

Aging in Adults with Down Syndrome

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Advocate Medical Group Adult Down Syndrome Center

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Advocate
Medical
Group

Adult Down
Syndrome Center
1610 Luther Lane



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.

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.

Resource Library

The screenshot shows the top navigation bar with the Advocate Medical Group logo and 'Adult Down Syndrome Center' text. A search bar contains 'I'm looking for...' and a 'MENU' button with a hamburger icon. Below the navigation is the 'Resource Library | All Resources' header. Three featured resource cards are displayed: 'People with Down Syndrome' (with a photo of a young girl), 'Families & Caregivers' (with a photo of a woman and a man), and 'Health Care Professionals' (with a photo of a healthcare provider interacting with two patients). At the bottom, five categories are listed with icons and links: 'Events, Classes & Programs' (with a bell icon and 'See the Schedule' link), 'Video Gallery' (with a play button icon and 'View All' link), 'Related Organizations' (with a sunburst icon and 'See Listing of Links' link), 'Projects' (with a book icon and 'See Our Latest Projects' link), and 'News' (with a document icon and 'View News Articles' link).

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I'm looking for... MENU

Resource Library | All Resources

People with Down Syndrome

Families & Caregivers

Health Care Professionals

Events, Classes & Programs
[See the Schedule](#)

Video Gallery
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Related Organizations
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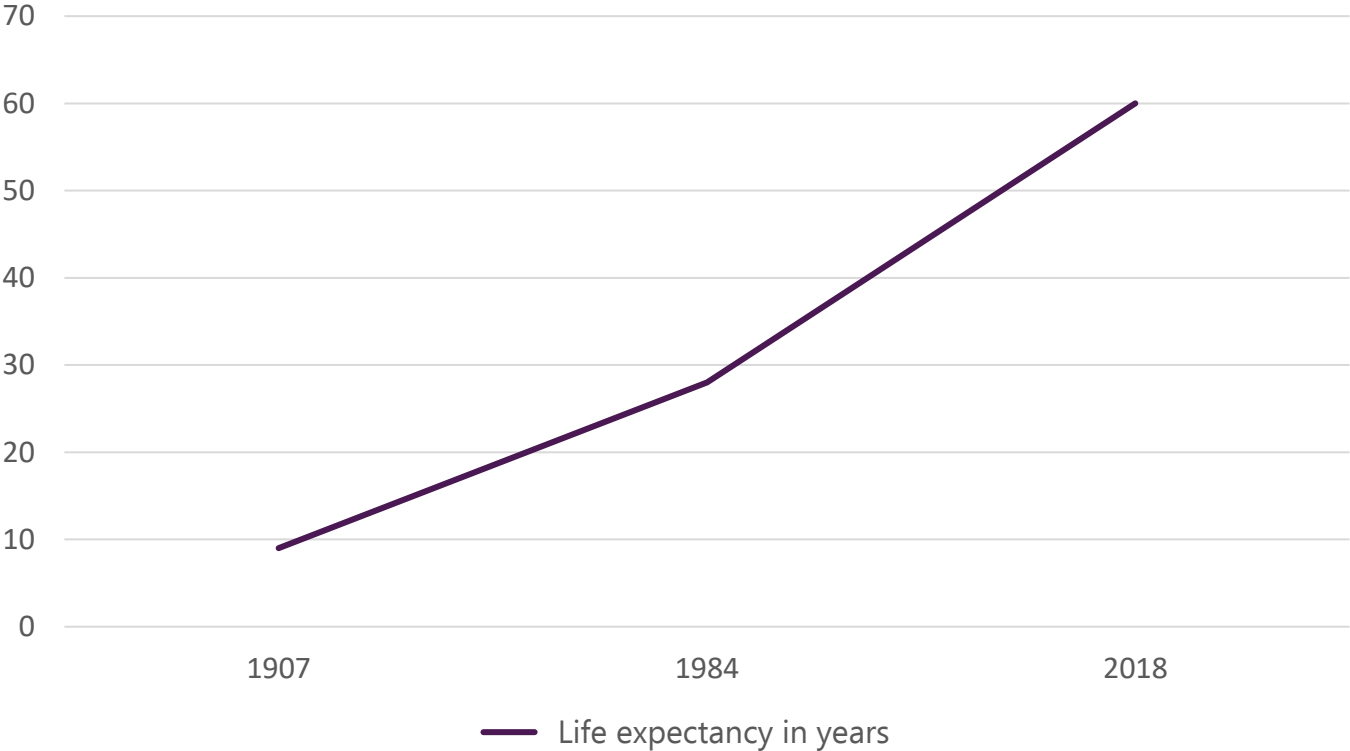
Projects
[See Our Latest Projects](#)

News
[View News Articles](#)

<https://adsresources.advocatehealth.com/>

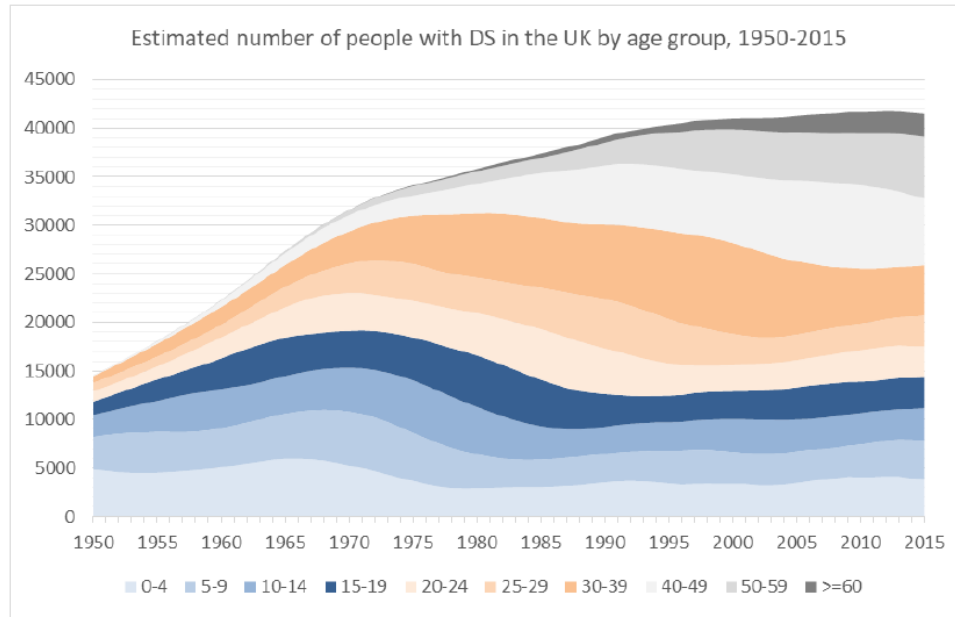
Today, people with Down syndrome are living *longer* and *healthier* than any other time in the past.

Life expectancy in years



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

People with DS in the United Kingdom



Estimated # of people with DS 20 years of age or older

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?

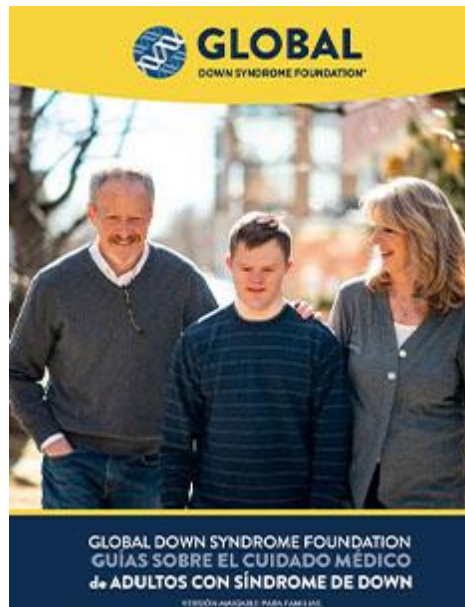
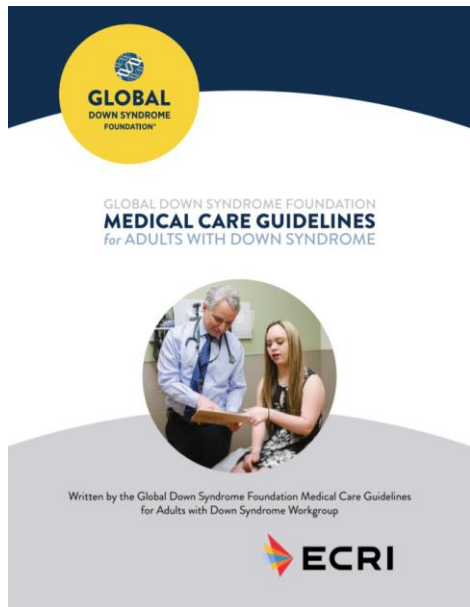
Osteoporosis

- 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

The connection between AD & DS

- 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.
- Prevalence
 - Estimates vary
 - 55% in those ages 50-59
 - Greater than 75% in those ages 60 and older

Diagnosis age

- Age when people with Down syndrome are diagnosed with Alzheimer's disease
 - Around 54-55 years old

Why is it more common?

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

Symptoms

- Psychological changes
- Memory impairment
- Loss of previously mastered skills
- Incontinence
- Weight loss
- Seizures
 - Higher rate (50-80% vs. 2-25%)
- Unsteady gait
- Swallowing difficulties

Diagnosis

History and physical exam

- Rule out other causes

Neuro-psychological testing

- Limitations


Imaging

- MRI? CT?

Diagnosis

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

NTG-EDSD



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: _____

Treatment

Associated symptoms

Alzheimer's disease

Depression

Anxiety

Agitation

Sleep challenges

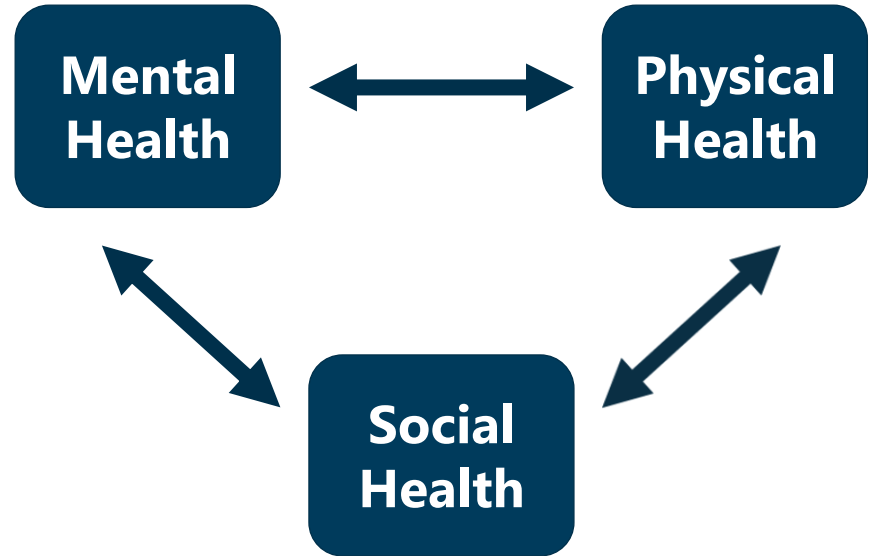
Seizures

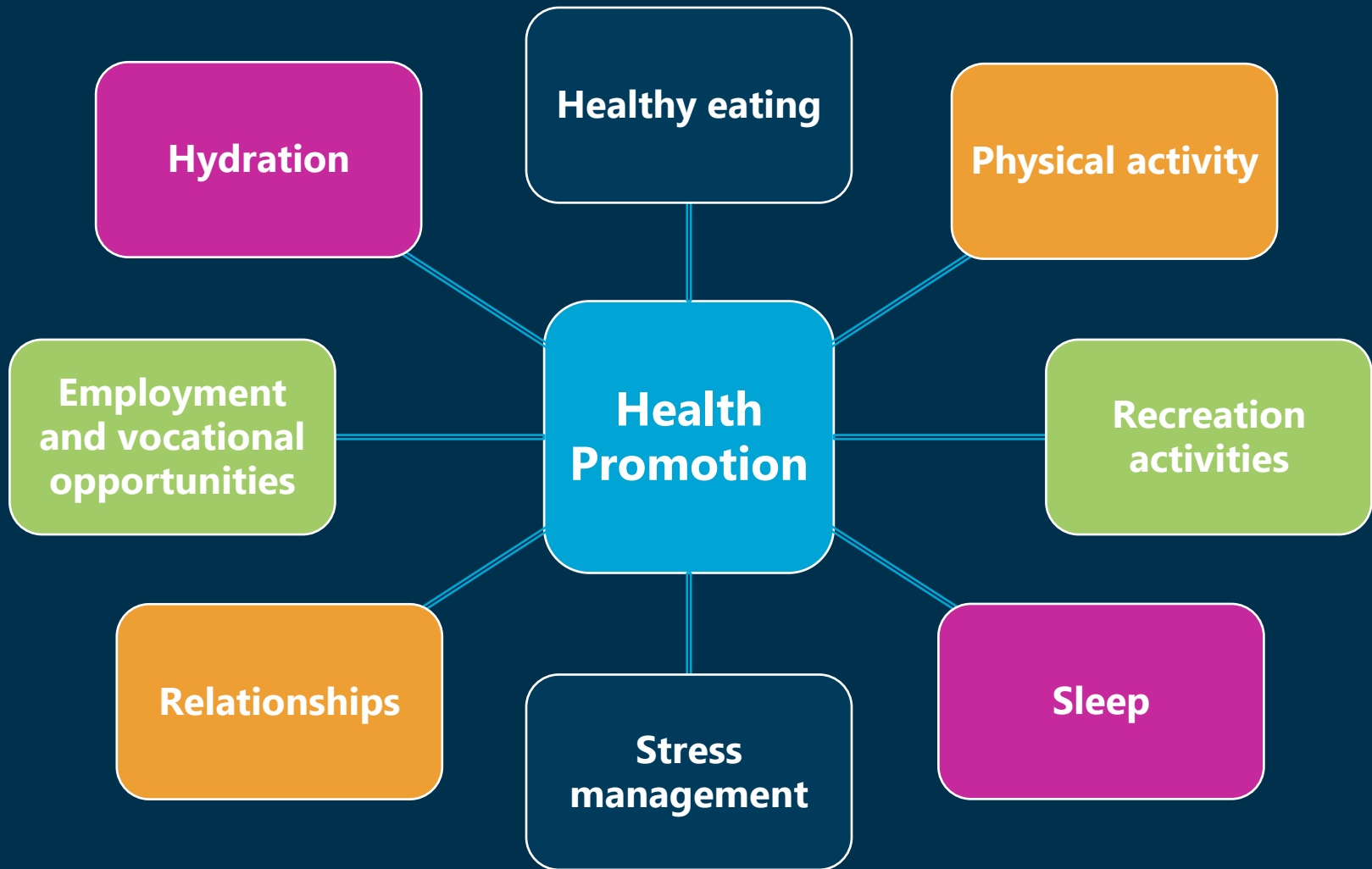
Pain

Healthy Aging

Promoting healthy aging

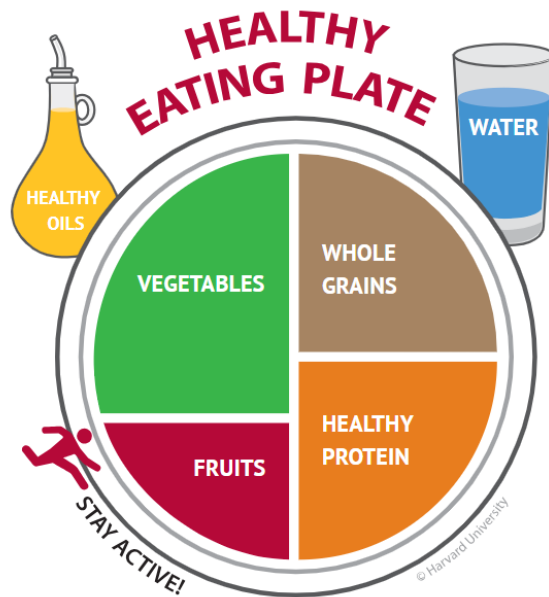
- Includes optimizing physical, mental, and social health
- Health promotion
- Medical care





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
 - Smoothies, pasta, soup, 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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HYDRATION

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



Tips

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

WHAT TO DRINK INSTEAD OF POP/SODA



★ WATER ★



SPARKLING / FLAVORED WATER

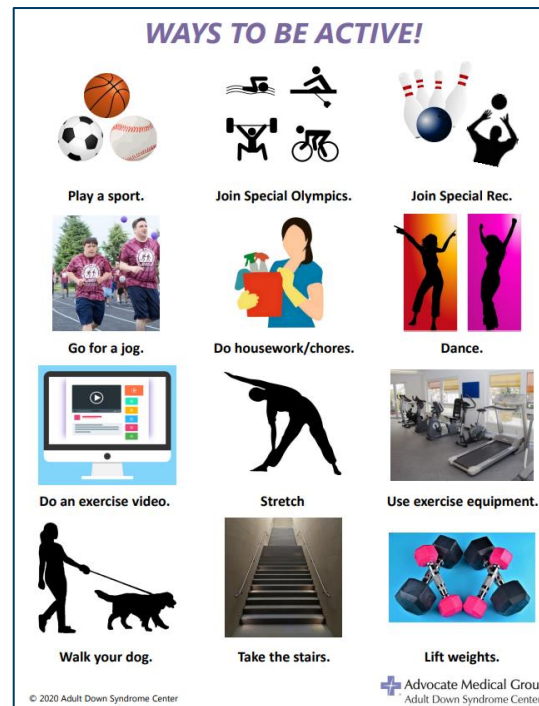


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PHYSICAL ACTIVITY

- 30 minutes, 5 or more days per week
- Many benefits
- Preferences may change with age



Tips

- Make it fun
- Be active throughout the day
- Incorporate a variety of types of physical activity (aerobic, strength, stretching)

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

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

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

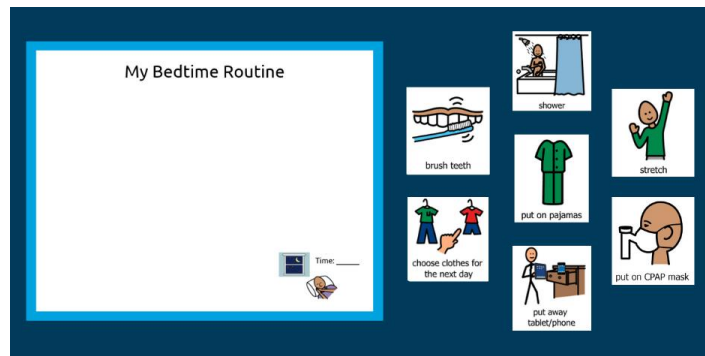
SLEEP

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



Tips

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



MENTAL STIMULATION

- Paid or volunteer work
- Games, puzzles, activities

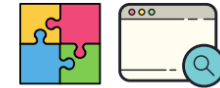
ACTIVITIES TO AVOID BOREDOM & HAVE FUN!

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

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



SOCIAL ENGAGEMENT

- Family, friends, housemates
- Recreation activities



Tips

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



MENTAL WELL-BEING

- Stress management
- Life stressors associated with aging
- Empathy radar





Tips

- Practice stress management techniques
- Work with a mental health provider
 - Consider therapies (talk, music, art, etc.)


Strategies To Help Me Calm Down


CALM BREATHING

 pretend to smell a flower to inhale


 pretend to blow out a candle to exhale


CALM THOUGHTS

 squeeze hands


 count to ten

CALM MUSCLES

 be stiff like a statue

 be loose like an inflatable man

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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.



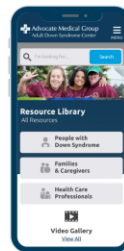
find out more at:
DSMIG-USA.ORG

Adult Down Syndrome Center

- [Resource Library](#)
- [Email List](#)
- [Facebook](#)
- [Instagram](#)

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

Facebook & Instagram



[@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](#)

[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](#)

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



Resource lists by topic

[Alzheimer's Disease and Dementia](#)

[Decline in Skills and Regression](#)

[Nutrition and Weight](#)

[Self-Care and Hygiene](#)

[Sensory](#)

[Sleep](#)

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