Healthy Aging in Adults with Down Syndrome

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Objectives

- Identify similarities and differences in aging of adults with Down syndrome compared to adults without Down syndrome.
- Discuss challenges 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.

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Aging

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

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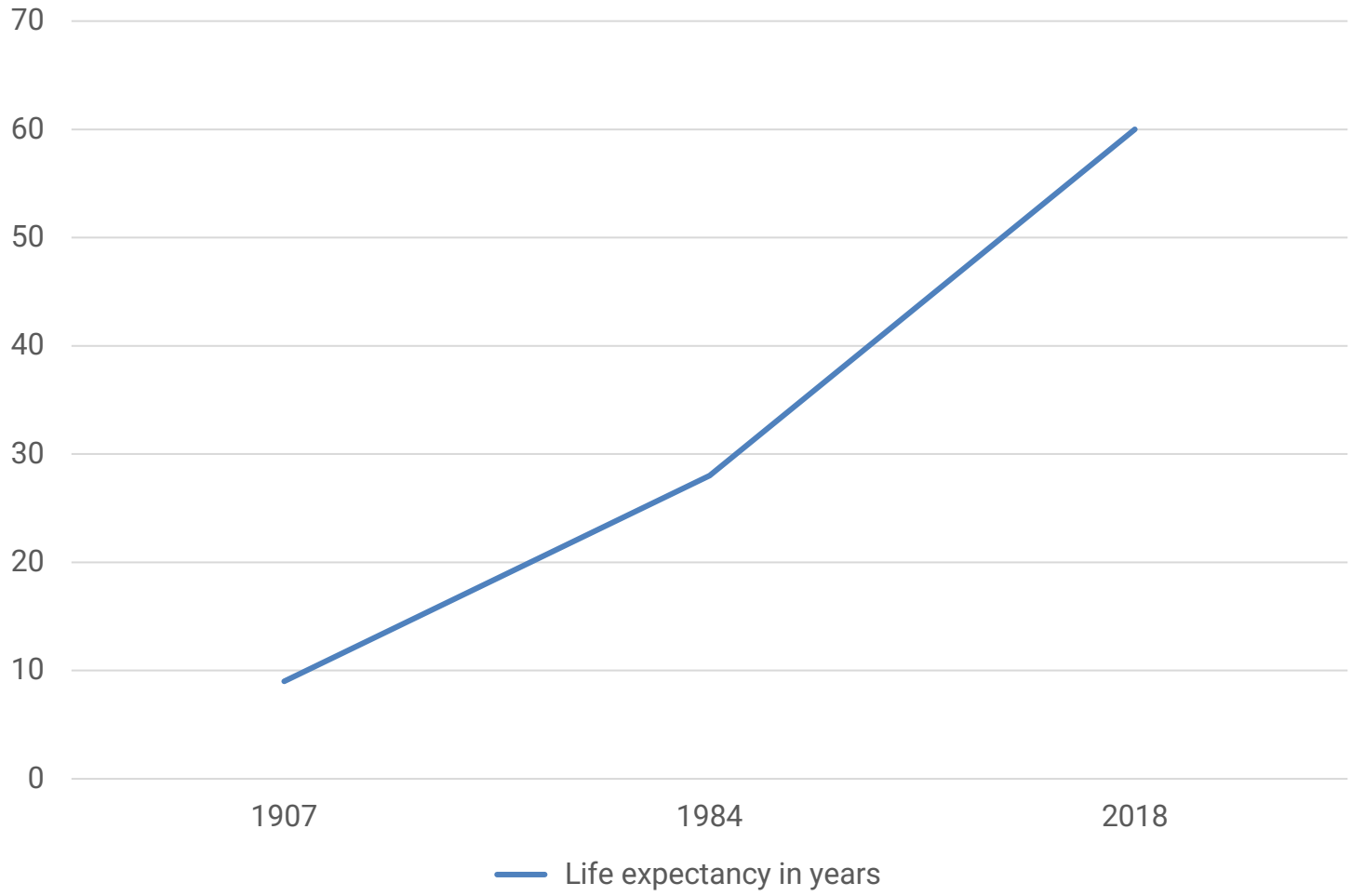
Life expectancy in years



Bittles et al. 2004, Coppus et al. 2008, Glasson et al. 2002, Zhu et al. 2013

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Aging similarities

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

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Aging differences

- Earlier aging
- Living arrangements
- Common health conditions
  - Cataracts
  - Osteoarthritis
  - Hearing

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Alzheimer's disease (AD)

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Overview of AD

- Progressive neurological condition
- Is a type of dementia
- Plaques and tangles = microscopic changes of the brain consistent with AD

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By age 40, nearly all people with Down syndrome have the brain pathology of AD.

Mann 1988, Hartley et al. 2014

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HOWEVER, symptoms of AD are uncommon before age 40.

Tsou et al. 2020

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Prevalence

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

McCarron et al. 2017, Sinai et al. 2018, Fortea et al. 2020

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Age of diagnosis

- Mean: about 55 years
- Median: about 54 years

McCarron et al. 2017, Sinai et al. 2018, Fortea et al. 2020

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Why is AD so common?

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

Zis & Strydom 2018, Lai et al. 2021, Tournissac et al. 2021

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Symptoms

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

Ballard et al. 2016, Altuna et al. 2021, Menendez 2005

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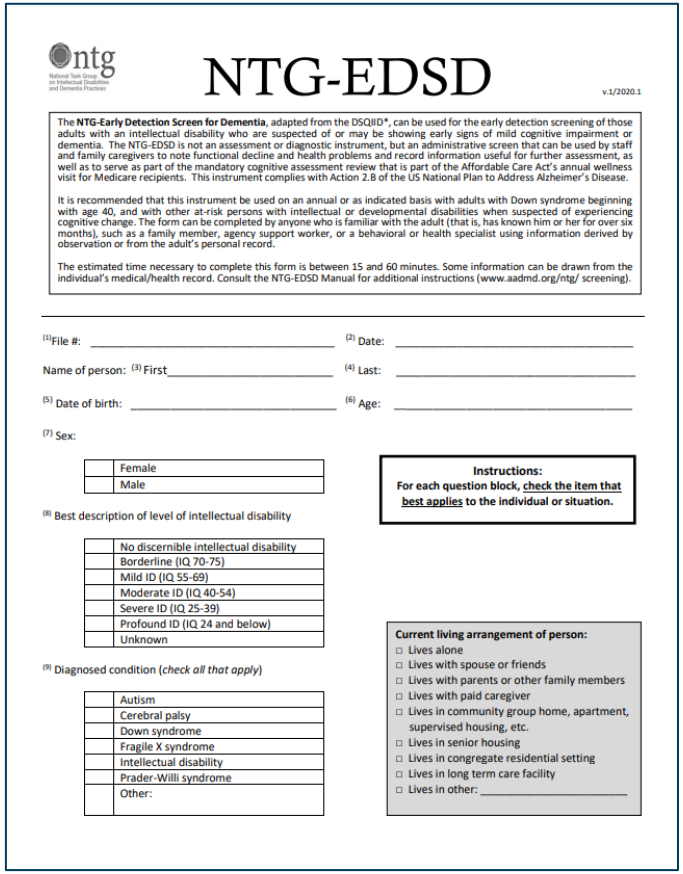
Diagnosis

History and physical exam	Neuro-psychological testing	Imaging
• Rule out other causes	• Limitations	• MRI? CT?

Diagnosis

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



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

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

(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

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: _____

(9) Diagnosed condition (*check all that apply*)

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

[NTG-EDSD]

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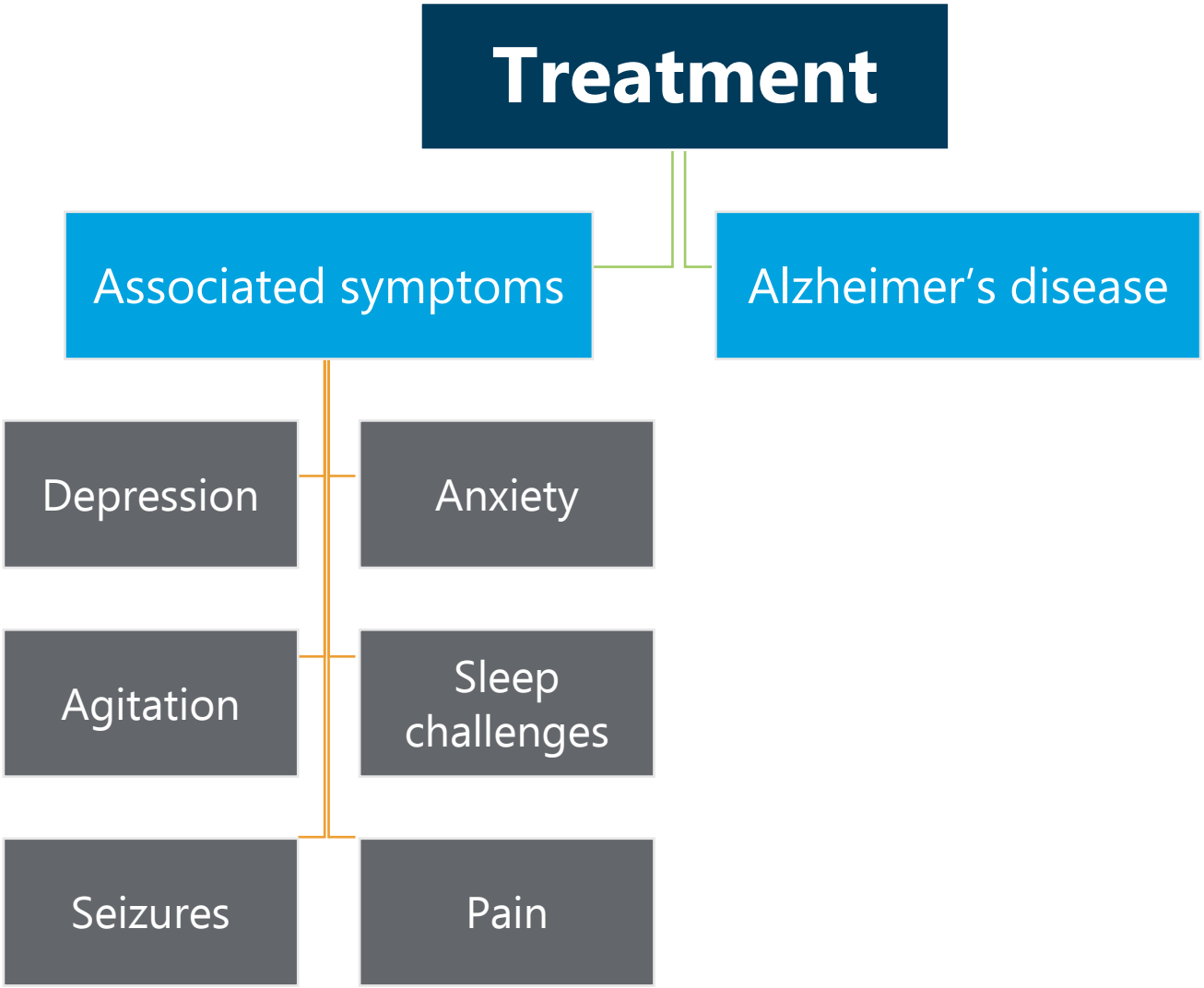

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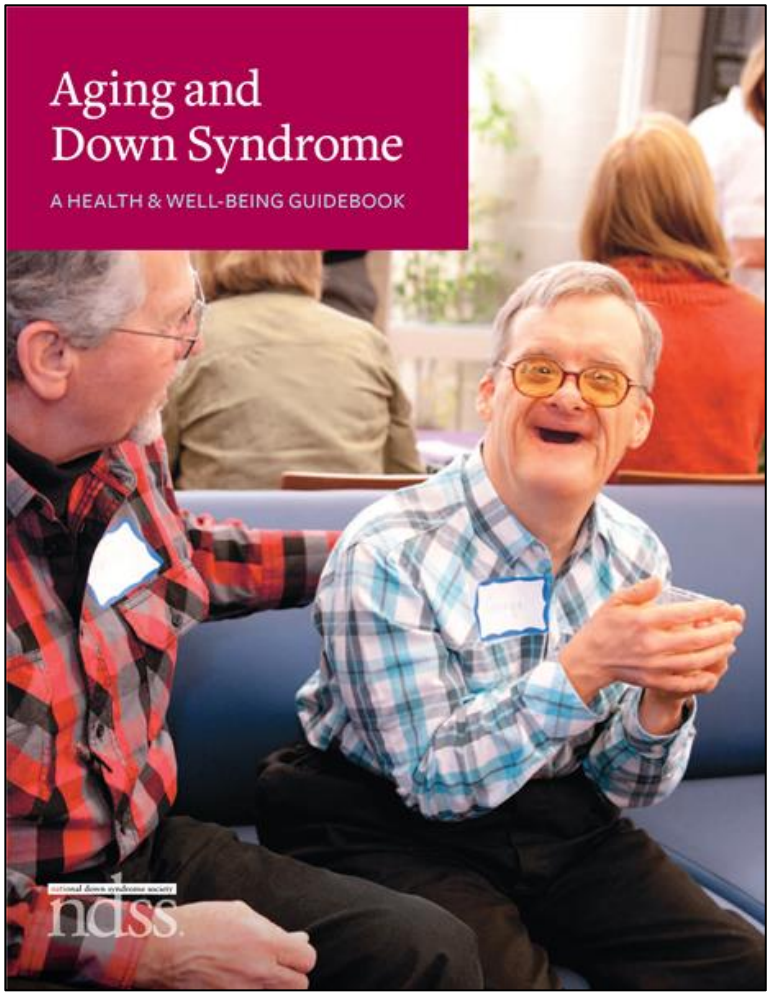

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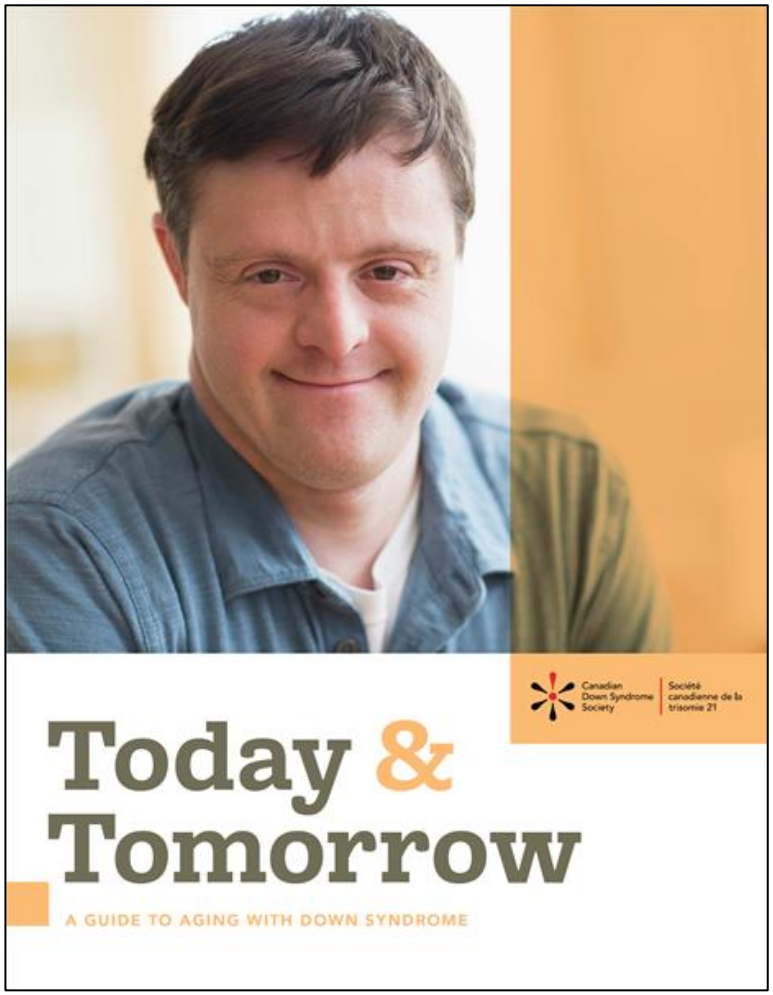

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Promoting healthy aging

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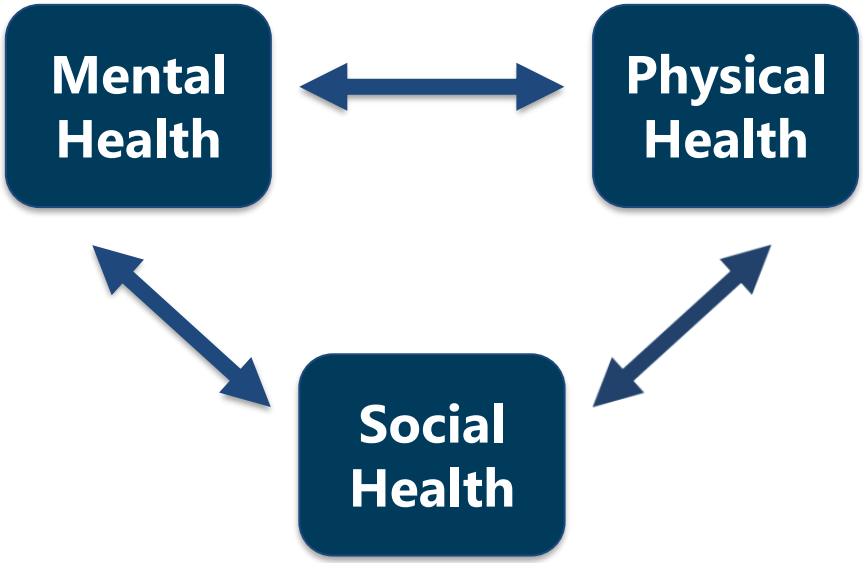
Health



- Optimize physical, mental, & social health
  - Health promotion strategies
  - Medical care

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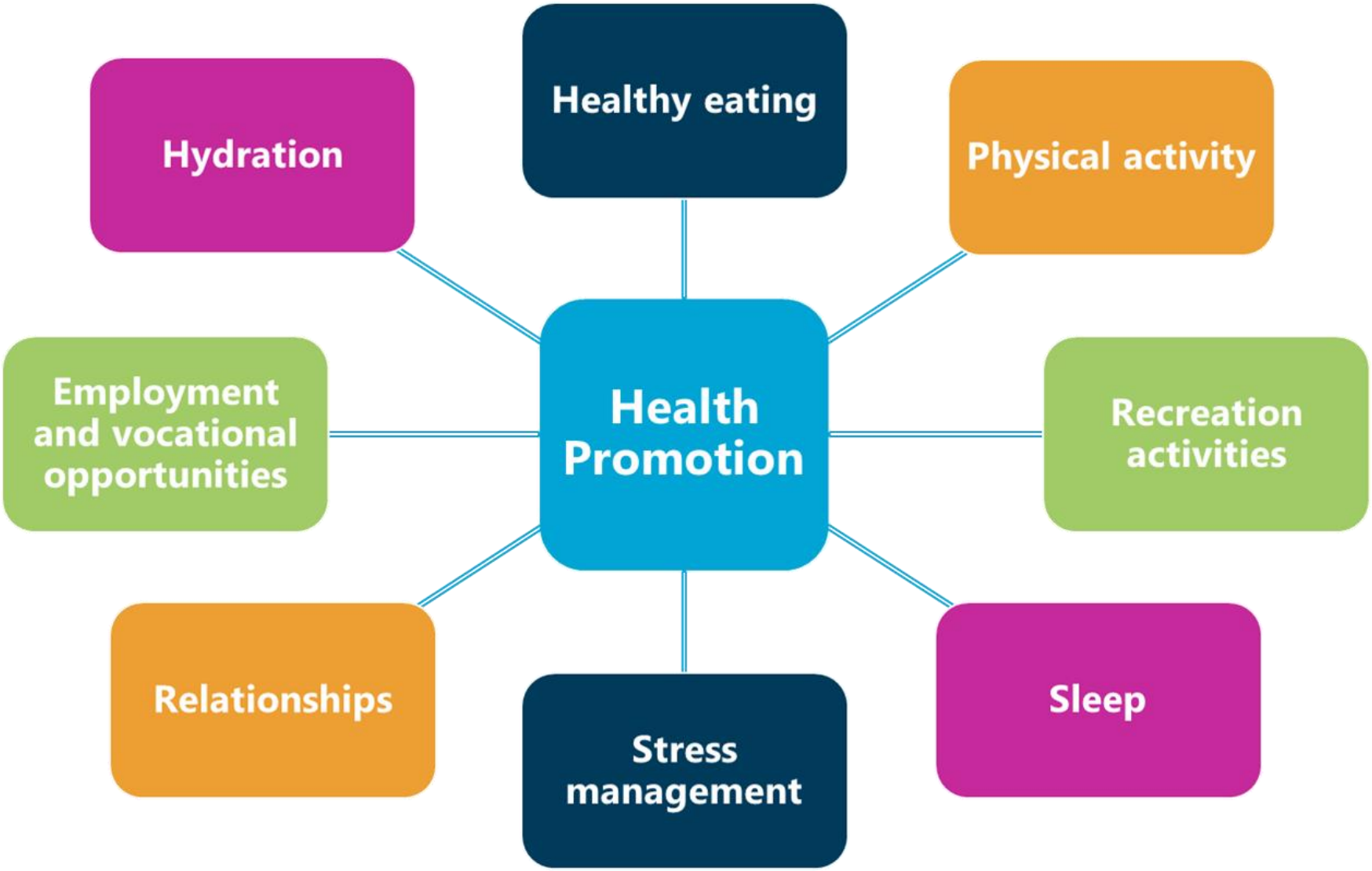
Hydration
Healthy eating
Physical activity
Employment and vocational opportunities
Health Promotion
Recreation activities
Relationships
Stress management
Sleep

Healthy eating

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

Nianogo et al. 2022, Agarwal et al. 2023

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Tips

- Avoid processed foods
- Add green, leafy vegetables to meals
  - Smoothies, pasta, soup, eggs
- Make food swaps
  - E.g., grilled instead of fried food

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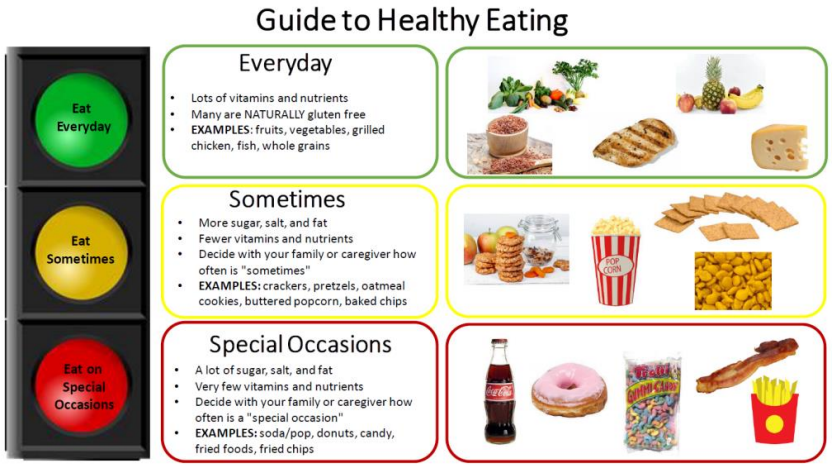
Resources

- [Nutrition and weight]



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Hydration

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

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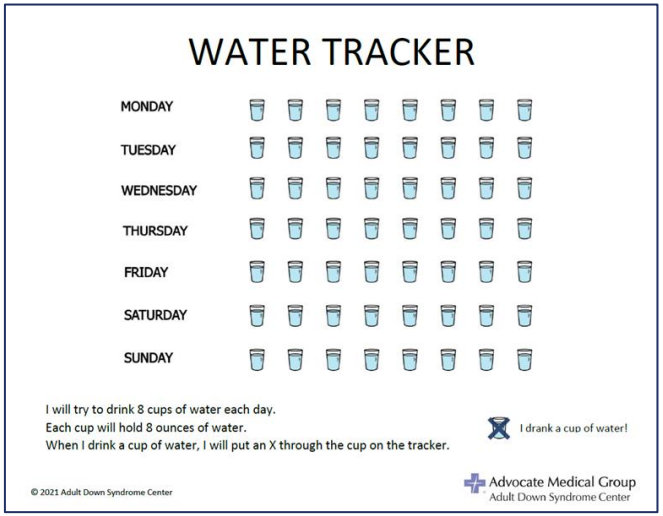
Tips

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

Resources

- Tips for Staying Hydrated



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Physical activity

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

De la Rosa et al. 2020, Nianogo et al. 2022

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Tips

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

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Resources

- Exercise and physical activity

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Sleep

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

Lao et al. 2022

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Tips

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

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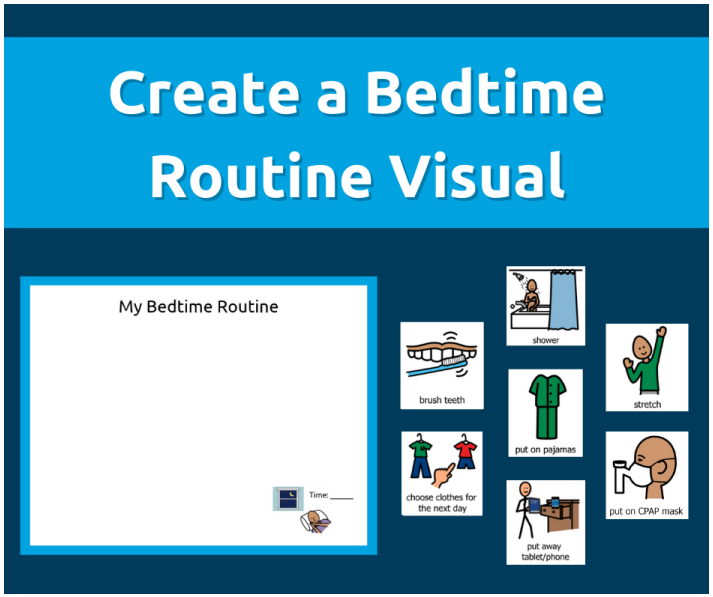
Resources

- Sleep



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Mental stimulation

- Paid or volunteer work
- Games, puzzles, activities

Nianogo et al. 2022

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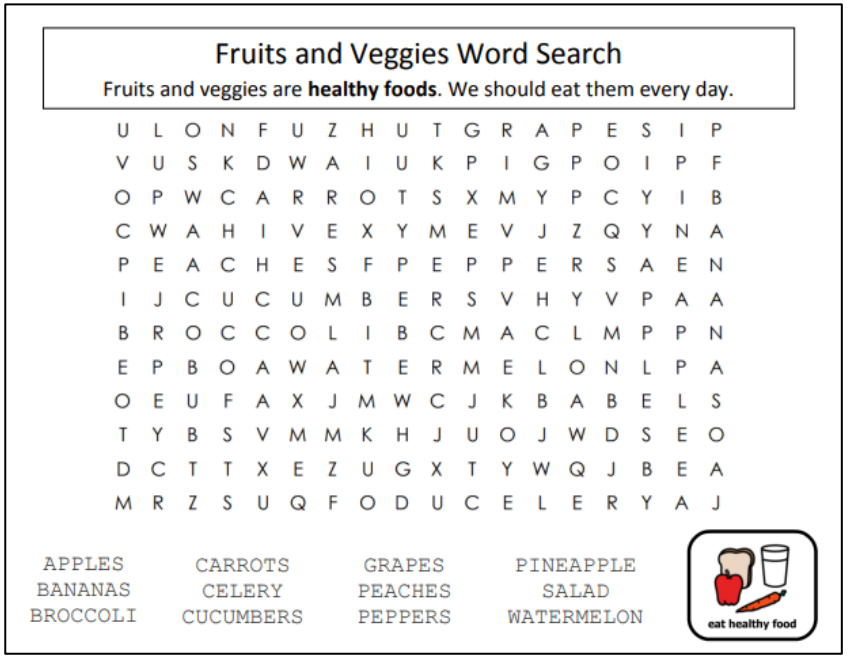
Tips

- Change the activities as an individual ages

Resources

- Activities You Can Do at Home
  - Suggestions for arts and crafts, cooking, education/learning, fitness and physical activity, games
- Therapeutic Use of Games



Fruits and Veggies Word Search

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

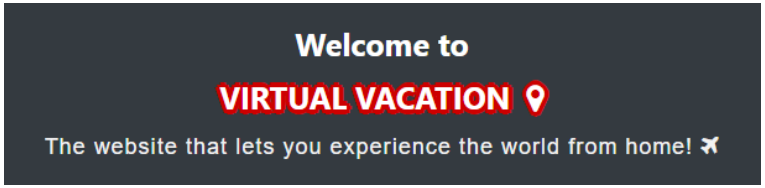
U	L	O	N	F	U	Z	H	U	T	G	R	A	P	E	S	I	P
V	U	S	K	D	W	A	I	U	K	P	I	G	P	O	I	P	F
O	P	W	C	A	R	R	O	T	S	X	M	Y	P	C	Y	I	B
C	W	A	H	I	V	E	X	Y	M	E	V	J	Z	Q	Y	N	A
P	E	A	C	H	E	S	F	P	E	P	P	E	R	S	A	E	N
I	J	C	U	C	U	M	B	E	R	S	V	H	Y	V	P	A	A
B	R	O	C	C	O	L	I	B	C	M	A	C	L	M	P	P	N
E	P	B	O	A	W	A	T	E	R	M	E	L	O	N	L	P	A
O	E	U	F	A	X	J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

CARROTS
CELERY
CUCUMBERS

GRAPES
PEACHES
PEPPERS

PINEAPPLE
SALAD
WATERMELON



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Social engagement

- Family, friends, housemates
- Recreation activities

Nianogo et al. 2022

Tips

- Change the frequency, length as an individual ages

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Resources

- Local Down syndrome organization
- Best Buddies
- Park district, library

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Mental well-being

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

Nianogo et al. 2022

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Tips

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

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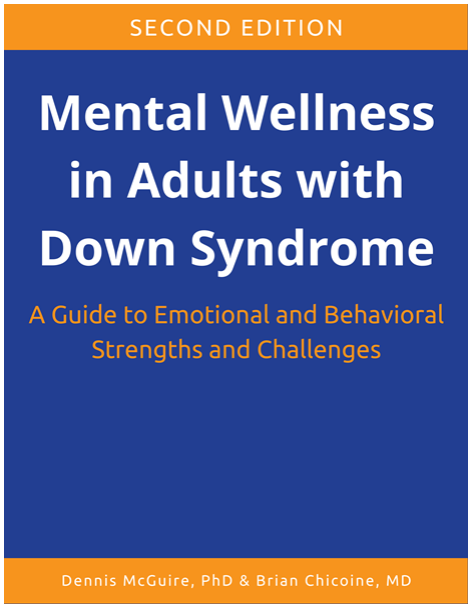
Resources

- Mental Health



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Medical care

- Frequency
- Observe and share history
- Screenings

Resources

- My Health Passport

My Health Passport

If you are a *health care professional* who will be helping me,
PLEASE READ THIS
before you try to help me with my care or treatment.

My full name is: _____
I like to be called: _____
Date of birth: ___/___/_____
My primary care physician: _____
Physician's phone number: _____

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

My signature: _____ Date completed: ___/___/_____

You can talk to this person about my health: _____

Phone number: _____ Relationship: _____

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/ support is needed)

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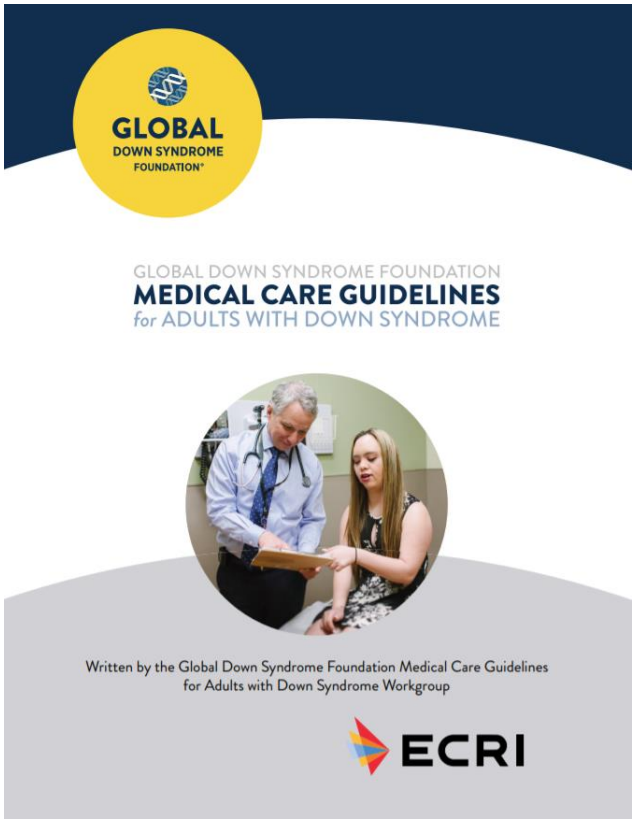
Resources

- [GLOBAL Medical Care Guidelines for Adults with Down Syndrome]



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Resources

[Down Syndrome Medical Interest Group Project ECHO]

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Takeaways

- Alzheimer's disease is more common in people with Down syndrome.
- There are many lifestyle choices that adults with Down syndrome can make to be healthy as they age and potentially prevent or delay Alzheimer's disease.
- So much is being learned!!

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Resource Library:
adscresources.advocatehealth.com

Facebook:
facebook.com/adultdownsyndromecenter

Email Newsletter:
eepurl.com/c7uV1v

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Health & Wellness Learning Session: NIH

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Why We Advocate

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"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." - Margaret Mead

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People with Down Syndrome Have a Radically Different Disease Spectrum

Cancer

Heart disease

Coronary Artery Disease
Atherosclerosis Hypertension
Angiopathies

Alzheimer's

Autoimmunity

Autism
Epilepsy, Infantile Spasms
Congenital Heart Defects
Autoimmune Disorders: Celiac, Hashimoto's, T1D, Vitiligo, Alopecia Areata, etc Vision Problems
Hearing Problems
Intestinal Atresia
Sleep Apnea

The ~400,000 Americans with trisomy 21 may hold the key to major medical conditions

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A Life-Threatening Disparity of Research Funding at NIH

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Year	NIH Budget (Millions)	CF Research Funding	Fragile X Research Funding	Autism Research Funding	Ds Research Funding	Ds Research Fundingto NIH Budget
2000	17,840				27	0.0015
2001	20,459				29	0.0014
2002	23,321				28	0.0012
2003	27,166				23	0.0008
2004	28,037				19	0.0007
2005	28,594				15	0.0005
2006	28,560				14	0.0005
2007	29,178				16	0.0006
2008	29,607				17	0.0006
2009	30,545				18	0.0006
2010	31,238				22	0.0007
2011	30,916				20	0.0006
2012	30,860	86	27	192	20	0.0006
2013	29,129	78	30	186	18	0.0006
2014	30,019	77	36	186	18	0.0006
2015	30,293	80	38	208	24	0.0008
2016	30,293	83	40	216	25	0.0008
2017 Est	30,293	83	40	216	25	0.0008

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The CRITICAL & TIMELY Need

A Population Explosion & A Eugenics Framework

- **There is a population explosion of people with Down syndrome in the U.S. that requires dramatically *more* funding not less**

  Population – is over 400,000

  Live Births – have increased to 1 in 691 today from 1 in 1,000 in 2002

  Lifespan – has more than doubled to 60 years from 28 years in the 1980s

  A Mini Population Explosion – will happen over the next several decades due to increased live births and lifespan

  Societal Trends – include a small but growing number of people with Down syndrome participating in college programs, choosing to get married, and living independently or semi-independently

- **There is a "eugenics framework" in countries like Iceland and Denmark…**

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National Heart Lung and Blood Institute

Lower risk of heart disease and higher risk of congenital heart defects

NIH National Institute on Aging

Significantly elevated risk for early-onset Alzheimer's

National Cancer Institute

Protected from solid tumor cancers and greater risk for blood cancers

National Institute of Neurological Disorders and Stroke

Much lower risk of stroke

National Institutes of Health:

Down syndrome offers research opportunities across many of the 27 Institutes and Centers

Eunice Kennedy Shriver NICHD
National Institute of Child Health & Human Development

Large pediatric population and unique pattern of development

National Human Genome Research Institute

Most prevalent chromosomal disorder

National Eye Institute
National Institutes of Health

>60% have vision problems

NIMH National Institute of Mental Health

~30% experience mental illnesses such as depression or OCD

NIDCD
National Institute on Deafness and Other Communication Disorders

>70% have hearing problems

NIH National Institute of Diabetes and Digestive and Kidney Diseases

Much greater risk of diabetes

NIAMS
National Institute of Arthritis and Musculoskeletal and Skin Diseases
NATIONAL INSTITUTES OF HEALTH

High rate of dermatological disorders and arthritis

National Institute of Allergy and Infectious Diseases

Unique pattern of immune dysregulation

NIAAA National Institute on Alcohol Abuse and Alcoholism

National Institute of Nursing Research

National Institute of General Medical Sciences

NIEHS National Institute of Environmental Health Sciences

NIH National Institute on Drug Abuse

National Library of Medicine

NIH National Institute of Dental and Craniofacial Research

National Institutes of Health Fogarty International Center

NIH National Center for Advancing Translational Sciences

NIMHD National Institute on Minority Health and Health Disparities

NIH Clinical Center America's Research Hospital

NIBIB National Institute of Biomedical Imaging and Bioengineering

center for scientific review

CIT Center for Information Technology

NIH National Center for Complementary and Integrative Health

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What is INCLUDE?

- INCLUDE (**IN**vestigation of **C**o-occurring conditions across the **L**ifespan to **U**nderstand **D**own syndrom**E**) Project Research Plan

- *"Down syndrome. The agreement directs the NIH Director to develop a new trans-NIH initiative – involving, at a minimum, NICHD, NIA, and NCI – to study trisomy 21, with the aim of yielding scientific discoveries to improve the health and neurodevelopment of individuals with Down syndrome and typical individuals at risk for Alzheimer's disease, cancer, cardiovascular disease, immune system dysregulation, and autism, among others. This initiative shall bring together research results that will be available to academic researchers, nonprofit organizations, and industry researchers. Funding for this trans-NIH initiative will supplement, not supplant, existing NIH funding levels for Down syndrome research."*

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What Research is INCLUDE funding?

Applying the expertise and resources from multiple NIH Institutes and Centers, INCLUDE will:

- **Conduct targeted, high-risk, high-reward basic science studies on chromosome 21.** Past research has shed light on the complex biology that results in three copies of chromosome 21 (trisomy 21) present in individuals with Down syndrome compared to the usual matched pair. Increased funding toward basic research on chromosome 21 will improve understanding of the biology of Down syndrome and support development of new treatments for health conditions experienced by individuals with Down syndrome. With advances in technology, researchers can further explore the effects of multiple genes on chromosome 21 and identify genetic pathways that may be most responsive to new therapies.
- **Assemble a large study population of individuals with Down syndrome.** A large study population, called a cohort, of individuals with Down syndrome is essential for following development of the condition over time and fully characterizing condition traits at different stages of development. Several smaller cohorts composed of this population currently exists. INCLUDE aims to connect these existing cohorts and enroll new participants at different ages to create one large cohort to study the full range of conditions experienced by individuals with Down syndrome across the lifespan. INCLUDE will supplement extensive data collected from the cohort with information from registries and other data sources to provide a rich resource for studying the condition more broadly.
- **Conduct clinical trials research inclusive of individuals with Down syndrome.** Currently, there are numerous clinical trials that study conditions and diseases that disproportionately affect individuals with Down syndrome but exclude this population from participation. Additionally, there are few clinical trials focused primarily on individuals with Down syndrome despite their relative frequency in the general population. INCLUDE will identify clinical trials that seek to address conditions common in the Down syndrome population and bolster recruitment and inclusion of people with Down syndrome, develop meaningful standards for inclusivity of individuals with Down syndrome in trials, and establish measures specific to individuals with Down syndrome for evaluating clinical success. These efforts should support development of new and existing therapies for co-occurring conditions in Down syndrome and establish a clinical trial infrastructure to support trials of these therapies.

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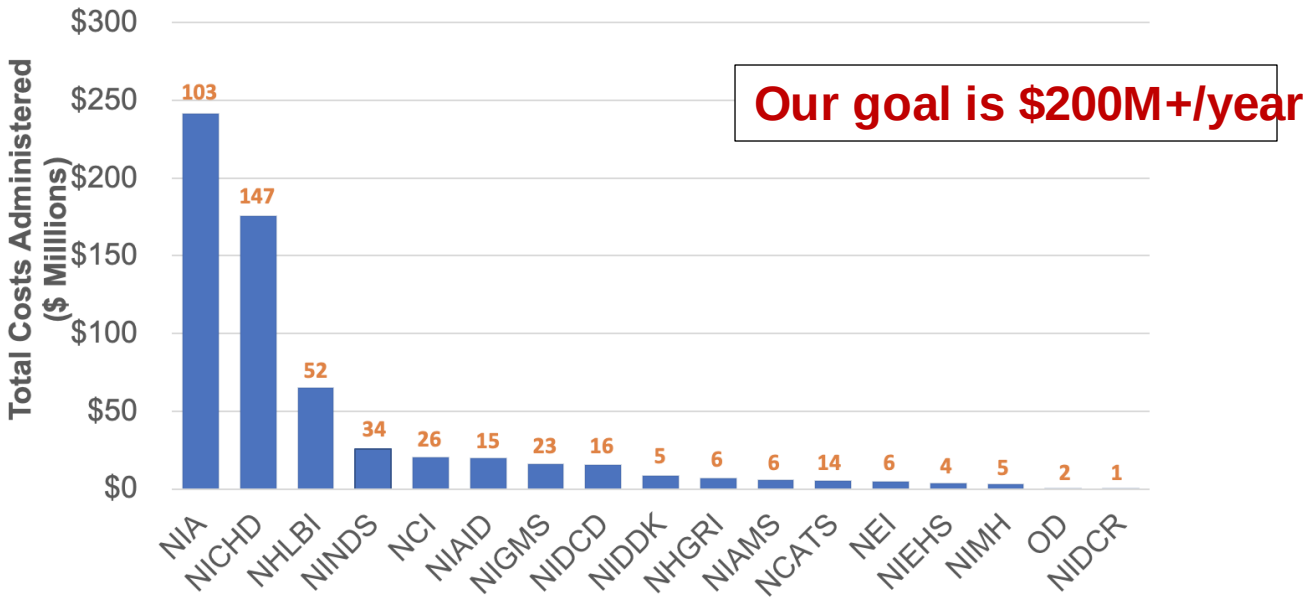
Our Advocacy is Working!
But We Still Have Work To Do…

$200M+ of NEW NIH DS funding over five years! FY2023 $130M Anticipated

465 unique awards involving 17 Institutes



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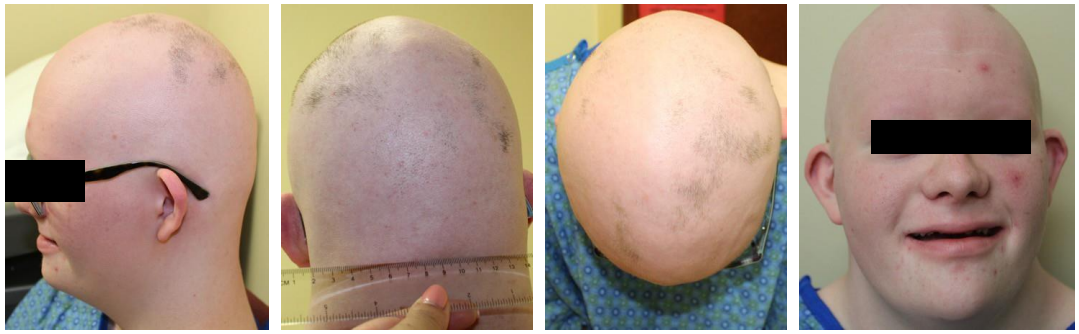
Elongating Life & Improving Health Outcomes *is* Achievable

NIH INCLUDE-FUNDED CLINICAL TRIAL TREATING ALOPECIA AREATA IN PATIENTS WITH DOWN SYNDROME

Baseline
SALT = 86



Week 16
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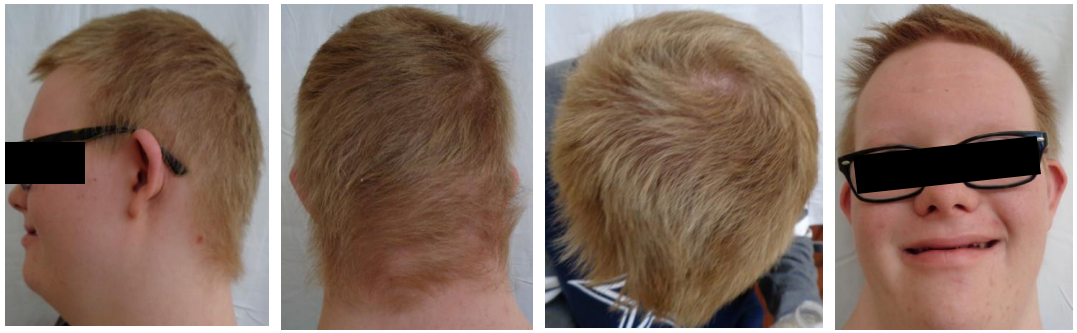

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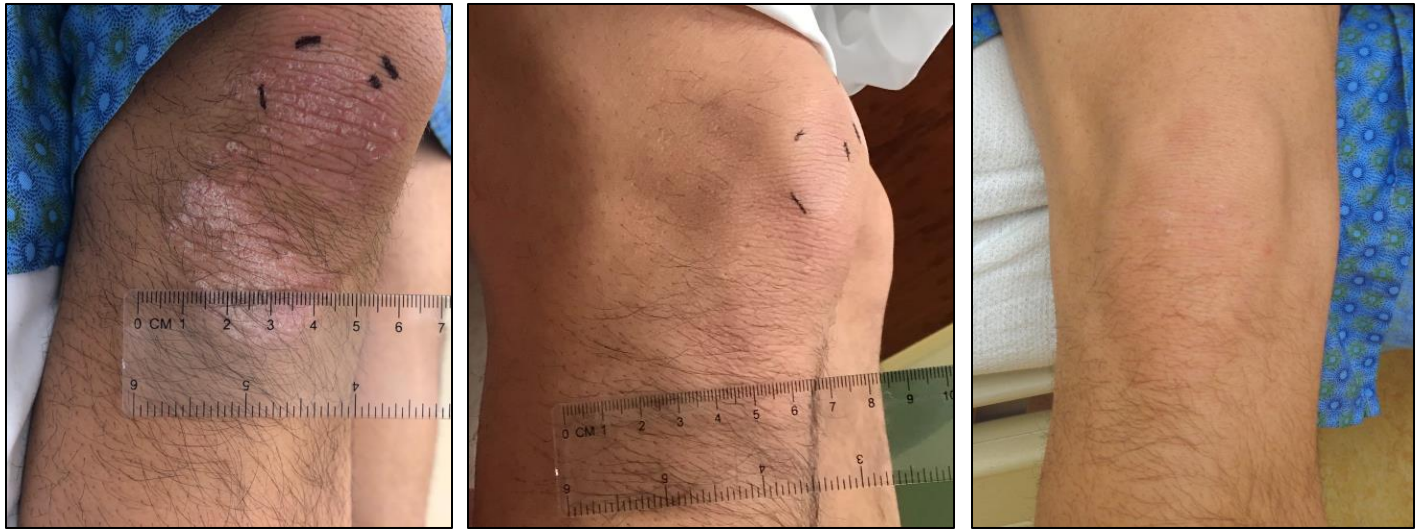
Elongating Life & Improving Health Outcomes *is* Happening!

NIH INCLUDE-FUNDED CLINICAL TRIAL TREATING PSORIATIC ARTHRITIS



Screening | Week 8 | Week 16

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Thank YOU! And To Our Hosts NDSS!

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Health & Wellness Learning Session: NAPA

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Kevin Brennan, GLOBAL DC Team
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National Alzheimer's Project Act (NAPA)

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- In 2010/2011, Congress passed and President Obama signed into law the National Alzheimer's Project Act (NAPA)
  - Sens. Evan Bayh (D-IN), Susan Collins (R-ME) & 32 Cosponsors
  - Reps. Ed Markey (D-MA), Chris Smith (R-NJ) & 110 Cosponsors
- 1st National Plan to Address Alzheimer's Disease, with the goal of preventing and effectively treating Alzheimer's by 2025
- Legislative Authorization ends December 31, 2025

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NAPA Legislative Summary

- Establish integrated national plan to overcome Alzheimer's
- Provide information and coordination of Alzheimer's research and services across all federal agencies
- Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's
- Improve the early diagnosis of Alzheimer's disease and coordination of the care and treatment of citizens with Alzheimer's
- Ensure the inclusion of ethnic and racial populations at higher risk for Alzheimer's, or least likely to receive care for Alzheimer's, in clinical, research, and service efforts with the purpose of decreasing health disparities in Alzheimer's
- Coordinate with international bodies to integrate and inform the fight against Alzheimer's globally

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NAPA Advisory Council on Alzheimer's Research, Care, and Services

- Establishes an Advisory Council on Alzheimer's Research, Care, and Services to advise the Secretary and Congress on:
  - All federally -funded efforts in Alzheimer's research, clinical care, and institutional-, home-, and community-based programs and their outcomes
  - Recommendations for priority actions to expand, eliminate, coordinate, or condense programs based on their performance, mission, and purpose
  - Initial recommendations to improve health outcomes and reduce the financial impact of Alzheimer's on Medicare and other federally-funded programs and on families living with Alzheimer's disease
  - Annual evaluation of the implementation and outcomes of the recommendations through an updated national plan

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Related Alzheimer's Legislation

- Alzheimer's Accountability Act, bipartisan legislation passed in 2014
- Requires NIH to submit an annual Alzheimer's research budget directly to Congress
- NIH has established 171 milestones across 16 areas of research, including drug development, biomarkers, non-pharmacological interventions, and clinical trail recruitment

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NAPA Reauthorization Act

- NAPA Reauthorization Act (H.R.619/S.133)
  - Reps. Paul Tonko (D-NY), Chris Smith (R-NJ) & 8 Cosponsors
  - Sens. Susan Collins (R-ME), Mark Warner (D-VA), & 11 Cosponsors
    - ** 7 Senate Original Cosponsors
- Focus on healthy aging and reducing risk factors associated with cognitive decline
- Adds new members to Advisory Council on Alzheimer's Research, Care, and Services to include a researcher with experience recruiting and retaining diverse clinical trial participants, an individual diagnosed with Alzheimer's disease, and representatives from additional federal agencies (DoJ & OMB)
- Extends NAPA authorization through 2035

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