

Good Sleep Practices for Individuals with Down Syndrome

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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.

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

Worley 2018

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

Brylewski, 1999

Sleep disturbances in people with Down syndrome

- Trouble falling asleep initially
- Trouble staying asleep
- Difficulty falling back to sleep if wake up in the middle of the night
- Restless sleep
- Sleep apnea
- Not wanting to sleep in their bed
- Switching days and nights/staying up very late and sleeping in

Medical and psychological issues that impact sleep

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

Treatment for sleep disturbances

- Sleep hygiene
- Behavioral approaches
- 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)

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 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 the first hour of waking up.

Sleep hygiene habits to avoid

- Consuming caffeine before bed.
- Eating sugar before bed.
- Drinking alcohol before bed.
- Vigorous exercise before bed.
- Watching TV in bed.
- Using 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.

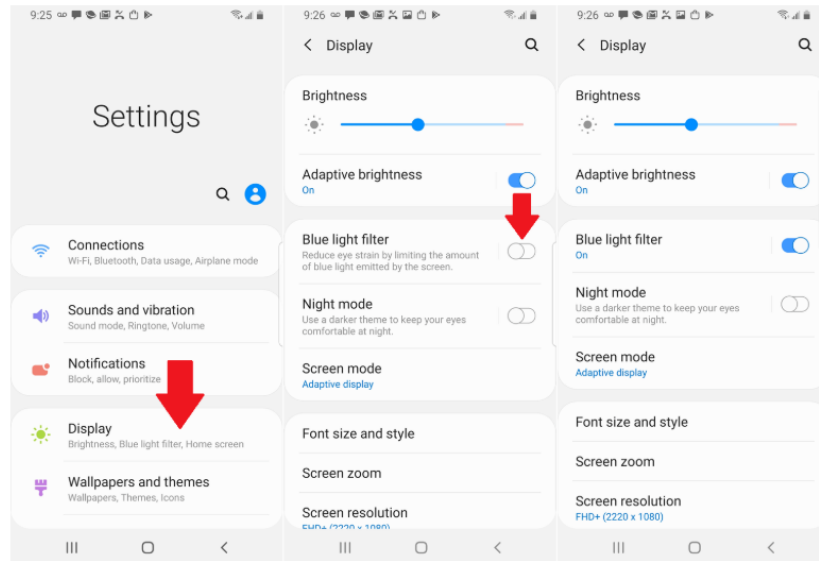


<https://support.apple.com/en-us/HT207570>

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.



TV



tablet



phone

Have a healthy bedtime routine.

Hygiene



brush teeth



wash face



go to
bathroom

Relaxation



write in
journal



pray



read



take deep
breaths



stretch

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



Light Alarms



Ear plugs



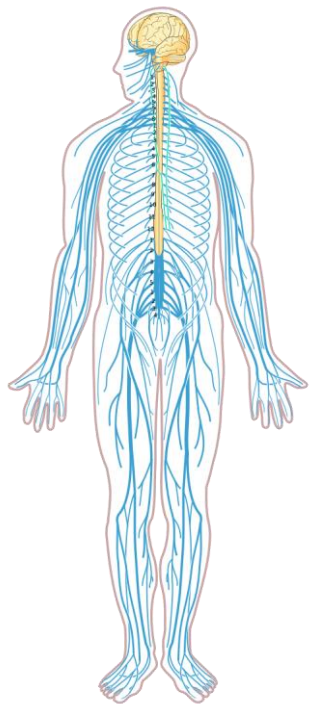
Fan



Sleep mask



What is sensory?



Our sensory system

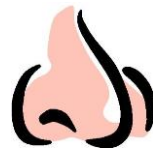


Calming sensory strategies



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

In order to activate these receptors and improve a person's proprioceptive system, activities can be encouraged throughout the day to get natural input into a person's joints. Activities can be done in preparation for a transition or when you start to see a person worked up. For instance, they need to complete a series of self-care tasks in the bath require verbal prompts to initiate the activity. Provide proprioceptive input to see if it helps body and prepare to complete the required task. This also goes for transitions. Do you leave the house and your loved one with DD doesn't want to go? Try some proprioceptive if it helps them transition. These activities may not be effective once a person is having a 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
- 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 theraput
- Log rolling
- Vibration
- Weighted blankets
- Sitting in a beanbag chair
- Rocking in a rocking chair
- Strength training activities or light weights
- Throwing a weighted ball
- Joint compression (see how complete joint compression)
- Massage
- Yard work like raking and
- House work like vacuuming, mopping, washing windows down the counter
- Eating chewy or crunchy food
- 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.mosaicweightedblankets.com/> (they even offer DIY kits)
- Amazon, Bed Bath & Beyond, and Etsy even carry weighted products

Weighted snuggly: 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. Schell'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 placed on a joint. It is important for developing body awareness and body in space, as well as for body and strength. It also promotes self-regulation and can be very calming, regulating, and organizing for 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 in an event that can be stressful for your loved one with Down syndrome. It should only take a few minutes.

For questions, please contact Kate Frank, PhD, OTR/L, at 847-318-2331 or katefrank@advocatehealth.com

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.



Ask the individual if it is alright that you touch her/his. Once joint compression becomes part of the routine, you can just announce that it's time for joint compression.

You can start on either the right or left side and you will plan on doing joint compression to both sides.

Place one of your hands on top of her/his shoulder and your other hand on her/his upper arm. Gently press your two hands toward one another to provide compression at the shoulder joint. Do this 10 times.



Sensory resources



Details

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

- Gentle pressure from the weighted blanket gives a similar effect to swaddling
- 100% Cotton Cover
- Polyester insert with weight
- Suitable for all ages
- 5 lb. blanket fits users 22-35 lb.
- 8 lb. blanket fits users 36-45 lb.
- 12 lb. blanket fits users 46-55 lb., measures 42" x 60"
- 16 lb. blanket fits users 56-65 lb., measures 54" x 70"
- 25 lb. blanket fits users 66 lbs. +, measures 57" x 80"
- Machine Washable
- Made in USA of local and imported materials
- Each Sommerfly Sleep Tight Weighted Blanket Sold Separately

Behavioral approaches for common sleep disturbances in Down syndrome

Behavior strategies

- Trouble falling asleep
 - Sleep hygiene and consistent bedtime routine.
- Waking up in the middle of the night
 - Make sure they are ok and then escort them back to their room or repeat part of bedtime routine.
 - Avoid nighttime drinks.
 - After 15 minutes, encourage a non-screentime activity out of bed like journaling or coloring or one of their relaxation activities.
- Unable to fall back to sleep
 - Check in every 5 minutes or longer and try to re-settle. Encourages them to fall asleep on their own.
 - Gradual withdrawal.

Behavior strategies cont.

- Early waking
 - Reduce light and noise.
 - Praise and positive reinforcement.
 - Alarm clock showing when ok to get out of bed.
 - If they need less sleep, put them to bed later.
- Sleeping in parents' bed
 - Return them to their bed.
 - Stop sign on your door or their door.

Behavior strategies cont.

- Reverse sleep/wake cycle
 - Determine reason for change.
 - Wake individual up in the morning at reasonable time.
 - Limit opportunities to nap during the day.
 - Have an activity to do that day.
 - Create a bedtime routine and gradually make bedtime earlier.
 - Make bedroom a place for sleep only.

General Reminders

- Ensure bedroom is conducive to sleep.
- Establish consistent evening and bedtime routines.
- From early on, teach individual to fall asleep on their own.
- Reward good nighttime behavior.
- Try to avoid bringing the individual into your room or bed for sleep.
- Avoid prolonged naps in the afternoon.
- Avoid drinks that contain caffeine.
- Restrict TV/videos and screentime in the bedroom around bedtime.
- Be kind, but also firm and consistent.

Sleep studies and CPAP machines

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



[Sleep resources](#)

Visual resources

My CPAP story

I do not sleep very well at night.

With the help of my doctor, I feel much better.

I take my mask off when I wake up. It is supposed to help me

ing it, but

eel well I

in a good

make my mom so happy!

I put on my mask when I
get into bed.



I fall asleep with my
mask on.



I take my mask off when I

Create a Bedtime Routine Visual

My bedtime routine




Mask options





Things to remember

- Sleep is important for good health.
- Be aware of the impact of sleep on health.
- The need for sleep is biological. However, how one sleeps is a learned behavior.
- People with Down syndrome can successfully improve sleep with good sleep hygiene and some behavioral approaches.
- Be positive!

Resource Library


 Advocate Medical Group
Adult Down Syndrome Center


I'm looking for... 


MENU 


COVID-19 Resources
Review articles, resource lists, and videos related to COVID-19 and Down syndrome.


Adult Down Syndrome Center | Resource Library





 **For People with Down Syndrome**




 **For Families & Caregivers**




 **For Health Care Professionals**




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




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<https://adsresources.advocatehealth.com>

Links to resources

All Sleep Resources

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

Going for a Sleep Study

[https://adscresources.advocatehealth.com/assets/1/13/Going for a Sleep Study.pdf?67](https://adscresources.advocatehealth.com/assets/1/13/Going_for_a_Sleep_Study.pdf?67)

Going to Get My Sleep Mask

[https://adscresources.advocatehealth.com/assets/1/13/Going to Get My Sleep Mask.pdf?68](https://adscresources.advocatehealth.com/assets/1/13/Going_to_Get_My_Sleep_Mask.pdf?68)

How to Use a CPAP Machine Video

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

Links to resources

Affordable Sensory Equipment

[https://adscresources.advocatehealth.com/assets/1/13/Affordable Sensory Equipment Recommendations.pdf?33](https://adscresources.advocatehealth.com/assets/1/13/Affordable_Sensory_Equipment_Recommendations.pdf?33)

Proprioceptive Input

<https://adscresources.advocatehealth.com/resources/proprioceptive-input/>

Upper Body Joint Compression

[https://adscresources.advocatehealth.com/assets/1/13/Upper Body Joint Compression.pdf?55](https://adscresources.advocatehealth.com/assets/1/13/Upper_Body_Joint_Compression.pdf?55)

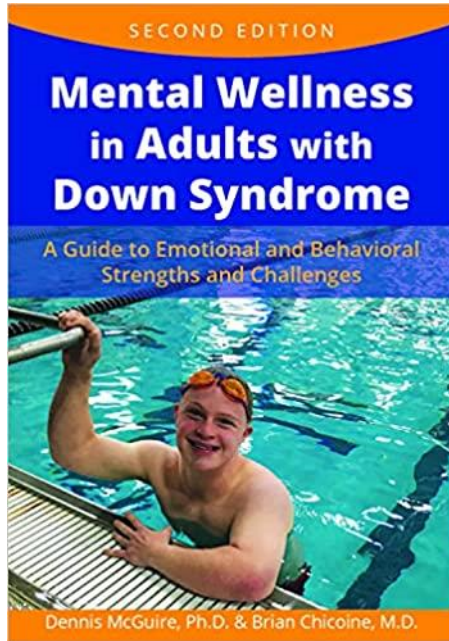
Lower Body Joint Compression

[https://adscresources.advocatehealth.com/assets/1/13/Lower Body Joint Compression.pdf?66](https://adscresources.advocatehealth.com/assets/1/13/Lower_Body_Joint_Compression.pdf?66)

Other resources

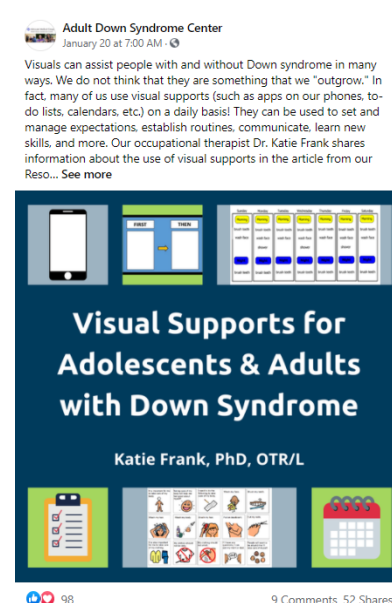
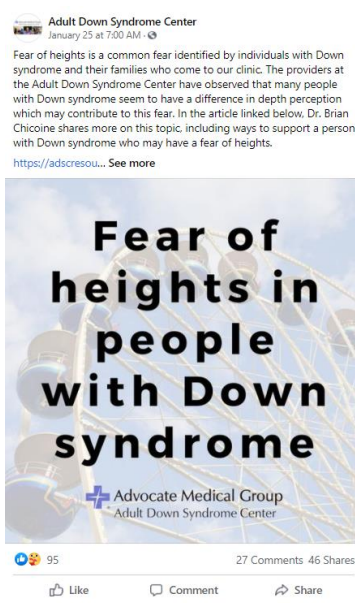
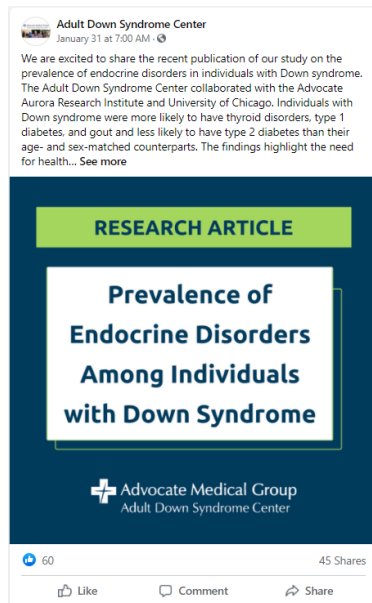
- [Managing-Sleep-Problems-In-Children-21st-March-KP-28th-June-SM_DSMIG.pdf \(downs-syndrome.org.uk\)](#)
- [Sleep & Down Syndrome | National Down Syndrome Society \(NDSS\)](#)
- [Sleep - Down Syndrome Resource Foundation \(dsrf.org\)](#)

Free Copy of the Mental Wellness book



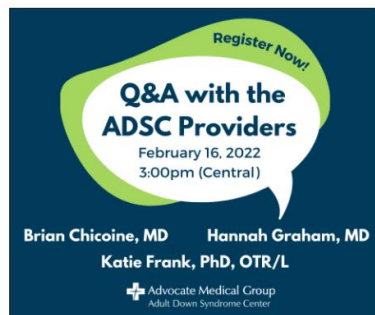
[https://adsresources.
advocatehealth.com/
mental-wellness-in-
adults-with-down-
syndrome-2nd-
edition/](https://adsresources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/)

Facebook



<https://www.facebook.com/adultdownsyndromecenter>

Email list



Do you have questions about health and wellness of adolescents and adults with Down syndrome? Our next webinar is for you! Join Brian Chicoine, MD, Katie Frank, PhD, OTR/L, and Hannah Graham, MD for a Q&A on Wednesday, February 16, at 3:00pm (Central). Questions may be submitted before the webinar and/or during the webinar. Please click the button below to register and submit a question.

REGISTER NOW

Resources



Even if the weather outside is frightful, there are many activities we can do at home to fight boredom, stay active, be social, and have fun. We recently updated our "Activities You Can Do at Home" resource. There are ideas for arts and crafts, cooking, education and learning, fitness and physical activity, games, and more.

Explore activities

<http://eepurl.com/c7uV1v>

Personal contact information

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