

Sleep in Adolescents and Adults with Down Syndrome

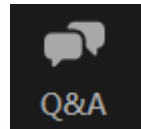
Adult Down Syndrome Center

August 4, 2020 | Brian Chicoine, MD & Katie Frank, PhD, OTR/L

Resource Library: adsresources.advocatehealth.com

Reminders

- This webinar is being recorded.
 - Available within two weeks in our Resource Library and on Facebook.
 - <https://adsresources.advocatehealth.com>
 - www.facebook.com/adultdownsyndromecenter
- Q&A
 - Please submit questions using the Q&A option.



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

Park Ridge, IL



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

Park Ridge, IL





Brian Chicoine, MD



Katie Frank, PhD, OTR/L

Agenda

- Discuss the importance of sleep.
- Describe ways to promote good sleep.
- Define and explain types of sleep disturbances.
- Share tips for adjusting to new sleep routines.

Why is sleep important?

Benefits of sleep

- Sleep cycle- REM and non-REM
- Restorative
- Learning and creative problem solving
- Promotes healthy mood
- Promotes cardiovascular health (lower BP)
- Improves immune health
- Improves body's use of blood sugar
- Controls appetite

National Institutes of Health 2011

Why is it important to get good sleep?

- It gives you energy.



- It helps you be happy.



- It helps you do your best at school, work, and other places.



- **It helps you stay healthy!**



Impact of poor sleep

- Hypertension (high blood pressure)
- Obesity
- Type 2 Diabetes
- Impaired immune function
- Cardiovascular disease
- Mood disorders
- Neurodegeneration and dementia (Alzheimer's disease)
- Loneliness
- Inattention
- Effect on family/group home

**How can we promote
good sleep?**

Sleep hygiene

- A series of healthy sleep habits that can improve your ability to fall asleep and stay asleep.
- Refraining from activities that promote excessive evening alertness or interrupt the natural process of falling asleep.

Good sleep hygiene habits

- Allow time for your body to digest dinner.
- Fall asleep at the same time each night.
- Set up a healthy sleep space.
- Establish a bedtime routine.
- Wake up at the same time each morning.
- Drink water as soon as you wake up.
- Walk/stretch within 1st hour of waking up.

Sleep hygiene habits to avoid

- Consume caffeine before bed.
- Eat sugar before bed.
- Drink alcohol before bed.
- Exercise vigorously before bed.
- Watch TV in bed.
- Use your phone or tablet in bed.
- Linger in bed in the morning.

Using devices at night

- Turn off alerts
 - Do Not Disturb or Silent Mode
- Minimize the impact of blue light
 - Night Shift / Night Mode device settings
 - Blue light filter apps

Use Night Shift on your iPhone, iPad, and iPod touch


Night Shift automatically adjusts the colors of your display to the warmer end of the spectrum—making the display easier on your eyes.

About Night Shift

Night Shift¹ uses the clock and geolocation of your device to determine when it's sunset in your location. Then it automatically shifts the colors of your display to warmer colors. In the morning, it returns the display to its regular settings.

Turn on Night Shift

There are two ways to turn Night Shift on and off:

- Open Control Center. Firmly press the Brightness control icon, then tap  to turn Night Shift on or off.
- Go to Settings > Display & Brightness > Night Shift.² On the same screen, you can schedule a time for Night Shift to turn on automatically and adjust color temperature.

By default, Night Shift turns on from sunset to sunrise.

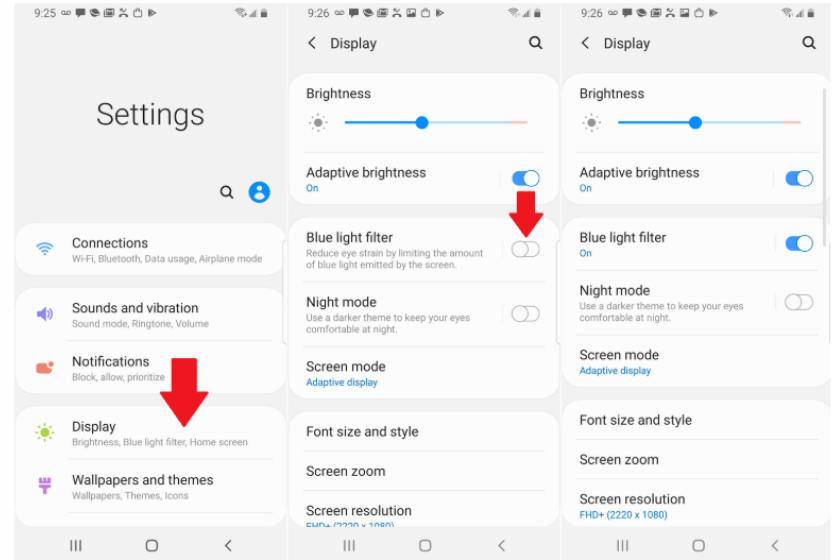


<https://support.apple.com/en-us/HT207570>

Android Device

Certain Android devices have built-in blue light filters, which can be enabled or disabled from the pull-down menu. However, as with many Android features, availability depends on your specific device and version of Android.

To seek out this feature on your Android phone or tablet, go to **Settings > Display**. Look for an option for Night Light or Blue Light filter. If you find it, tap on it to turn on the filter.



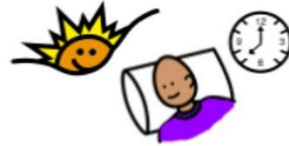
<https://www.pcmag.com/how-to/how-to-stop-blue-light-from-disturbing-your-sleep>

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

What can cause sleep disturbances?

Sleep disturbances in people with intellectual disabilities

- Insomnia
 - Including difficulty falling asleep or staying asleep
- Hypersomnia
 - Excessive sleepiness
- Sleep related breathing problems
 - E.g. sleep apnea

Medical and Psychological Issues

- Thyroid - hypo and hyperthyroidism
- Depression
- Anxiety
- Obsessive compulsive disorder
- Sleep apnea
- Gastroesophageal reflux disease
- Urinary issues

Treatment

- Sleep hygiene
- Natural products (e.g. melatonin, magnesium, valerian root, tryptophan)
- Medications (e.g. sedatives, trazodone)
- Sleep apnea
 - Sleeping position
 - CPAP
 - Hypoglossal nerve stimulator
 - Medications (for daytime sleepiness)

Adjusting to new sleep routines

Establishing a sleep routine

- Relaxation
- Sleep aids
- Sensory

Relaxation

Read

Journal

Pray

Drink warm
tea

Take a warm
bath

Meditate

Stretch

Take deep
breaths

Use essential
oils

Listen to slow
music or
white noise

Dim lighting

Sleep aids

Sound machine



Night light



Ear plugs



Light Alarms



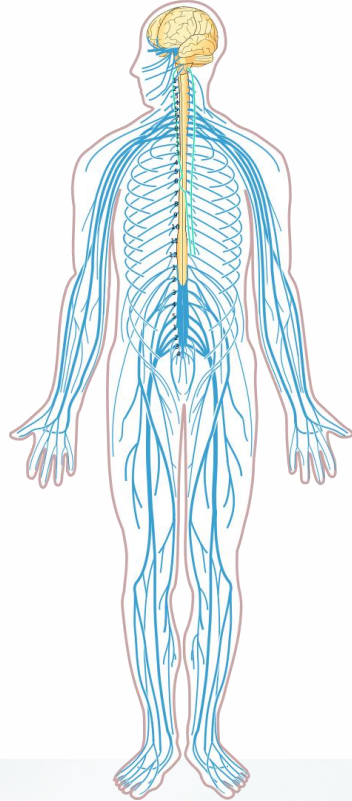
Sleep mask



Fan



What is sensory?



Our sensory system



Calming sensory strategies



Music, white noise

Essential oils



Drink warm tea

Dim lights



Massage

Calming sensory strategies

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



Proprioceptive Input

Many individuals with Down syndrome 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 DD 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 meltdowns.

- 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
- Sports like swimming, yoga, Pilates and martial arts
- Completing an obstacle course
- Carrying a heavy backpack
- Moving furniture
- Pushing a cart/stroller/wagon
- Rolling up in a blanket like a burrito
- Bear hugs or being squeezed between pillows or cushions

- Using play-doh or therapy
- Log rolling
- Vibration
- Weighted blankets
- Sitting in a bearbag chair
- Rocking in a rocking chair or on a glider
- Strength training activities with a theraband or light weights
- Throwing a weighted ball
- Joint compression (see handout on how to complete joint compression)
- Massage
- Yard work like raking and shoveling
- House work like vacuuming, sweeping, mopping, washing windows, and wiping down the counter
- Eating chewy or crunchy foods
- Sucking through a straw

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. It is **NOT** recommended to sleep under weighted blankets.

Weighted blankets and lap pads: Prices vary, but range from \$30- \$100+ depending on size and weight.

Custom weighted blankets and lap pads:

- <http://www.sensacalm.com/weighted-blankets/>
- <http://www.cosmicweightingblankets.com/> (They even offer DIY kits)
- Amazon, Bed Bath & Beyond, and Etsy even carry weighted products

Weighted snuggles: Prices range from \$25 - \$50+

Amazon has a few versions. They vary in weight.



Alternative ideas to expensive weighted objects

- Deer stoppers and neck wraps and warmers (priced \$30 and up)



- Available at drug stores and websites like Amazon, Bed Bath and Beyond and Amazon carry a brand called Bed Buddy.
- Talk with your dentist as you may be able to get an old lead vest used for x-rays.

Vibrating products:

- **Hand held massager:** Amazon as well as drug stores, Target, WalMart etc. (priced under \$30) 
- **Vibrating cushion:** Amazon carries a brand by Dr.Scholl's (priced under \$30) 
- **Vibrating neck massager**  or **vibrating cushion**  (priced \$20-\$50)

Joint compression-Upper body

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 Kate Frank, PhD, OTR/L at 847-318-2331 or 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 his/her. Once joint compression becomes part of the routine, you can just announce that it's time for joint compression.
3. You can start on either the right or left side and you will place 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.



Adscresources.advocatehealth.com



Details

Sommerfly Sleep Tight Weighted Blankets provide gentle soothing pressure which promotes calmness and a restful night sleep.

- Gentle pressure from the weighted blanket gives a similar effect as swaddling
- 100% Cotton Cover
- Polyester insert with weighted glass beads
- Suitable for all ages
- 5 lb. blanket fits users 22-35 lbs.
- 8 lb. blanket fits users 36-45 lbs.
- 12 lb. blanket fits users 46-55 lbs., measures 42" x 60"
- 16 lb. blanket fits users 56-65 lbs., measures 54" x 72"
- 25 lb. blanket fits users 66 lbs. +, measures 57" x 80"
- Machine Washable
- Made in USA of domestic and imported materials
- Each Sommerfly Sleep Tight Weighted Blanket Sold Separately

Tolerating a sleep study

- Use sensory strategies to help relax the body.
- Take a tour of the sleep center.
- Practice with a pap nap.
- Request supplies to practice at home.
- Use a social story beforehand.
- Complete bedtime routine at the sleep center.
- Be positive!

Tolerating a CPAP

- Use sensory strategies to help relax the body.
- Practice with a pap nap.
- Use behavior strategies and/or visual supports to increase tolerance.
- Consider alternative masks.
- Be positive!

Visual resources

Going for a sleep study



maxiSHARE

Going to get my sleep mask



maxiSHARE



Visual resources

Jack's Evening Routine



WHEN I WEAR MY CPAP... For Paul

IF the water is below the line in
the water chamber in the
morning...



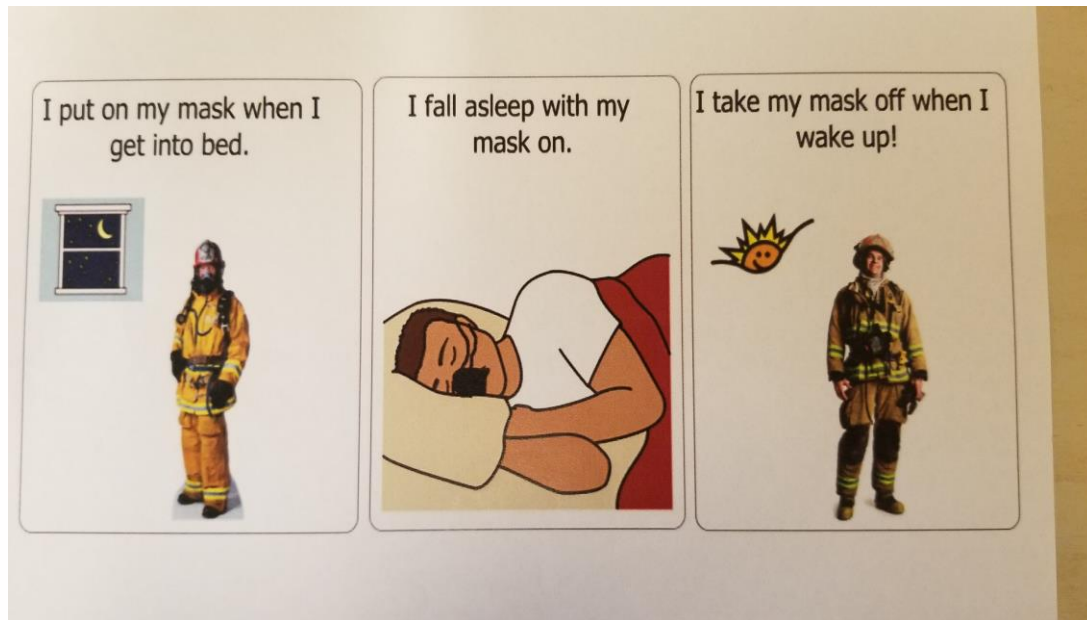
THEN I earn a quarter!



At the end of the month, I
can use my money to buy
something I want like cards,
dinner, or a movie.



Visual resources



My CPAP story

I do not sleep very well at night.

When I wake up I sometimes feel tired and grumpy.

I have been told to use a CPAP machine.

It is a mask, attached to a machine that blows out air. It is supposed to help me sleep better.

The mask might look scary, but it does not hurt! I think I look silly wearing it, but that's ok because no one sees me when I sleep.

My mask is really cool because it just sits inside my nose. When I don't feel well I have a mask that makes me look like a fighter pilot. Aren't you jealous?

It is easy for me to put my mask on and take it off all by myself.

When the air blows it feels like a fan blowing on me, but it doesn't hurt!

Wearing the mask is good because it helps me sleep better and wake up in a good mood!

If I need help with my mask or my machine, I can ask my mom or dad.

Using my machine and mask when I sleep will make my mom so happy!

Mask options



Things to remember

- Sleep is important for good health.
- Be aware of the impact of sleep on health.
- People with Down syndrome can successfully improve sleep with good sleep hygiene.

Questions?

Resource Library

adsresources.advocatehealth.com

Facebook

www.facebook.com/adultdownsyndromecenter

Contact Us

adsresources.advocatehealth.com/contact/

Links to resources

- **All Sleep Resources**

<https://adscreources.advocatehealth.com/resources/?category=Sleep>

- **Going for a Sleep Study**

https://adscreources.advocatehealth.com/assets/1/13/Going_for_a_Sleep_Study.pdf?67

- **Going to Get My Sleep Mask**

https://adscreources.advocatehealth.com/assets/1/13/Going_to_Get_My_Sleep_Mask.pdf?68

- **How to Use a CPAP Machine Video**

<https://adscreources.advocatehealth.com/how-to-use-a-cpap-machine-video/>

Links to resources

- **Affordable Sensory Equipment**
https://adsresources.advocatehealth.com/assets/1/13/Affordable_Sensory_Equipment_Recommendations.pdf?33
- **Proprioceptive Input**
<https://adsresources.advocatehealth.com/resources/proprioceptive-input/>
- **Upper Body Joint Compression**
https://adsresources.advocatehealth.com/assets/1/13/Upper_Body_Joint_Compression.pdf?55
- **Lower Body Joint Compression**
https://adsresources.advocatehealth.com/assets/1/13/Lower_Body_Joint_Compression.pdf?66