

Supporting People with Down Syndrome in Their Health Journeys

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Medical
Group

Adult Down
Syndrome Center
1610 Luther Lane





Objectives


- Explain changes in the health and health promotion of people with Down syndrome over time
- Describe common characteristics of people with Down syndrome.
- Discuss concepts that are important to consider when supporting people with Down syndrome.
- Share resources that can be used by adults with Down syndrome and those who care for, work with, and support them.

Resource Library





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I'm looking for... 


MENU 


Resource Library | All Resources





 **People with Down Syndrome**




 **Families & Caregivers**




 **Health Care Professionals**




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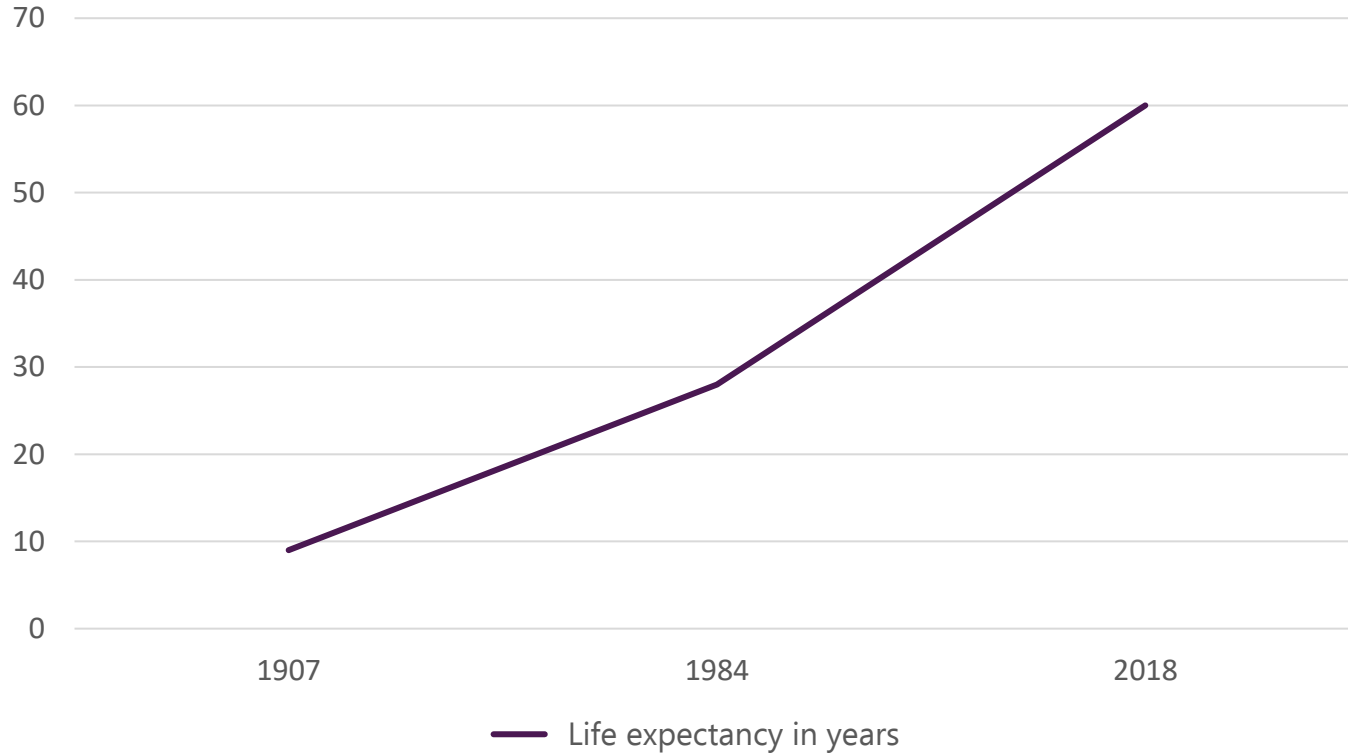
<https://adsresources.advocatehealth.com/>

Please note:

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

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

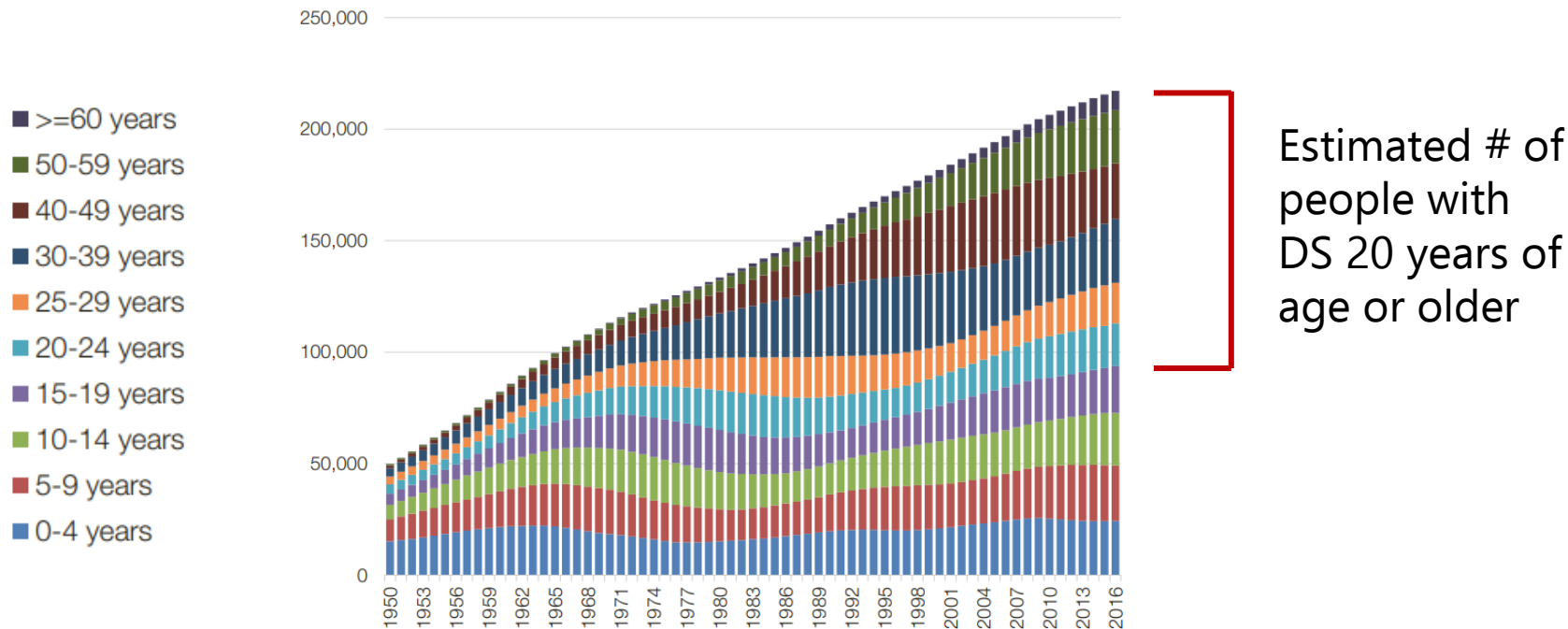


Figure 5. Population of people with Down syndrome in the USA, 1950-2016

A look at the past...

Then (1992)



Now (2025)



Then (1992)

- Healthcare
 - Lack of physicians:
 - Knowledgeable about health of **adults** with Down syndrome
 - Treated people with Down syndrome with dignity and respect
 - Something done **for** or **to** adults with Down syndrome
- Inclusion
 - Mostly in schools

Now (2025)

- Healthcare
 - Lack of physicians:
 - Knowledgeable about health of **adults** with Down syndrome
 - Treating people with Down syndrome with dignity and respect
 - Something done **with** adults with Down syndrome
- Inclusion
 - Throughout society

What have we learned?

Common characteristics of many (but not all) people with Down syndrome

**Each person with
Down syndrome
is unique.**

**Many people with
Down syndrome
share common
characteristics.**

Physical

- Almond-shaped eyes that slant up
- Short neck
- Small ears
- Small hands and feet
- A single line across the palm of the hand (palmar crease)
- Shorter in height
- Lower heart rate, lower blood pressure

Cognitive

- Mild to moderate to severe intellectual disability
- Better receptive language than expressive language
- Concrete thinking
 - Difficulty with abstract concepts (e.g., time)
- Visual memory

Behavioral

- Self-talk and imaginary friends
- The “Groove”
- Empathy radar

THE “GROOVE”

The “groove” is a preference for **sameness, repetition, and routine.**

Possible Advantages

The groove can...

- Give structure and order to daily life
- Support successful completion of tasks
- Increase independence
- Help manage stress

Possible Disadvantages

The groove can make it difficult to...

- Be flexible
- Transition from one task to the next
- Deal with changes
- Apply skills across different settings

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Health conditions

More common and/or common

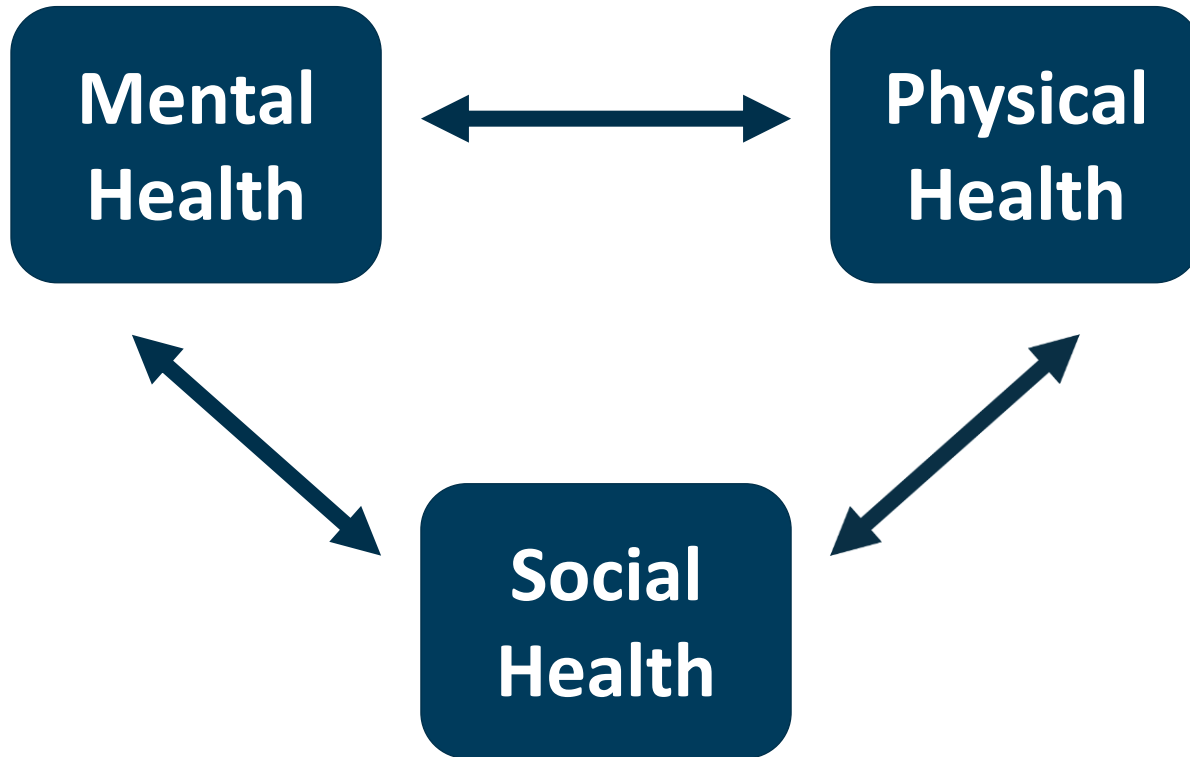
- Thyroid disorders
- Anxiety
- Obsessive-compulsive disorder
- Depression
- Obesity
- Pneumonia
- Swallowing dysfunction
- Skin conditions (e.g., folliculitis)
- Gum disease
- Gastroesophageal reflux (GERD)
- Celiac disease
- Constipation
- Seizures
- Atlantoaxial instability
- Vision and hearing problems
- Sleep apnea
- Congenital heart disease
- Alzheimer's disease

Less common and/or uncommon

- Many solid tumor cancers
- Atherosclerotic disease ("hardening of the arteries," plaques in the arteries)
- Myocardial infarctions (heart attacks)
- Hypertension (high blood pressure)

Pain

- People with Down syndrome experience pain.
 - Some people with Down syndrome report it less often than people without Down syndrome.
 - May have difficulty localizing pain.
 - May have delayed response to pain.
- Some people with Down syndrome appear to experience greater pain than people without Down syndrome.
- Certain conditions may increase pain perception (e.g., aging, Alzheimer's disease).



**Any and all behavior change
should be viewed as a possible
communication tool.**

Important concepts

Diagnostic overshadowing

- To cause something to seem less important
- The attribution of symptoms to an existing diagnosis rather than a potential co-morbid condition (The Joint Commission)
- Co-occurring conditions
 - Misdiagnosis
 - Underdiagnosis
 - Overdiagnosis

“It’s just Down syndrome.”

Dignity of risk

- Respect for an individual's right to:
 - Make their own decisions
 - Participate in a broad range of desired activities
 - Expose themselves to potential consequences or learning opportunities

**Unrestricted
freedom**

No freedom



**Unrestricted
freedom**

Education

No freedom



Health promotion

"With" instead of "for"

Patient Education and Health Promotion Videos

Appropriate Touch

How to Wash Your Hands

How to Brush Your Teeth

Tips for Being Physically Active

How to Put Your Hair into a Ponytail

Erin's Tips for Living a Healthy Lifestyle

How to Use a CPAP Machine

Tips for Dealing with Stress

Fruits and Veggies

Getting Ear Wax Removed

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MENOPAUSE

Page 1 of 1
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What is Celiac Disease?

I have celiac disease.

That means I should not eat foods with gluten.

Gluten is a part of some foods.

Page 1 of 8
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Recipe for health

Ingredients

- Nutritious food
- Physical activity
- Sleep
- Stress management
- Meaningful activities and social connections
- Social skills



Nutritious food

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



Guide to Healthy Eating



The Traffic Light Eating Plan



Physical activity

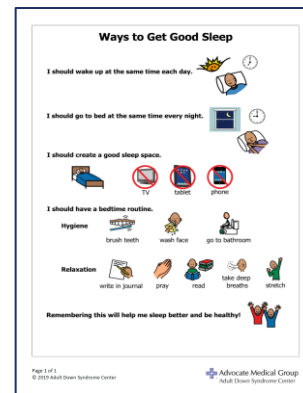
- Build it into the schedule/calendar
- Break it into shorter periods throughout the day
- Make it fun
 - Listen to music
 - Be active with others
 - Turn it into a game



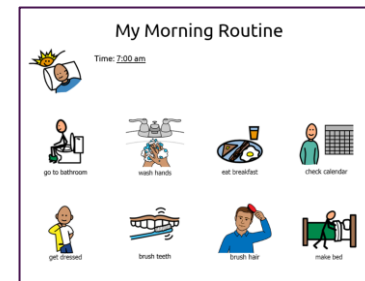
Be Active Throughout the Day

Sleep

- 7-9 hours per night
- Encourage good sleep hygiene
 - Going to bed and waking up at the same time each day
 - Setting up a good sleep space
 - No TV, tablet, or phone
 - Establishing a bedtime routine
 - Hygiene and relaxation
 - Avoiding sugar, caffeine, and alcohol before bed
- Set an alarm for when it is time to start getting ready for bed



Ways to Get Good Sleep



Create a Morning or Bedtime Routine Visual



Stress management

- Identify what stress feels like
- Identify emotions
- Identify “triggers” (causes of stress)
- Calming strategies
 - Counting to 10, taking deep breaths, walking away, coloring
- Coping strategies
 - Reframing thoughts, asking for help, “I” statements
- Anticipate and prepare for life changes
 - Transition out of school, moving, staff changes, siblings going to college, etc.
- Practice during times that are not stressful

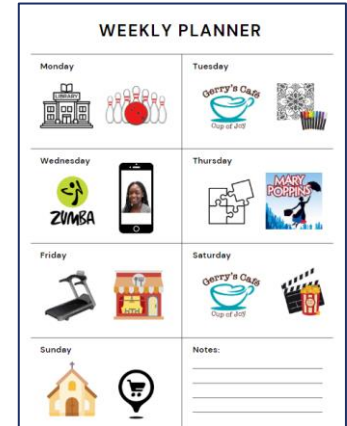


[How to Cope with Stress Resources](#)



Meaningful activities, social connections

- Building community
 - Down syndrome organizations
 - Next Chapter Book Club
 - Theater program
 - Art program
 - Special Olympics
 - Special recreation associations
 - Best Buddies (Best Buddies Citizens, eBuddies)
 - Religious organizations
- Jobs
- Volunteering
- Hobbies
- Relationships
- Support changing interests
- Use calendars and other visuals



Visual schedule
example




Social skills

- Ongoing learning and practice

Relationships


One-Way

- You like a person and want to be friends or romantic partners, but they do not like you or want to be your friend or romantic partner.
- Someone wants to be your friend or romantic partner, but you do not want to be their friend or romantic partner.
- One-way connections do NOT lead to friendships or romantic relationships.



Two-Way

- You like a person and want to be friends or romantic partners with them and that person wants to be your friend or romantic partner too!
- Two-way connections can lead to friendships and romantic relationships.



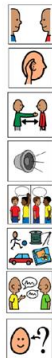
Page 1 of 2
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One-Way and Two-Way Relationships

My Rules for Conversations

- I will look at the person talking.
- I will listen to what others are saying.
- I will maintain good personal space.
- I will speak in a loud and clear voice.
- I will take turns talking.
- I will only talk about appropriate topics.
- I will stay on topic.
- I will ask questions when I am confused.



Page 1 of 2
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Conversation Rules


COMPROMISE

What does it mean?


- Not always getting your way.
- Doing something that is **not** your idea.

Compromise...

- Requires flexible thinking.
- Is a skill that helps us develop & maintain healthy relationships.



Jacob




Cristina


WHAT SHOULD JACOB & CRISTINA DO?

Compromise 1

Do one thing that they both want to do.



Jacob




Cristina

Compromise 2


Do one of their choices this time and the other person's choice the other time.

Time 1



Jacob



Time 2



Cristina

Compromise 3

Decide together to do something that is not either of their first choices.



Jacob AND Cristina

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Compromise

A look at the future...

Looking ahead

Life expectancy and health conditions

- Alzheimer's disease
- Inflammation (interferonopathy)
- Metabolic issues (obesity and related health conditions)

Supporting people with Down syndrome

- Exercise
- Nutrition

Health professionals

- Educating and supporting health professionals to give the care people with Down syndrome desire and deserve.
 - Knowledgeable
 - Dignity and respect

Key points

- Each person with Down syndrome deserves to receive health care from health care professionals who treat them with dignity and respect and are informed about their health needs.
- While each person with Down syndrome is unique, there are some common characteristics.
- Health changes are not “just Down syndrome” and should be evaluated with special attention to the pattern of co-occurring conditions (some more common, some less common).
- People with Down syndrome can and should be involved in their own health promotion.

Resources



Articles

[Alzheimer's Disease Guidebook \(NDSS\)](#)

[Atlantoaxial Instability](#)

[Celiac Disease](#)

[Constipation](#)

[Depression](#)

[Diagnostic Overshadowing](#)

[Gastroesophageal Reflux Disease](#)

[Hypothyroidism and Hyperthyroidism](#)

[Pain](#)

[Pneumonia](#)

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

[Regression \(NDSS\)](#)

[Self-Talk](#)

[Sleep Apnea](#)

[Swallowing Problems \(Dysphagia\)](#)

[The Groove](#)

[Tips for Staying Hydrated](#)

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



Webinars

[Adapting Activities for Older Adults](#)

[Behavior Changes](#)

[Common and Uncommon Health Conditions](#)

[Decline in Skills and Regression](#)

[Gastrointestinal Health](#)

[Healthy Aging](#)

[Key Insights from the PCP's Guide to Women's Health and Down Syndrome](#)

[Personal Hygiene](#)

[Promoting Mental Health Across the Lifespan](#)

[Self-Talk](#)

[The Groove](#)

[The Recipe for Health](#)



Videos and visuals

[Boundaries](#)

[Celiac Disease Visuals](#)

[Create a Morning/Bedtime Routine Visual](#)

[Fun Activities for Promoting Health](#)

[Getting Good Sleep Visuals](#)

[Guides to Healthy Eating and Drinking](#)

[Healthy Eating at Buffets Video & Visual](#)

[Healthy Pace for Eating Video & Visuals](#)

[How to Cope with Stress Visuals](#)

[Hydration Video & Visuals](#)

[Relationships](#)

[Resources on Phone, Social Media,
and Internet Safety and Etiquette](#)

[Tips for Being Physically Active Video](#)

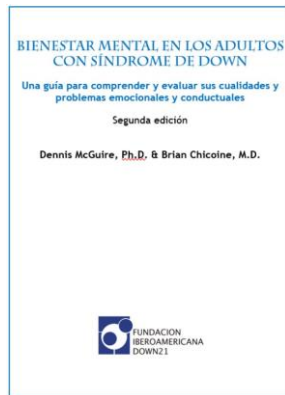
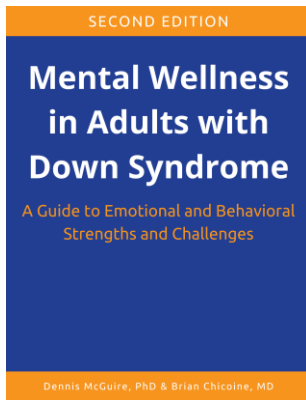
[Tips for Eating Health Meals](#)

[Visuals About the Food Groups](#)

[What to Drink Instead of Soda](#)

Resources

- [Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges](#)
 - Available as a free PDF in English and Spanish



Resources for health professionals

- [Down Syndrome Medical Interest Group](#)
(DSMIG-USA)
 - Project ECHO
 - Webinars
 - Resources
 - Membership

Welcoming Participants to the Down Syndrome Medical Interest Group-USA Project ECHO  

All health care professionals and trainees are invited to participate in the Down Syndrome Medical Interest Group-USA (DSMIG) Project ECHO.

This is a case-based opportunity for health care professionals to:

- Learn about health care for children and adults with Down syndrome.
- Earn FREE continuing education credits.
- Present a de-identified case and learn with a panel of experts.

Health care professionals from any discipline welcome.



Non-DSMIG members welcome!

Find out more here: dsmig-usa.org
or contact us at info@dsmig-usa.org

DSMIG-USA
Down Syndrome Medical Interest Group

Resources



National Down
Syndrome Congress
(NDSC) Convention

Down Syndrome
Medical Interest
Group-USA (DSMIG-
USA) Symposium

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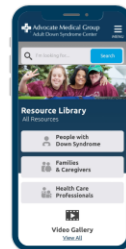
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FREE HEALTH RESOURCES

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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Email List



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