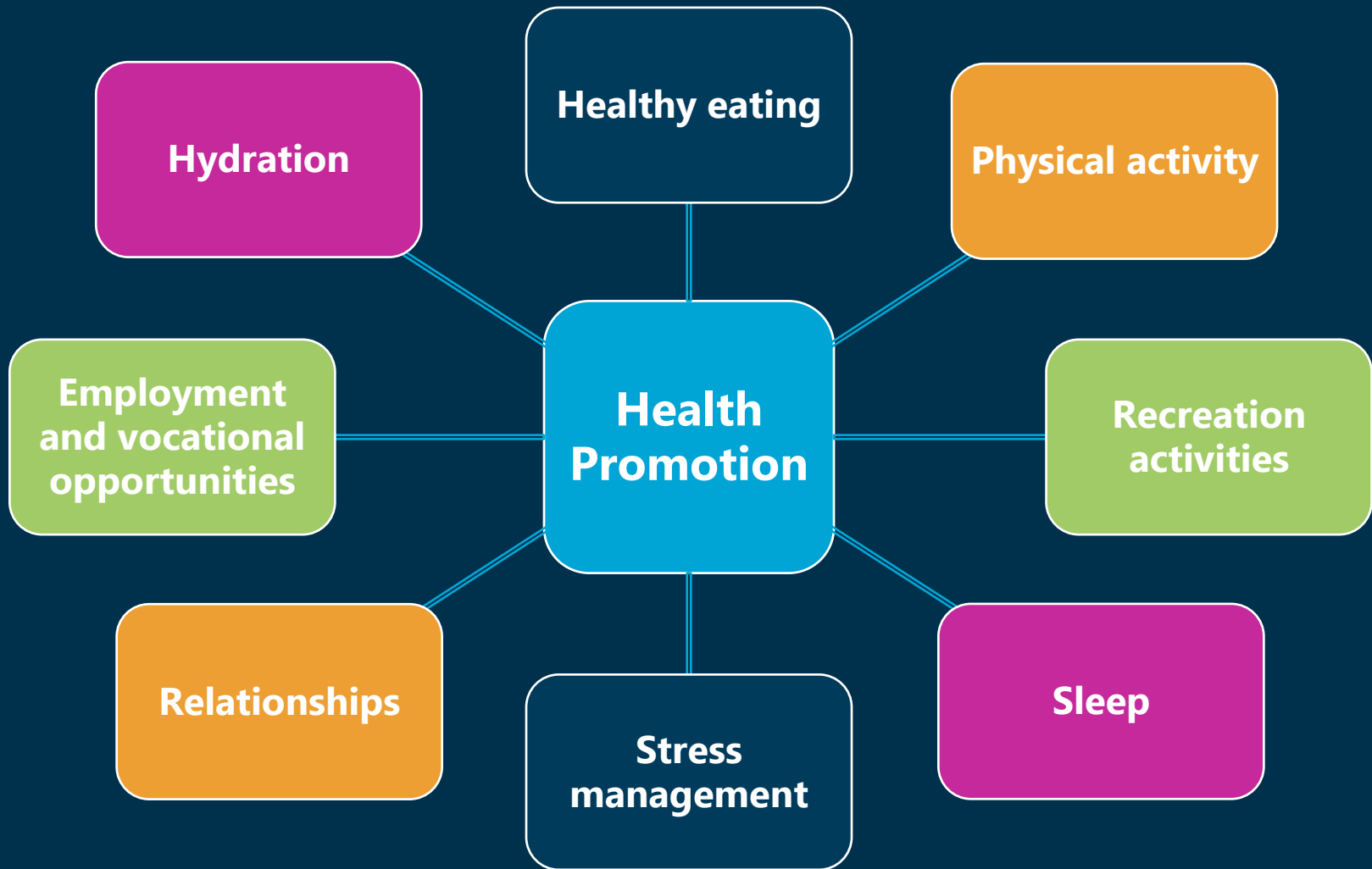
- First thing to consider – it does impact some individuals
- Can cause fear and anxiety
- Can cause resentment
- Can bring out the best “caregiver”

Healthy Aging

Promoting healthy aging

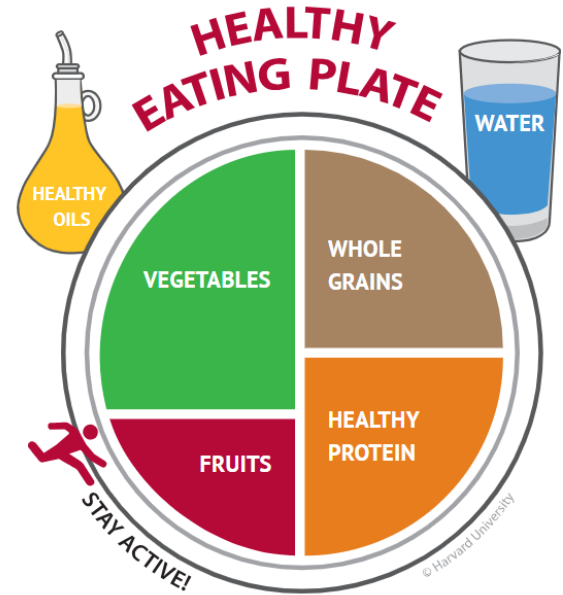
- Includes optimizing physical, mental, and social health
- Health promotion
- Medical care





HEALTHY EATING

- Maintain a healthy diet and weight
- No one diet is best
 - DASH
 - Mediterranean
 - MIND
 - Combines Mediterranean and DASH
 - Intermittent fasting?



[Harvard University](https://www.harvard.edu/healthy-eating-plate/)

Tips

- Reduce processed foods in diet
- Add green, leafy vegetables to meals
 - Pasta, soup, sauces, eggs
- Make food swaps
 - Grilled instead of fried food
 - Cauliflower pizza crust
 - Zucchini noodles


Tips for Eating Healthy Meals

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.





Eat whole grains.

Eat wheat bread instead of white bread.





Eat brown rice instead of white rice.



Choose grilled food instead of fried food.

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



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[Tips for Eating Healthy Meals](#)

Tips

- Involve the person in planning meals and shopping for/preparing foods
- Label foods
- Use apps and visuals
- Use portion control products
- Discuss which parts of the meal to have seconds of (e.g., fruits or vegetables)



[Guide to Healthy Eating](#)



[The Traffic Light Eating Plan](#)

HYDRATION

- Dehydration is common in many people with Down syndrome.
- Symptoms
 - Fatigue
 - Dizziness
 - Confusion




[Hydration Video](#)


Tips


- Limit pop/soda
- Try seltzer or sparkling water
- Flavor water with fruit

STAYING HYDRATED




Drinking water is important!

It is good for your skin. 




It is good for your teeth. 



It helps you go to the bathroom regularly. 

It helps you do your best at home, school, work, and other places!


  

Each day you should drink...

2 large water bottles 
OR
4 regular water bottles 
OR
8 cups of water 

 Drinking water helps you stay healthy! 

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[Tips for Staying Hydrated](#)

PHYSICAL ACTIVITY

- 30 minutes, 5 or more days per week
- Many benefits
- Incorporate a variety of types of physical activity (aerobic, strength, stretching, balance)
- Preferences may change with age



[Ways to Be Active](#)

Tips

- Make it fun
 - Listen to music/watch TV
 - Be active with others
 - Turn it into a game
- Break it into shorter periods throughout the day
- Build it into the schedule/calendar

Be active throughout the day!

Moving our bodies throughout the day can help us be healthy.

Be active in the morning	<p>Go for a walk.</p>	<p>Do an exercise video.</p>
Be active in the afternoon	<p>Dance break!</p>	<p>Lift weights.</p>
Be active in the evening	<p>Stretch/do yoga.</p>	<p>Clean.</p>

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

[Be Active Throughout the Day](#)

SLEEP

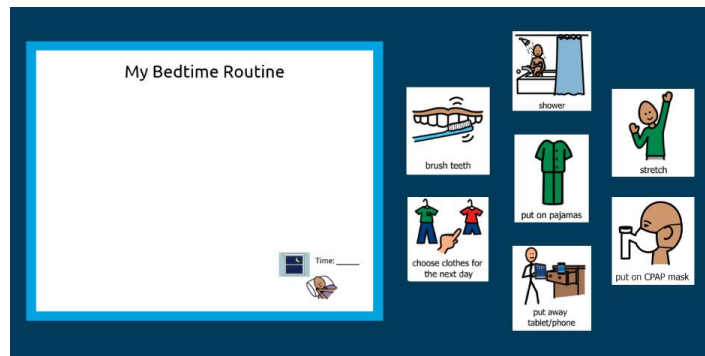
- Symptoms
 - Fatigue
 - Confusion
- Sleep hygiene
- Sleep apnea



[How to Use a CPAP Machine Video](#)

Tips

- Create a bedtime routine
- Review current medications
- Consider natural products
- Talk with health care provider about prescription medications, if needed



[Create a Bedtime Routine Visual](#)

MENTAL STIMULATION

- Paid or volunteer work
- Games, puzzles, activities

ACTIVITIES TO AVOID BOREDOM & HAVE FUN!

Arts and Crafts



- Draw
- Paint
- Color
- Make a card
- Sing
- Write a story
- Write a song
- Scrapbook
- Do origami
- Make jewelry
- Knit or crochet
- Sew
- Take photos
- Make pottery
- Do a craft
- Act in a play
- Make a collage
- Make movies
- Play an instrument
- Create a new playlist

Learning and Thinking



- Do a jigsaw puzzle
- Play a board game
- Read a book
- Listen to a podcast or audiobook
- Research an interesting topic
- Plan a vacation
- Fix something
- Build something
- Do a crossword or word search
- Learn a new skill

[Fun Activities for Promoting Health](#)

Tips


- Change the activities as an individual ages

Fruits and Veggies Word Search

Fruits and veggies are **healthy foods**. We should eat them every day.

U L O N F U Z H U T G R A P E S I P
V U S K D W A I U K P I G P O I P F
O P W C A R R O T S X M Y P C Y I B
C W A H I V E X Y M E V J Z Q Y N A
P E A C H E S F P E P P E R S A E N
I J C U C U M B E R S V H Y V P A A
B R O C C O L I B C M A C L M P P N
E P B O A W A T E R M E L O N L P A
O E U F A X J M W C J K B A B E L S
T Y B S V M M K H J U O J W D S E O
D C T T X E Z U G X T Y W Q J B E A
M R Z S U Q F O D U C E L E R Y A J

APPLES	CARROTS	GRAPES	PINEAPPLE
BANANAS	CELERY	PEACHES	SALAD
BROCCOLI	CUCUMBERS	PEPPERS	WATERMELON



[Healthy Lifestyle Activity Book](#)

SOCIAL ENGAGEMENT

- Family, friends, housemates
- Recreation activities



Tips

- Change the frequency and/or length as an individual ages



[Visual Schedules](#)

MENTAL WELL-BEING

- Stress management
- Life stressors associated with aging
- Empathy radar
- The "Pace"



[Tips for Dealing with Stress Video](#)

Tips

- Practice calming strategies
 - Counting to 10, taking deep breaths, walking away, coloring
- Practice coping strategies
 - Reframing thoughts, asking for help, "I" statements
- Work with a mental health provider
 - Consider therapies (talk, music, art, etc.)



[How to Cope with Stress Resources](#)

Key Points

- The life expectancy of people with Down syndrome is about 60 years old.
- There are similarities and differences in the aging process between adults with Down syndrome and adults without Down syndrome.
- Some health conditions are more common in adults with Down syndrome as they age.
- There are many lifestyle choices that people with Down syndrome can make to be healthy as they age.

Resources

DSMIG-USA

- Down Syndrome Medical Interest Group

- Membership
- Speaker Series
- Project ECHO



DSMIG-USA
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

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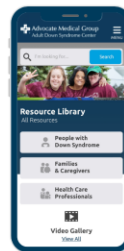
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FREE HEALTH RESOURCES

for people with Down syndrome, families and caregivers, and professionals



Resource Library



Find information on aging, puberty, mental health, self-talk, weight management, Alzheimer's disease, social skills, and more.

adscresources.advocatehealth.com

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[@adultdownsyndromecenter](https://www.facebook.com/adultdownsyndromecenter)

Email List



www.eepurl.com/c7uV1v



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Articles

[Agitated or Challenging Behavior in People with DS and Alzheimer's Disease](#)

[Down Syndrome EyeWiki](#)

[Hearing Loss](#)

[Helping a Person with Down Syndrome Prepare for a Hospital Stay](#)

[Menopause](#)

[Pneumococcal Vaccines](#)

[Recurrent Pneumonia](#)

[Reducing Risk of Getting Alzheimer's Disease](#)

[Resources on Healthy Ways to Manage Stress](#)

[Vision in Adults with DS](#)

[Weight Management in Adults with Down Syndrome](#)



Videos and visuals

[Be Active Throughout the Day Visual](#)

[Create a Bedtime Routine Visual](#)

[Fun Activities for Promoting Health](#)

[Hydration Video and Visuals](#)

[Tips for Eating Health Meals Visual](#)

[Ways to be Active Visual](#)

[What to Drink Instead of Pop/Soda Visual](#)



Webinars and podcasts

[Aging and Alzheimer's Disease in Adults with DS Webinar](#)

[Alzheimer's Disease Prevention and Healthy Aging Webinar](#)

[Behavior Changes in Individuals with DS Webinar](#)

[Common and Uncommon Health Conditions in Adolescents and Adults with DS Webinar](#)

[Decline in Skills and Regression in Adolescents & Adults with DS Webinar](#)

[Enhancing Women's Health: Key Insights from the PCP's Guide to Women's Health and DS Webinar](#)

[Promoting Mental Health Across the Lifespan in Individuals with DS Webinar](#)



Resource lists by topic

[Aging](#)

[Self-Care and Hygiene](#)

[Alzheimer's Disease and Dementia](#)

[Sensory](#)

[Decline in Skills and Regression](#)

[Sleep](#)

[Grief and Loss](#)

[Symptoms](#)

[Healthy Lifestyle](#)

[Mental Health](#)

[Nutrition and Weight](#)

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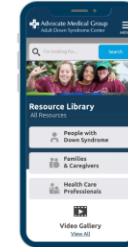
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FREE HEALTH RESOURCES

for people with Down syndrome, families and caregivers, and professionals



Resource Library



Find information on aging, puberty, mental health, self-talk, weight management, Alzheimer's disease, social skills, and more.

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