

# Mental Health Causes for Behavior Change During a Pandemic in Adolescents and Adults with Down Syndrome

Adult Down Syndrome Center

March 28, 2021 | Brian Chicoine, MD & Katie Frank, PhD, OTR/L

# Disclaimer

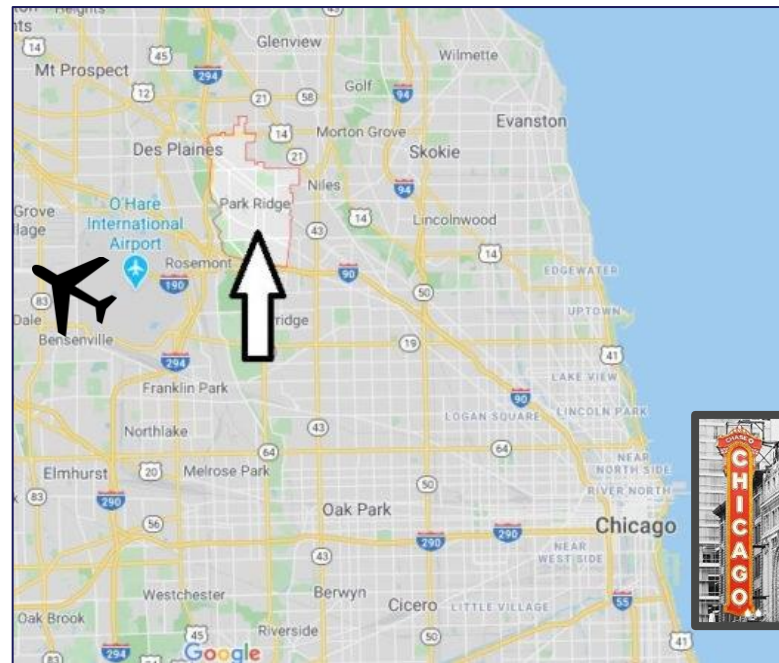
This information is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.

# Adult Down Syndrome Center



*Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, community-based health care services.*

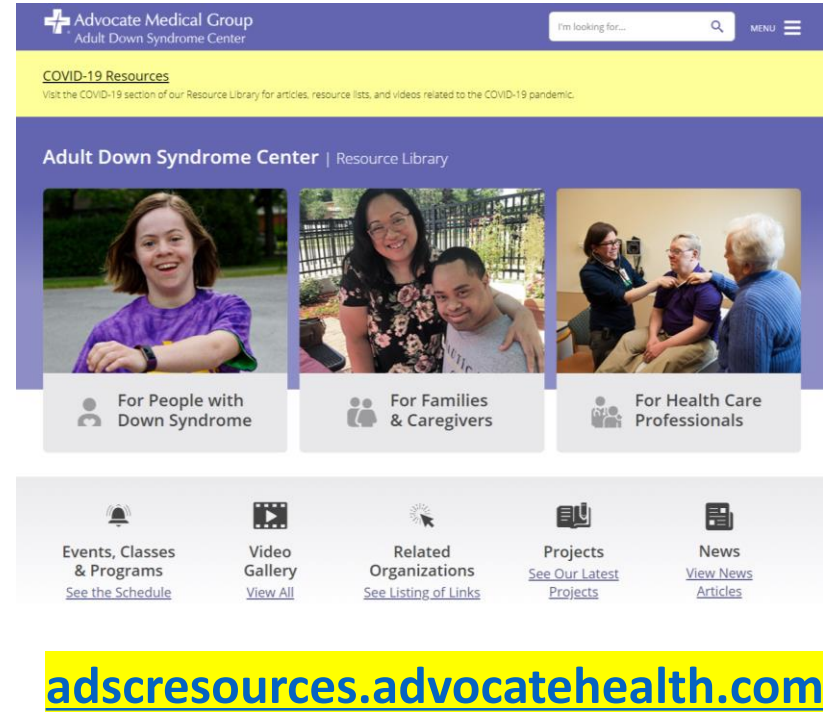
# Adult Down Syndrome Center



We are **AdvocateAuroraHealth**

# Online Resource Library

- Contains videos, articles, and booklets on a variety of topics, including behavior strategies and mental health.
- Resources are continually being updated.



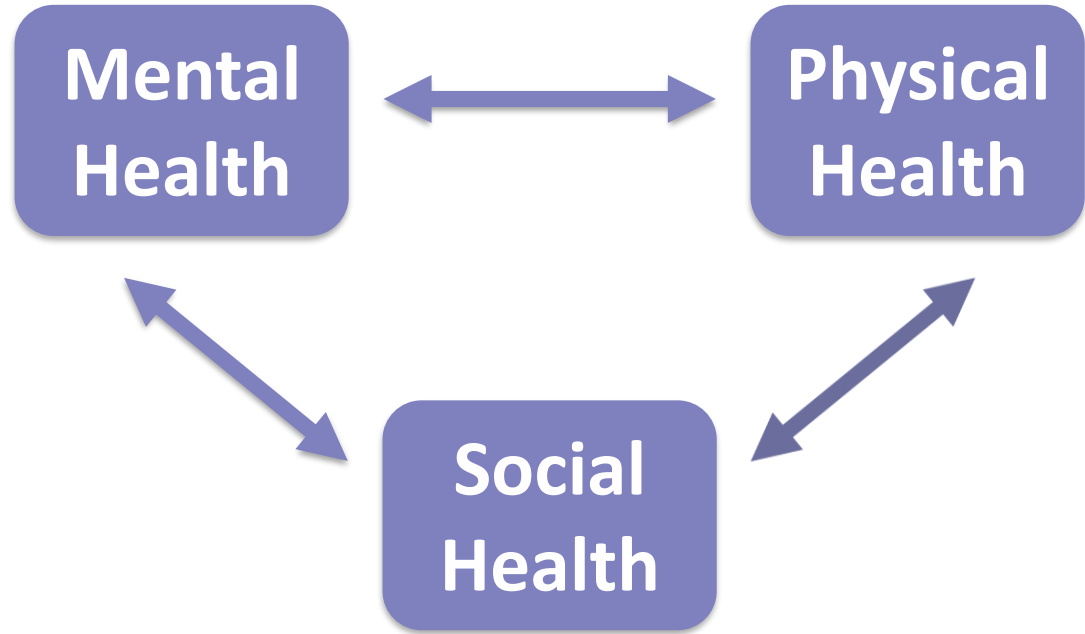
# Objectives

- Define behavior change.
- Identify reasons for behavior changes during COVID-19.
- Discuss strategies and solutions to address behavior changes.

# Health and well-being

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”

(World Health Organization)



# What is a behavior change?

# A behavior change is...

- A new action or pattern of actions that are atypical for an individual.
- A form of communication.

# Causes during COVID-19

Changes in routine

News overdose

Grief and loss

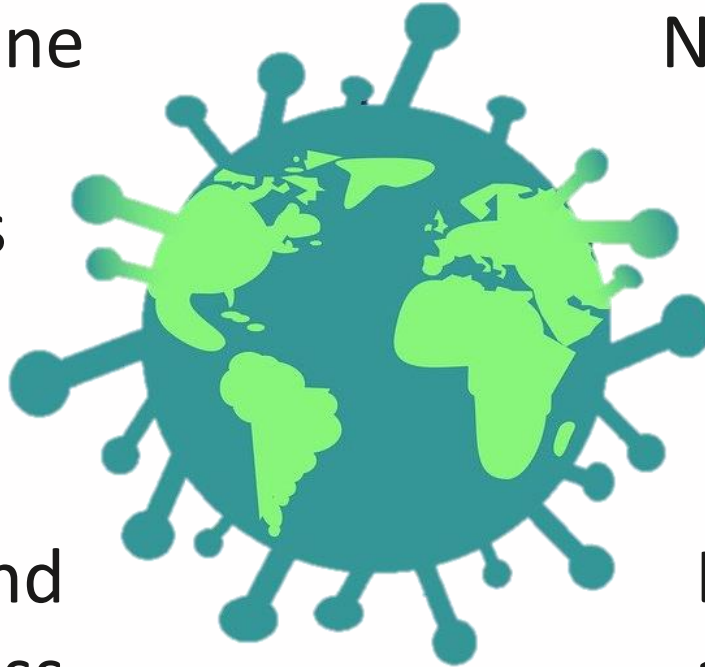
Changes in diet

Social isolation

Family stress

Family and  
personal illness

Lack of physical  
activity



# Clinical examples

# Example 1

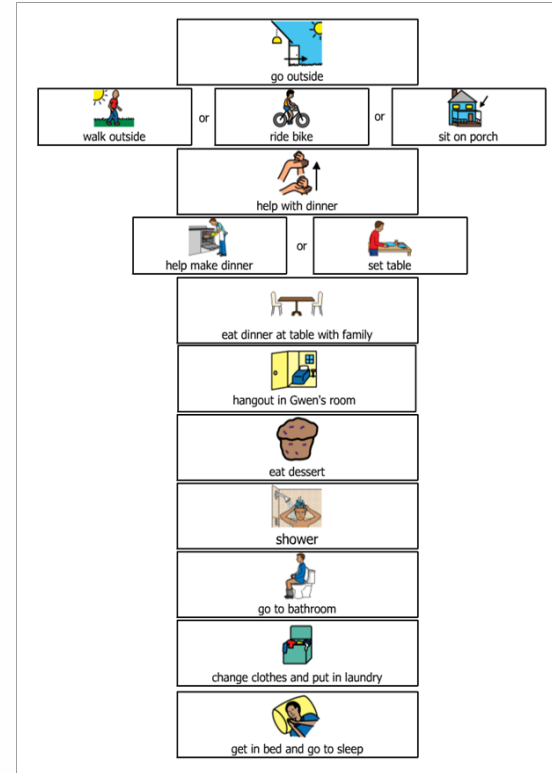
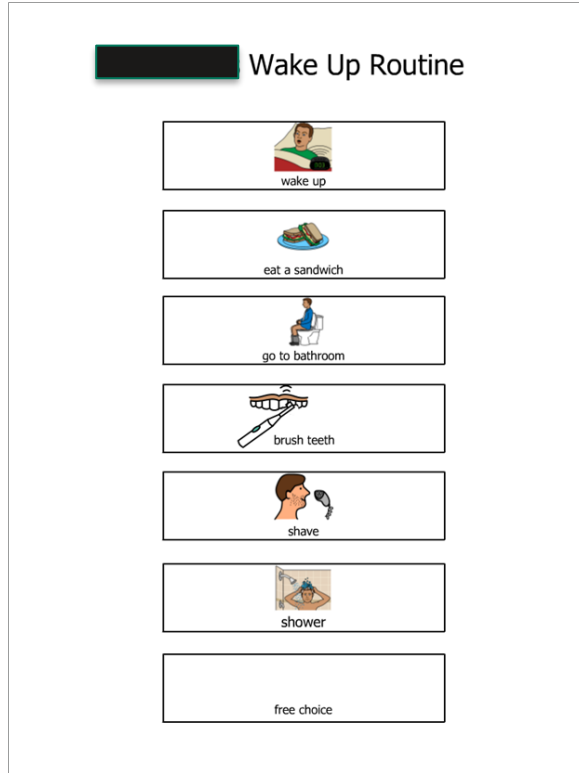
# Clinical presentation

- Individual with Down syndrome experiencing a change in sleep habits.
- Changes to his routine and living situation because of COVID-19.
- Led to social withdrawal.

# Addressing the change

- Addressed physical and mental health causes.
- No medications or treatments indicated.
- Established new routines using visual supports.
- Utilized sensory strategies.

# Morning and evening visuals



# Sleep hygiene

**Go to bed at the same time every night.**



**Wake up at the same time each morning.**



**Get 7 to 9 hours of sleep each night.**



**Make a good sleep space.**



**Have a healthy bedtime routine.**

**Hygiene**



brush teeth



wash face



go to bathroom

**Relaxation**



write in journal



pray



read



take deep breaths



stretch

[Ways to Sleep Better Visual Support](#)

[Addressing Challenges with Falling or Staying Asleep](#)

# Sleep aids



Sound machine



Ear plugs



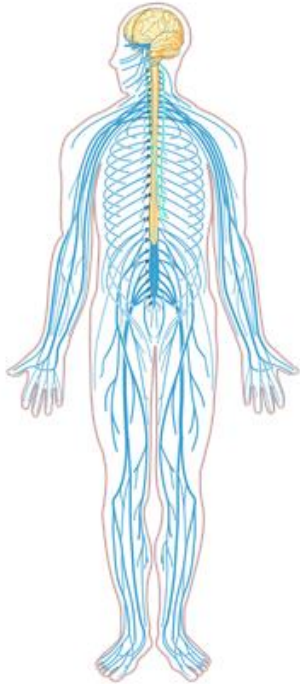
Sleep mask

Alarms



Fan

# What is sensory?



# Calming sensory strategies

- Proprioceptive input
  - Massage/vibration
  - Weighted blankets/objects



# Calming sensory strategies

## Proprioceptive Input

January 2016 | Katie Frank, PhD, OTR/L - Occupational therapist, Adult Down Syndrome Center

Many individuals with Down syndrome (DS) experience difficulty with their proprioceptive system. The proprioceptive sensors in our body are responsible for providing feedback so we know where our body is in space. When these sensors aren't working like they should, someone may experience difficulty with motor coordination, meaning they appear clumsy. This could also impact a person's ability to actually carry out a movement even though they know how to do it, this is called motor planning. They may carry out activities and have difficulty grading their movements, perhaps they do things too hard or too soft. Another feature is the person may have difficulty with postural stability so they often appear slumped over or lethargic.

In order to activate these receptors and improve a person's proprioceptive system, the following activities can be encouraged throughout the day to get natural input into a person's joints. These activities can be done in preparation for a transition or when you start to see a person becoming worked up. For instance, they need to complete a series of self-care tasks in the bathroom but often require verbal prompts to initiate the activity. Provide proprioceptive input to see if it helps restart their body and prepare to complete the required task. This also goes for transitions. Do you ever need to leave the house and your loved one with DS doesn't want to go? Try some proprioceptive input to see if it helps them transition. These activities may not be effective once a person is having a tantrum or melt-down.

- Animal walking (like bear or crab, even crawling like a cat or dog, or hopping like a bunny)
- Jumping up and down, maybe even on a trampoline
- Dancing
- Jumping jacks
- Push-ups on the floor or against the wall
- Bouncing on a therapy ball
- Sitting on a sit-disc
- Riding a bike/scooter

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## Affordable Sensory Equipment Recommendations

### Weighted products:

Key points to remember: Please consult with an Occupational therapist to help you determine the best size and weight. It is typically recommended to have a blanket be 7-10% of a person's body weight.

### Weighted blankets and lap pads

Custom weighted blankets and lap pads:

<http://www.sensacalm.com/weighted-blankets/>

<http://www.mosaicweightedblankets.com/> (they even offer DIY kits)

Amazon and Etsy even carry weighted products

### Weighted snake

Amazon has a few versions (be careful though because their prices fluctuate).



### Alternative ideas to expensive weighted objects



Door stoppers and neck wraps and warmers  
Available at drug stores and websites like Amazon. Bed Bath and Beyond carries a brand called Bed Buddy.



Talk with your dentist as you may be able to get an old lead vest used for x-rays.

### Vibration:

Hand held massager: Amazon as well as drug stores, Target, WalMart etc.



Vibrating cushion: Amazon carries a brand by Dr.Scholl's



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 Advocate Medical Group

2016

## Upper Body Joint Compression

Katie Frank, PhD, OTR/L  
Occupational Therapist

Joint compression is a form of proprioceptive input. It occurs when there is compression, push, or weight bearing placed on a joint. It is important for developing body awareness and body in space, as well as for joint stability and strength. It also promotes self-regulation and can be very calming, regulating, and organizing for the brain and nervous system. This is a technique that seems to be effective for individuals with Down syndrome.

It can be used to help with transitions as well as to help calm the body. Therefore, complete this quick activity **prior** to an event that can be stressful for your loved one with Down syndrome. It should only take a few minutes.

For any questions, please contact Katie Frank, PhD, OTR/L at 847-318-2331 or [katherine.frank@advocatehealth.com](mailto:katherine.frank@advocatehealth.com)

1. Have the individual sit down in a chair or on the floor. If they want or need to stand, joint compression can still take place.



2. Ask the individual if it is alright that you touch him/her. Once joint compression becomes part of the routine, you can just announce that it is time for joint compression.
3. You can start on either the right or left side and you will plan on doing joint compression to both sides.
4. Place one of your hands on top of his/her shoulder and your other hand on his/her upper arm. Gently press your two hands toward one another to provide compression at the shoulder joint. Do this 10 times.

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## Sensory Resources



## Details

Sommerfly Sleep Tight Weighted Blankets provide deep pressure, pressure which promotes relaxation and a restful night sleep.

- Gentle pressure of weighted blanket provides the same experience as swaddling
- 100% Cotton
- Polyester insert with glass or plastic pellets
- Suitable for all ages
- 5 lb. blanket fits users up to 36"
- 8 lb. blanket fits users up to 48"
- 12 lb. blanket fits users up to 60", measures 48" x 72"
- 16 lb. blanket fits users up to 72", measures 60" x 72"
- 25 lb. blanket fits users 141 lbs. +, measures 72" x 84"
- Machine washable
- Made in U.S. of U.S. and imported materials
- Each Sommerfly Sleep Tight Weighted Blanket Sold Separately

# Example 2

# Clinical presentation

- Individual with Down syndrome had been living independently.
- Stopped working because of COVID-19.
- Moved back in with family.
- Concerns about possible grief and depression from loss of independence and inability to work.

# Addressing the change

- More time to focus on health.
  - Focused on healthy eating and cooking own meals.
  - Stayed socially engaged through virtual opportunities.
  - Spent more time exercising.
- Family support

# Healthy eating

## 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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## Fruits and Vegetables

Fruits and vegetables are healthy for me. I can eat many different fruits and vegetables.



Half of my plate should be fruits and vegetables. This makes my plate colorful!



There are many ways I can eat more fruits and vegetables!



Add fruit to cereal or yogurt



Add vegetables to eggs



Add lettuce and tomato to a sandwich



Eat an apple instead of chips



Add orange and cucumber slices to my lunch



Put vegetables on pizza

Fruits and vegetables fill half my plate and make it colorful. I can eat many fruits and vegetables!

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## Healthy Snack Ideas



Handful of cherry tomatoes



Greek yogurt



Almonds



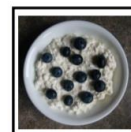
Turkey and zucchini roll-ups



Carrots with hummus



String cheese



Cottage cheese with blueberries



Apple slices with reduced fat peanut butter



Cucumber slices with yogurt dip

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## Healthy Eating Resources

### Example #2

# Hydration



## Hydration Resources

### 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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# Social opportunities

## Tips for Successful Video Calls

**Remember:** Video calls like Zoom are **public** spaces. This means that other people can see or hear what we do, say, and show.

**Find a good space to be in while you are on the call. A good space...**

- Is quiet.
- Has a background that is not distracting.
- Has appropriate lighting. It is not too dark or too bright.



**Wear appropriate clothing.**

- Dress for the audience (e.g. work vs. church vs. talking with friends).



**Check your internet connection.**

- Try moving to a different spot if the connection is not strong.



**Make sure you can hear others and they can hear you.**

- Test your microphone and speakers before a call.



**Make sure others can see you.**

- Test your camera before a call.
- Test the angle of your camera to make sure you're head (and shoulders, if possible) can be seen.



**Pay attention.**

- Avoid distracting behaviors.
- Be a good listener.
- Take turns talking.
- Use the chat box if needed.



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## An Introduction to Zoom



A resource developed by the  
Advocate Medical Group  
Adult Down Syndrome Center

## An Introduction to Zoom



## Tips for Successful Video Calls

### Example #2

# Physical activity

## Exercises You Can Do at Home



### JUMPING JACKS

Stand with your feet together and your hands at your sides (make an "I" with your body). Jump out while raising your arms up (make an "X" with your body). Then jump your feet together while lowering your arms (make an "I" with your body again). For a modified version, step one foot out while raising your arms. Bring your foot in while lowering your arms. Repeat with the other leg.

### WALK/RUN IN PLACE

Stand in one spot and pick your feet up and down like you do when you are walking. To make it more challenging, move your feet faster or lift your knees higher. It is even harder if you run in place!



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## WAYS TO BE ACTIVE!



Play a sport.



Go for a jog.



Do an exercise video.



Walk your dog.



Join Special Olympics.



Do housework/chores.



Stretch



Take the stairs.



Join Special Rec.



Dance.



Use exercise equipment.



Lift weights.

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## Exercise & Physical Activity Resources

# Example 3

# Clinical presentation

- Individual with Down syndrome who presented with psychotic symptoms
  - Dramatic change in self-talk

# Addressing the change

- Short course of medication.
- Utilized strategies for anxiety that worked in the past.
- Symptoms returned.
- Restarted the medication.
- Symptoms improved.

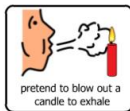
# Mental health

- Depression
- Anxiety
- OCD
- Regression syndrome
- Situational stressors
  - Grief / loss

# Managing stress and anxiety

## Strategies To Help Me Calm Down

### CALM BREATHING



### CALM THOUGHTS



### CALM MUSCLES



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## Tips for Dealing with Stress Video

November 2017 | Adult Down Syndrome Center - Video

Print

We all experience stress in our lives. What causes stress and how stress is managed varies from person-to-person. In the video below, Cindy and Nora describe stress and share tips on how to manage it. A corresponding visual handout can be found at [this link](#).



 Down Syndrome Australia  
Down syndrome and mental health



## Down Syndrome and Mental Health

Author: Down Syndrome Australia - Resource

The resource found at the link below is an 11-page summary for individuals with Down syndrome and their families on promoting and maintaining good mental health. Dr. Chicoine and Dr. McGuire's book *Mental Wellness in Adults with Down Syndrome* was used in the development of

## Strategies to Control my Anger



# Example 4

# Clinical presentation

- Individual with Down syndrome who recently changed his seizure medication (valproic acid).
- Experienced increased agitation, unsteady gait.

# Addressing the change

- Did a thorough history and physical.
- Ordered a variety of blood tests, including ammonia level.
  - Elevated ammonia level is a side effect of valproic acid.
- Talked with individual's neurologist and changed the seizure medication.
- Ammonia level went down.
- Symptoms improved...but didn't resolve.

# Physical health causes

- Sleep apnea
- Vitamin B12 deficiency
- Celiac disease
- Vision or hearing impairment
- Hypothyroidism
- Pain
- Alzheimer's disease
- Medication side effects

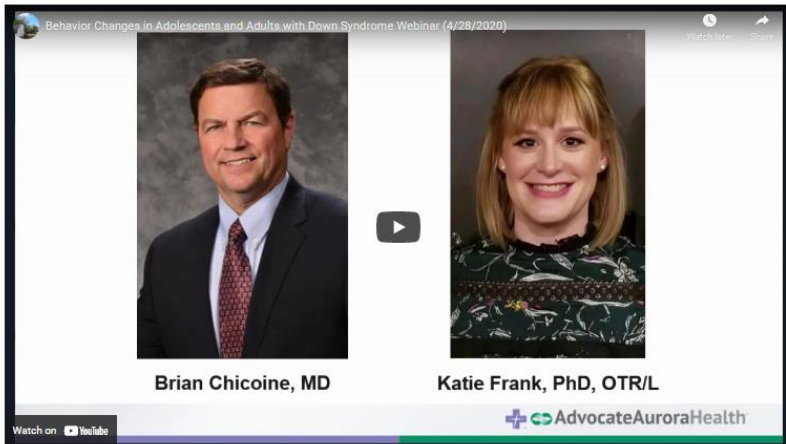
# Behavior change

## Behavior Changes in Adolescents and Adults with Down Syndrome Webinar Recording (4/28/2020)

May 2020 | Brian Chicoine, MD and Katie Frank, PhD, OTR/L - Webinar

Print

The video below is a recording of a webinar presented by Brian Chicoine, MD and Katie Frank, PhD, OTR/L on April 28, 2020. Dr. Chicoine is the co-founder and medical director of the Adult Down Syndrome Center and Dr. Frank is the occupational therapist at the Center. In this presentation, they define, identify reasons for, and discuss strategies and solutions to address behavior changes. The presentation slides can be found at [this link](#).



## [Behavior Changes Webinar Recording](#)

Example #3

## Behavior Change

October 2013 | Brian Chicoine, MD - Medical Director, Adult Down Syndrome Center

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

In the office, via email, at conferences, and most anywhere we talk about Down syndrome, someone will ask about a change in behavior. When I teach medical students and residents, I always tell them that if they are going to sleep through the rest of my presentation, this is the one slide they should review.

"There is an interaction between physical and mental health. Any and all behavior change should be viewed as a possible communication tool."

When there is a behavioral change, it is imperative to look at possible contributing factors. Could there be a physical health problem? A social issue? A psychological stress? A problem in any and all of these areas can contribute to behavioral change.

We have seen hypothyroidism present as depression, celiac disease present with agitated behavior, sleep apnea present as psychoses, and atlanto-axial instability present as a disinterest in school work. The list is endless. We must take a look at physical issues when there is a change in behavior.

Likewise, social issues can create behavioral change. Years ago, we were asked to see a man with DS who was "whacking people." The request was for an anti-psychotic medication. In evaluating the situation, we asked the patient what the problem was and he reported his roommate was discretely stealing his things. Our patient wasn't so discrete when he retaliated. We certainly didn't condone his aggressive behavior but the treatment was a social solution rather than a medication.

Might the person be trying to share grief, depression, a sense of fear due to a parent's health problems, or some other psychological stress?

Might it be a combination of all three, like the man we evaluated years ago who wasn't doing his job as well? He was about to lose his job. Our evaluation uncovered hypothyroidism (underactive thyroid) and depression. Hypothyroidism can cause depression. Although he had improvement with treating the hypothyroidism, his symptoms didn't resolve. He also required an anti-depressant. Then, despite him feeling well, the social situation needed attention. His employer was reluctant to let him return. A meeting was held, the employer's concerns were addressed, and the man with DS successfully returned to work.

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## [Behavior Change Article](#)

# Summary

# Causes of behavior change

- Health
  - Physical
  - Mental
- Sensory
- Social
- **Combination**

# Strategies

- Slowing down
- Creating schedules and routines
  - Sleep
  - Healthy eating
  - Physical activity
- Using time to focus on health and wellness
- Family self-care
- Limiting exposure to news and stressful conversations
- Helping with communication
- Relaxation activities
- Addressing physical health issues
- Encouraging safe social interactions

# Life after COVID-19

- What have we learned?
- What strategies and routines should continue?

# Questions?

Resource Library

[adscresources.advocatehealth.com](https://adscresources.advocatehealth.com)

Facebook

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

E-mail Newsletter

<http://eepurl.com/c7uV1v>