

# Puberty in Down Syndrome

June 30 | Hannah Graham, MD and Katie Frank, PhD, OTR/L





Advocate  
Medical  
Group

Adult Down  
Syndrome Center  
1610 Luther Lane



# Resource Library



The screenshot shows the homepage of the Advocate Medical Group Adult Down Syndrome Center. At the top left is the logo with a cross icon and the text "Advocate Medical Group Adult Down Syndrome Center". To the right is a search bar with the placeholder text "Search for resources, events, and more" and a magnifying glass icon. Further right is a "Support Our Mission" button with a heart icon. Below the header is a navigation menu with links for "Resources", "Events & Programs", "For Professionals", "About Us", and "FAQs". The main content area features a large photograph of a healthcare professional in a white lab coat high-fiving a young woman with Down syndrome. Overlaid on the photo is the text "Adult Down Syndrome Center" in a large white font. Below this is a paragraph: "Founded in 1992, the Advocate Medical Group Adult Down Syndrome Center (ADSC) has served the physical, mental, and social health needs of thousands of teens and adults with Down syndrome." At the bottom of the main area are three colored buttons: "Find a Doctor" (light blue), "Browse Resources" (light green), and "For Professionals" (orange).

[adulldownsyndrome.org](http://adulldownsyndrome.org)

# Reminders

- This webinar is being recorded.
  - The link to the recording and slides will be emailed to attendees within 1 week.
- Certificates of attendance
  - Certificates will be emailed within 1 week.
- Q&A
  - Please submit questions using the Q&A option.





**Hannah Graham, MD**



**Katie Frank, PhD, OTR/L**



<https://adultdownsyndrome.org/meet-our-team/>

# Please note:

- This presentation is meant to support families, caregivers, and professionals who care about and for individuals with Down syndrome.
- The information shared today is for learning and discussion, not to replace medical or therapeutic care.
- Everyone is different. If you have questions specifically about your loved one, you are encouraged to talk to their doctor or therapist.
- Neither ADSC staff nor Advocate Health endorse any products discussed in this presentation.

# Objectives

- Understand the basics of puberty in Down syndrome and describe the developmental process and changes.
- Identify strategies and resources to support individuals with Down syndrome during puberty.

# Puberty - the what

# What is puberty

- When a young person's body starts to become sexually mature
  - Characterized by:
    - Development of reproductive organs
    - Rapid growth in height
    - Voice changes
    - Moodiness
    - And more!!



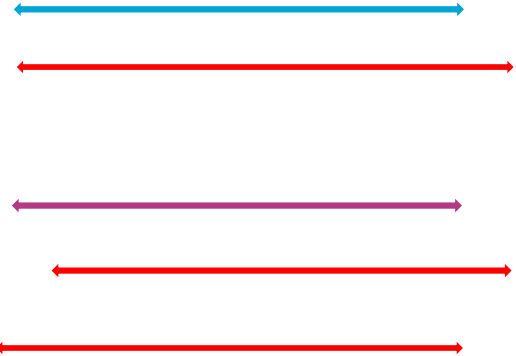
# Age of puberty

- In individuals without Down syndrome:
  - In girls:
    - Can start as early as age 8
    - Usually around age 11
  - In boys:
    - Can start as early as age 9
    - Usually around age 12



# Age of puberty

- Few studies on puberty in Down syndrome
- Some data that boys with Down syndrome:
  - Start puberty at the same age
  - Length of puberty is longer
- Some data that girls with Down syndrome:
  - Start breast development later
  - Finish breast development later
  - Start periods earlier – maybe?



# Puberty for males

- First sign of puberty in males is increase in testicle size
- Typical pattern of development:

	Tanner Stage 1	Tanner Stage 2	Tanner Stage 3	Tanner Stage 4	Tanner Stage 5
Testicular and penile growth	Prepuberty	Enlargement of testicles and scrotum but not the penis	Continued testicular and scrotal growth with penile growth	Continued testicular, scrotal, and penile growth with maturation of penis	Mature male genitalia
Pubic hair growth	Prepuberty	Sparse, slightly pigmented pubic hair	Still sparse but darker, coarser, more curled pubic hair	Adult type pubic hair but area covered is smaller	Adult type and distribution of pubic hair with spread to medial thighs
Height			Peak height velocity	Peak height velocity, facial hair, acne, voice change	
Age		9.5-14 years old	11-15 years old	11.5-16.6 years old	No further height increase after age 17

\*Breast tissue may appear around stage 3 and resolve during stage 4

# Puberty for males with DS

\*May occur slightly later in men with Down syndrome

- First sign of puberty in males is increase in testicle size
- Typical pattern of development:

	Tanner Stage 1	Tanner Stage 2	Tanner Stage 3	Tanner Stage 4	Tanner Stage 5
Testicular and penile growth	Prepuberty	Enlargement of testicles and scrotum but not the penis	Continued testicular and scrotal growth with penile growth	Continued testicular, scrotal, and penile growth with maturation of penis	Mature male genitalia
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\*Breast tissue may appear around stage 3 and resolve during stage 4

# Fertility in males

- Fertility in men with Down syndrome:
  - May be reduced (decreased sperm production)
  - Some men with Down syndrome are fertile



# Nocturnal emissions and masturbation

- Nocturnal emissions are common in the general population (Maiolino et al. 2026)
  - Some variation amongst different cultures
  - Typically begin between ages 12.6-15.6 years old (usually 13-14)
- Masturbation also reported to be common, and frequency increased with age (Robbins et al. 2011)
  - 62.6% of males at age 14
  - 80% of males at age 18
- No studies specifically looking at men with Down syndrome

# Puberty for females

- First sign of puberty in females is breast buds (breasts start developing)
- Typical pattern of development:

	Tanner Stage 1	Tanner Stage 2	Tanner Stage 3	Tanner Stage 4	Tanner Stage 5
Breast development	Prepuberty	Breast buds	Breasts further enlarged with a rounded contour	Areola and nipple form separate mound on breast	Mature adult stage
Pubic hair growth	Prepuberty	Sparse, slightly pigmented pubic hair	Still sparse but darker, coarser, more curled pubic hair	Adult type pubic hair but area covered is smaller	Adult type and distribution of pubic hair, sometimes with spread to medial thighs
Height		Peak height velocity	Peak height velocity, acne, body odor, armpit hair	First period may start	
Age		8.9-12.9 years old	9.9-14 years old	10.5-15 years old	No further height increase after age 16

# Puberty for females with DS

- First sign of puberty in females is breast buds (breasts start developing)
- Typical pattern of development:

	Tanner Stage 1	Tanner Stage 2	Tanner Stage 3	Tanner Stage 4	Tanner Stage 5
Breast development	Prepuberty	Breast buds	Breasts further enlarged with a rounded contour	Areola and nipple form separate mound on breast	Mature adult stage
Pubic hair growth	Prepuberty	Sparse, slightly pigmented pubic hair	Still sparse but darker, coarser, more curled pubic hair	Adult type pubic hair but area covered is smaller	Adult type and distribution of pubic hair, sometimes with spread to medial thighs
Height		Peak height velocity	Peak height velocity, acne, body odor, armpit hair	First period may start	
Age		8.9-12.9 years old	9.9-14 years old	10.5-15 years old	No further height increase after age 16

\*Breast development may start later, periods may be earlier?, and length of puberty longer

# Fertility in females

- Fertility rates for women with Down syndrome are reduced, but there have been many documented cases of women with Down syndrome giving birth
- Less than half of children born to a woman with Down syndrome have Down syndrome themselves
- Women with mosaic Down syndrome are more likely to be able to become pregnant



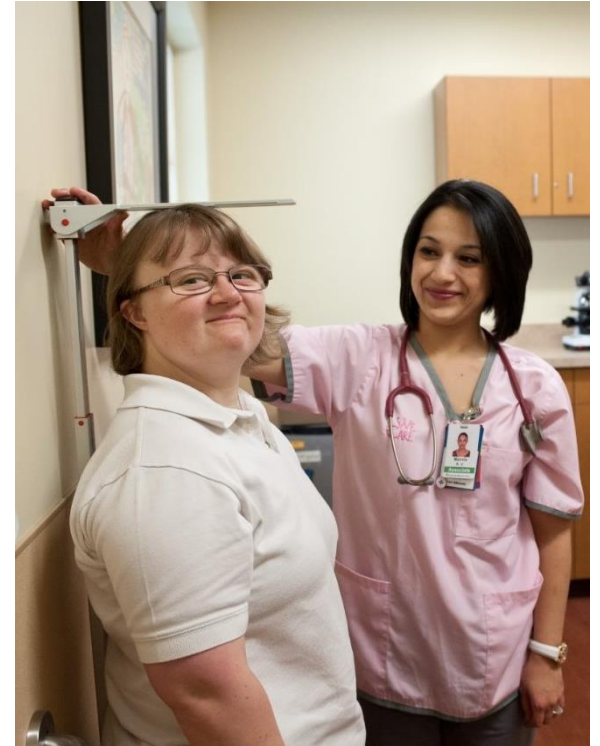
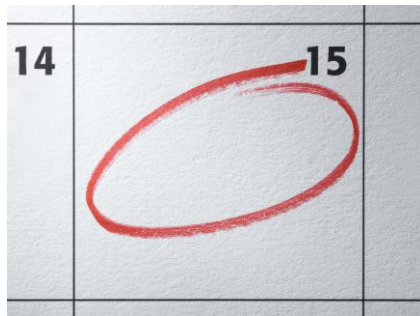
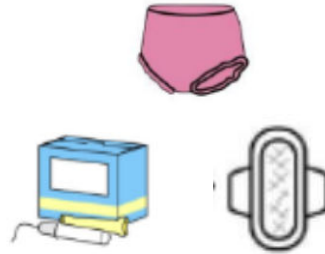
# Periods

- Some studies suggest age of first period is a little bit earlier in women with DS
- Others suggest age is about the same as women without DS/same age as their mothers
- Managing periods
  - Can be challenging
  - With support, skills to succeed can be learned!



# Managing periods

- Period Kits for school
- Variety of products
- Practice!
- Period tracking
- Period suppression



# What about contraception?

- Many reasons for using contraceptives:
  - Contraception
  - Heavy or painful periods
  - Period suppression
  - PMS
  - Etc.
- Many types of contraceptives
- More information available in resources

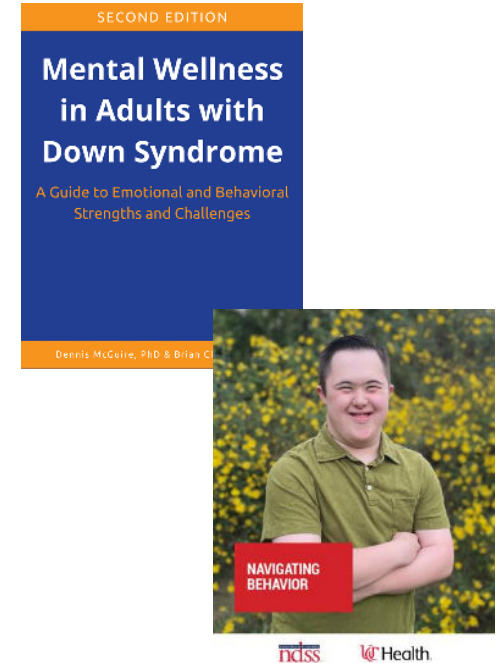


# What about mood and behavior during puberty?

- Mood swings and irritability are common and normal during puberty
- One half of all cases of mental health disorders reportedly start before age 18, and average age of onset is 14 (Luo et al. 2024)
- Mental health disorders are more common in adults with Down syndrome

# Resources for behavior management

- [All Behavior Resources](#)
- [All Mental Health and Wellness Resources](#)
- [Behavior Change in People with Down Syndrome Article](#)
- [Behavior Changes in Individuals with Down Syndrome Webinar Recording](#)
- [Mental Wellness in Adults with Down Syndrome Book](#)
- [Navigating Behavior Guide](#) (National Down Syndrome Society)



# Puberty - the how

# Parents role as sexuality educators

- Recognize sexuality as a healthy and positive aspect of being human.
- Acknowledge your own attitudes about sexuality and disability.
- Communicate your values.
- Share information
  - Teach how the individual learns best.
  - Provide opportunities to practice new skills.
  - Use teachable moments.
  - Be a role model.

# Ways to approach sexuality education

## Planful approach

When a situation involving sexuality or sexual behavior arises, **the parent/disability service provider takes the initiative and uses the opportunity to teach** instead of punish or scold. Being planful creates a learning experience for everyone involved, leading to improved communication and knowledge.

## Reactive approach

When a situation involving sexuality or sexual behavior arises, **the parent/disability service provider responds to the situation by restricting, punishing or limiting the behavior or communication.** This response contributes to a negative message about sexuality and sexuality education.

# Example

Your teenager frequently humps or grinds on the floor or on furniture.

## Reactive approach

- Yell at them to stop.
- Tell them they are embarrassing you.
- Take away access to Ipad.

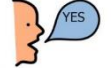





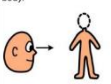

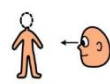








## Planful approach

- Politely redirect.
- Talk about concepts of public and private.
- This action needs to be done in private only.
- Confirm that the bedroom at home with the door closed is a private space.
- Review masturbation visuals.
- Let them know they can come to you with any questions.

# Consent

- Give permission

## Story About Consent

<p>Consent means to give permission for something to happen.</p> 	<p>It is ok for me to change my mind after I give consent.</p> 	<p>That means I can say yes one time and say no another time.</p> 	<p>I will NOT get in trouble if I change my mind.</p> 	<p>My consent is important to decide who will touch my body.</p> 
<p>My consent is important to decide who will see the private parts of my body.</p> 	<p>My consent is important to decide if I will see or touch another person's body.</p> 	<p>Other people can give consent too.</p> 	<p>The other person gets to choose if I can see or touch his or her body.</p> 	<p>For intimate behavior to happen both people need to give permission.</p> 
<p>The law says children can NOT give consent for intimate behavior.</p> 	<p>Intimate behavior without consent is against the law.</p> 	<p>If this happens you or your parents can report it to the police.</p> 	<p>It is NOT consent if someone asks you to keep a secret about intimate behavior.</p> 	<p>It is NOT consent when someone gives you gifts, money, or treats to get you to do something sexual you do not want to do.</p> 
<p>It is NOT consent when someone threatens or forces you to do something sexual you do not want to do.</p> 	<p>If I have questions about consent I can ask my parents.</p> 			

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## Story About Consent

# Privacy

## Private body parts, private places, private behaviors, and private talk

<p>Privacy means no one should see my body without my permission.</p>	<p>My body is private.</p>	<p>My body parts that can be covered by a bathing suit are private.</p>	<p>My penis, scrotum, and bottom are private body parts.</p>	<p>My parents can see my private body parts with my permission.</p>
<p>My doctor can see my private parts during a medical exam with my permission.</p>	<p>No one else should see my private parts without my permission.</p>	<p>Some behaviors are private.</p>	<p>No one can enter my space without my permission.</p>	<p>Getting dressed is a private behavior.</p>
<p>Going to the bathroom is a private behavior.</p>	<p>Some places are private.</p>	<p>My bathroom at home is private.</p>	<p>The bathroom at school or work is not private. It is public.</p>	<p>My bedroom is a private place.</p>
<p>When I want privacy in my room, I can close the door.</p>	<p>I can talk about private things with my parents at home.</p>	<p>I should not talk about private things when I am in public.</p>	<p>If I have questions I can talk to my parents.</p>	<p>Privacy means my body is special.</p>

Story about Privacy for Boys

### [Story About Privacy](#)

**PRIVATE VS. PUBLIC**

FEMALE

PRIVATE	PUBLIC

<p>Public means lots of other people are around.</p>	<p>School is a public place.</p>	<p>My classroom at school is a public place.</p>	<p>Work is a public place.</p>	<p>The bathroom at school or work is a public place.</p>
<p>The bathroom stall at school or work is a private space.</p>	<p>I can change clothes at school or work in a bathroom stall because it is private. The door closes and locks.</p>	<p>I can use the toilet in a bathroom stall because it is private. The door closes and locks.</p>	<p>Stores are public places.</p>	<p>Restaurants are public places.</p>
<p>I can do lots of things in public.</p>	<p>I can eat in public.</p>	<p>I can play with my toys and my friends in public.</p>	<p>I can talk to my parents and friends in public.</p>	<p>There are things I can NOT do in public.</p>
<p>When I am in public I should NOT show the private parts of my body.</p>	<p>When I am in public I should NOT show private behaviors.</p>	<p>When I am in public I should NOT talk about private things.</p>	<p>If I have questions about public and private, I can talk to my parents.</p>	

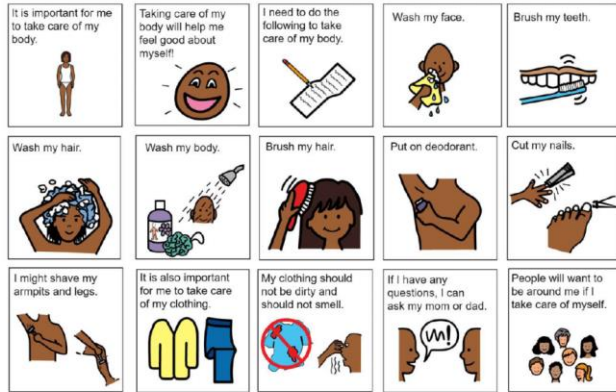
Story about Public

### [Private vs. Public Visual](#)

### [Story About Public](#)

# Hygiene

## Story About Personal Hygiene

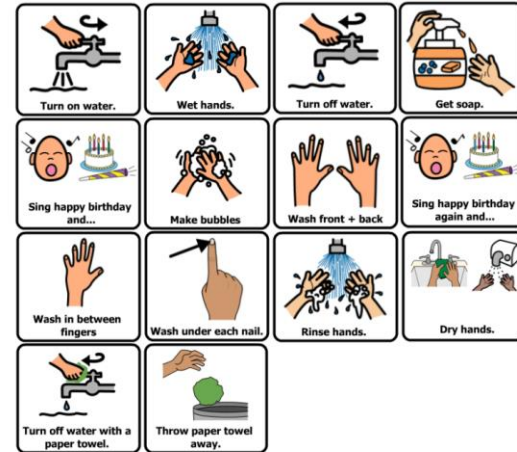


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## Story About Personal Hygiene

## How to Wash Your Hands



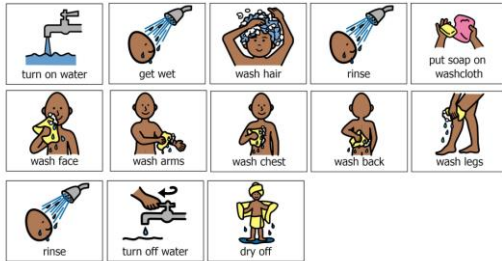
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## How to Wash Your Hands

# Hygiene

## My Shower Routine



[Create a Showering or Bathing Routine Visual](#)

## PERSONAL HYGIENE CHART

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
take teeth to shower							
brush teeth							
wash face							
use deodorant							
use lotion							
brush hair							
shave							
trim nails							

My outfit should...

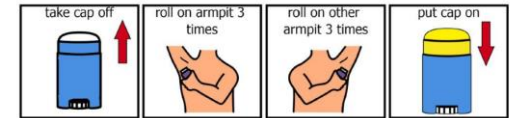
be clean

match

be okay for the weather

[Personal Hygiene Chart](#)

## How To Put On Deodorant

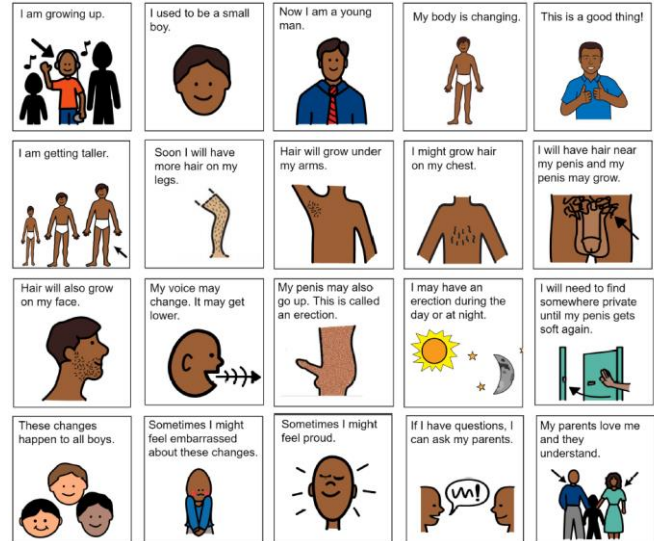


[How To Put On Deodorant](#)

# Body changes



Story about Body Changes for Girls



Story about Body Changes for Boys

## Story About Body Changes

# Menstruation

## Story About Getting My Period

<p>I am growing up.</p>	<p>My body is changing.</p>	<p>I will start my period soon.</p>	<p>I am not able to start or stop my period. My body is in control. This can be frustrating.</p>	<p>Sometimes it may surprise me.</p>
<p>It will happen one time a month for many years.</p>	<p>It may last 4 to 7 days each time I have it.</p>	<p>My mom can help me keep track of my menstrual cycle.</p>	<p>When I get my period I will see blood in my underpants.</p>	<p>When this happens I will need a hygiene product like a sanitary pad, tampon, or period panties.</p>
<p>Using a hygiene product will stop the blood from getting on my clothes.</p>	<p>Menstruation is private.</p>	<p>I can ask my mom questions about menstruation; she can help me decide which hygiene product is best for me to use.</p>	<p>My mom can help me choose a safe person at school or work to help me if I have my period.</p>	<p>During my period I may notice other changes in my body.</p>
<p>I may notice breast tenderness or stomach pain.</p>	<p>I can't start to think of my usual activities when I have my period.</p>			

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## Story About When to Change My Menstrual Hygiene Product

<p>I have my period.</p>	<p>I use hygiene products like a sanitary pad in my underwear, a tampon, or period panties when I have my period.</p>	<p>I need to change my hygiene product every few hours when I have my period.</p>	<p>There are some times when I will need to change my hygiene product.</p>
<p>When I wake up in the morning I will use a new hygiene product.</p>	<p>I will change my hygiene product at lunchtime.</p>	<p>I will change my hygiene product before dinner.</p>	<p>Finally, I will change my hygiene product when I get ready for bed.</p>
<p>Sometimes blood may get on my underwear by accident if I use a pad or tampon. If that happens I will need to change my underwear too!</p>	<p>I will let my mom know if there is blood in my underwear so she can help me wash it out. I will also need to tell her about my used period panties.</p>	<p>If I have questions, I can talk to a parent.</p>	

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## Menstruation (Period) Visuals

# Menstrual hygiene products

**Story About How to Change My Period Panties**

 This is how I will change my period panties.	 I will go to the bathroom for privacy.	 I can keep clean period panties in a bag so I can bring the supplies to the bathroom with me.	 When I go to the bathroom I will pull down my pants and my underwear.	 I will sit on the toilet.
 I will take off my pants and my dirty period panties.	 I will put my dirty period panties in the small bag.	 I will put the small bag inside the larger bag.	 I will take out the new pair of clean period panties and put them on with my pants.	 I should also use the toilet and wipe to make sure I am clean.
 I will stand up and put up my clean period panties and pants.	 I will flush the toilet.	 I will take the bag of supplies with me.	 I will wash my hands.	 If I have questions or need help, I can ask a parent.

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**Story About How to Change My Pad**

 This is how I will change my sanitary pad.	 I can keep clean pads and underwear in a bag so I can bring the supplies to the bathroom with me.	 When I go to the bathroom, I will pull down my pants and my underwear. I will sit on the toilet.	 I will make sure there is no blood on my underwear. If there is, I will use a paper towel to clean the blood.	 I will make sure there is no blood on my underwear. If there is, I will use a paper towel to clean the blood.
 I will remove my dirty sanitary pad by pulling down on the string.	 I will flush the paper to clean the toilet.	 I will remove the paper to clean the toilet.	 I will make sure the pad stays in my underwear.	 I will make sure the pad stays in my underwear.
 I will cover the wrapper and take the pad out.	 I will flush the toilet.	 I will take the bag of supplies with me.	 I will wash my hands.	 If I have questions or need help, I can ask a parent.

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**Story About How to Change My Tampon**

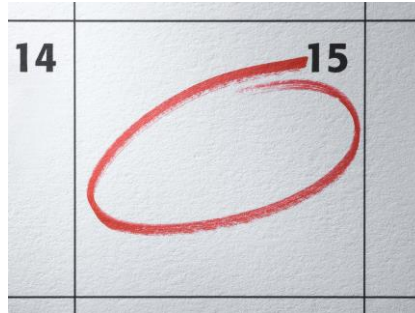
 This is how I will change my tampon.	 I can keep my tampons and clean underwear in a bag so I can bring the supplies to the bathroom with me.	 When I go to the bathroom, I will pull down my pants and my underwear.	 I will make sure there is no blood on my underwear. If there is, I will use a paper towel to clean the blood.	 I will make sure there is no blood on my underwear. If there is, I will use a paper towel to clean the blood.
 I will remove my dirty tampon by pulling down on the string.	 I will flush the paper to clean the toilet.	 I will remove the paper to clean the toilet.	 I will make sure the tampon stays in my underwear.	 I will make sure the tampon stays in my underwear.
 I will cover the wrapper and take the tampon out.	 I will flush the toilet.	 I will take the bag of supplies with me.	 I will wash my hands.	 If I have questions or need help, I can ask a parent.

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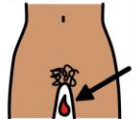




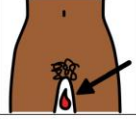


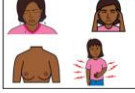






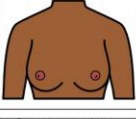














## Menstruation (Period) Visuals

# Menstrual hygiene tracking

- Use a calendar
- Apps
  - **Apple Health/Apple Cycles**
  - **Fitbit**
  - **Flo**
- Keep a journal



# PMS symptoms

<p>I get my period now.</p> 	<p>I may notice changes in my body up to 1 week before my period starts.</p> 	<p>These changes are premenstrual symptoms or PMS.</p> 	<p>I may have some of these symptoms each month.</p> 	<p>Or I may not have any symptoms at all.</p> 	<p>I get my period now.</p> 	<p>I may notice changes in my body up to 1 week before my period starts.</p> 	<p>These changes are premenstrual symptoms or PMS.</p> 	<p>I may have some of these symptoms each month.</p> 	<p>Or I may not have any symptoms at all.</p> 
<p>When I have symptoms, I can do things to help me feel better.</p> 	<p>I can take medicine if I am in pain.</p> 	<p>I can use a heating pad if I have cramps.</p> 	<p>I want to make sure I get good sleep.</p> 	<p>Exercise can also help me feel better.</p> 	<p>My breasts might be painful to touch.</p> 	<p>My stomach might hurt or feel crampy. I may have diarrhea or feel constipated.</p> 	<p>I may feel more tired during the day.</p> 	<p>My head might hurt.</p> 	<p>I may see pimples on my face.</p> 
<p>Eating healthy foods can also help me feel better.</p> 	<p>Calming activities can help with my mood.</p> 	<p>Calming activities might by doing yoga, reading, listening to music, or going for a walk.</p> 	<p>I can ask my mom to help me with my PMS and how to feel better.</p> 	<p>I can still do most of my usual activities when I have PMS.</p> 	<p>I may cry or have trouble managing my emotions.</p> 	<p>PMS is a private topic.</p> 	<p>I can ask my mom questions about how I am feeling and she can help me.</p> 	<p>My mom can help me choose a safe person at school or work to help me if I have PMS.</p> 	<p>I can still do most of my usual activities when I have my period.</p> 

## Stories About Period Symptoms

# Erections

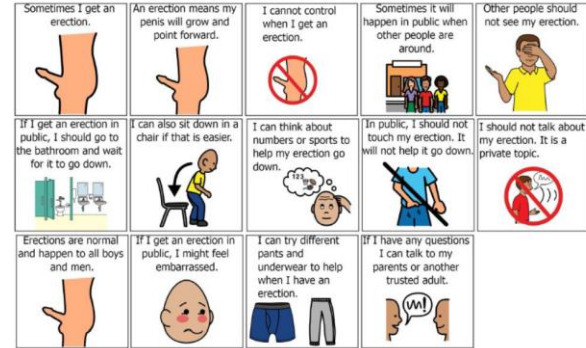
A Story About Erections



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A Story About Erections



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## Stories About Erections and Wet Dreams

# Nocturnal emissions

A Story About Wet Dreams



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A Story About Wet Dreams

















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Advocate Medical Group  
Adult Down Syndrome Center

## Stories About Erections and Wet Dreams

# Masturbation

<p>My special private time.</p> 	<p>My body is mine.</p> 	<p>I can touch myself.</p> 	<p>Some touches feel very good.</p> 	<p>I like to touch my private parts.</p> 
<p>NO ONE should see me touch my private parts.</p> 	<p>My bedroom is a private place.</p> 	<p>My bathroom at home is a private place.</p> 	<p>I will close the door so I can have privacy.</p> 	<p>Touching my private parts is something I do when I am alone.</p> 
<p>If Mom or Dad knocks on my door, I can say, "I'm busy."</p> 	<p>It is ok for ME to touch MY OWN penis and testicles.</p> 	<p>If my penis feels sticky, I can clean it off with a towel or washcloth.</p> 	<p>I put my clothes on and wash my hands when I am done.</p> 	<p>If I have questions, I can talk to my Mom and Dad about my special private time.</p> 
<p>Touching myself is one way I can make myself feel good. And that is ok!</p> 				

A Story about Male Masturbation

<p>My special private time.</p> 	<p>It is ok for ME to touch MY OWN penis and testicles.</p> 	<p>NO ONE should see me touch my private parts.</p> 	<p>It is NOT ok to rub or touch my private parts in front of others even if I have my clothes on.</p> 	<p>My bedroom is a private place.</p> 
<p>My bathroom at home is a private place.</p> 	<p>I will close the door so I can have privacy.</p> 	<p>Touching my private parts is something I do when I am alone.</p> 	<p>If Mom or Dad knocks on my door, I can say, "I'm busy."</p> 	<p>My penis may get big and firm. This is called an erection. It is ok. It will get soft again!</p> 
<p>When I have an erection, I can touch my penis.</p> 	<p>I take off my clothes when I want to masturbate.</p> 	<p>I hold my penis and move my hand up and down the shaft.</p> 	<p>I can use a lubricant to help if it hurts to touch my penis.</p> 	<p>I can look at pictures or a movie to help me think sexy thoughts.</p> 
<p>I can touch my penis while it feels good. It may take a few minutes.</p> 	<p>A little sticky liquid might squirt out of my penis. This is ok. It is not pee. It is semen.</p> 	<p>I will wipe my penis when I am done.</p> 	<p>I put my clothes on and wash my hands.</p> 	<p>If I have questions, I can talk to my Mom or Dad about my special private time.</p> 

Story about How to Masturbate-Male

## Stories About Masturbation

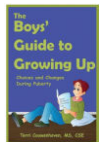
# Books for boys with DS



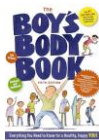
[What's Happening to Tom?: A book about puberty for boys and young men with autism and related conditions \(Sexuality and Safety with Tom and Ellie\): Reynolds, Kate E., Powell, Jonathon: 9781849055239: Amazon.com: Books](#)



[What's Happening to My Body? Book for Boys: Revised Edition: Madaras, Lynda, Madaras, Area, Sullivan, Simon: 9781557047656: Amazon.com: Books](#)



[The Boys' Guide to Growing Up: Choices & Changes During Puberty: Couwenhoven, Terri: 9798218151744: Amazon.com: Books](#)

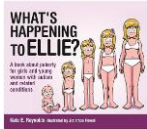


[The Boy's Body Book \(Fifth Edition\): Everything You Need to Know for a Healthy, Happy YOU! \(Boys & Girls Body Books\): Dunham, Kelli, Robert Anastas: 9781604338324: Amazon.com: Books](#)



[Guy Stuff: The Body Book for Boys \(American Girl® Wellbeing\): Natterson, Dr. Cara, Player, Micah: 9781683370260: Amazon.com: Books](#)

# Books for girls with DS



[What's Happening to Ellie?: A book about puberty for girls and young women with autism and related conditions \(Sexuality and Safety with Tom and Ellie\): Reynolds, Kate E., Powell, Jonathon: 9781849055260: Amazon.com: Books](#)



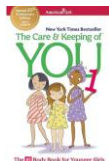
[What's Happening to My Body? Book for Girls: Revised Edition – An Essential Puberty and Health Guide for Ages 10 and Up: Madaras, Lynda, Madaras, Area, Sullivan, Simon: 9781557047649: Amazon.com: Books](#)



[The Girls' Guide to Growing Up: Choices and Changes in the Tween Years: Couwenhoven, Terri: 9798218243463: Amazon.com: Books](#)



[The Girl's Body Book \(Fifth Edition\): Everything You Need to Know for a Healthy, Happy YOU! \(Boys & Girls Body Books\): Dunham, Kelli, Tallardy, Laura, Robert Anastas: 9781604338331: Amazon.com: Books](#)



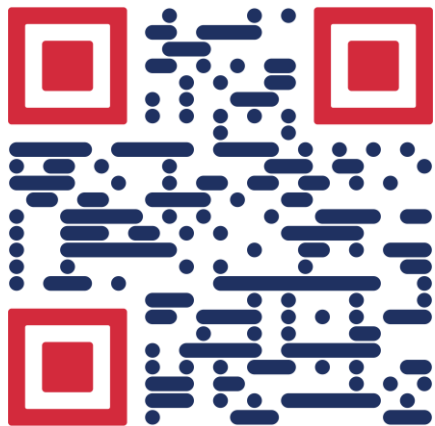
[The Care and Keeping of You 1: The Body Book for Younger Girls \(American Girl® Wellbeing\): Schaefer, Valorie, Natterson, Cara: 9781683372301: Amazon.com: Books](#)

# Resources

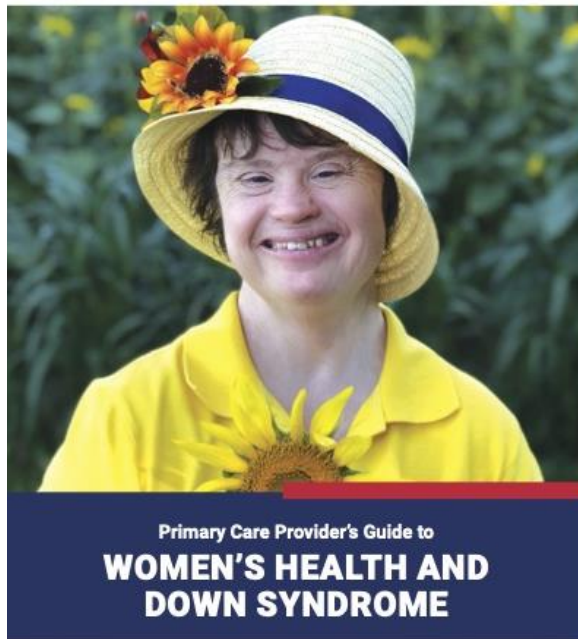


<https://adultdownsyndrome.org/resources/sexuality-resources/>

# Women's Health and Down Syndrome



[Women's Health Guide](#)



## INTRODUCTION

Down syndrome is the most common chromosomal condition diagnosed in the United States.<sup>1</sup> The mean life expectancy of a person with Down syndrome in 1950 was 26 years old; that mean has increased to 53 in the mid 2010s, although ethnic differences in life expectancy do persist, as a result of disparities in social determinants of health.<sup>2</sup> As the population of people living with Down syndrome grows, the understanding of the condition and its associated health differences continues to increase. In 2016, there were estimated to be 217,163 people with Down syndrome in the United States.<sup>1</sup>

Despite this increase in Americans with Down syndrome, it is estimated that only 5% of individuals aged 18 and older have access to a clinic specializing in caring for adults with Down syndrome.<sup>3</sup> Most people with Down syndrome receive medical care from their primary care physicians.

Additionally, one study estimated that women with Down syndrome received substantially less gynecological health care compared to women without Down syndrome, and women with Down syndrome received less gynecological care compared to other forms of health care.<sup>4</sup>

To help address the need for improved health care for women with Down syndrome, this guide provides primary care providers with current data and information about their unique health care needs. It is arranged into cases to demonstrate how clinicians may encounter these topics. The cases presented are not actual patients but are based on frequently met concepts and questions.

This guide is informed by women with Down syndrome. Their participation, comments, and questions provide an underlying current to every topic. Their self-advocate perspectives will be outlined throughout the guide. They send an unapologetically clear message: life with Down syndrome is great!



<sup>1</sup> NATIONAL DOWN SYNDROME SOCIETY

# CARE Down Syndrome



## CARE Down Syndrome

Education and resource hub  
for healthcare professionals

- Free CME
- 2-hour course
- Reference articles



# DSMIG-USA



## Down Syndrome Medical Interest Group-USA

Interdisciplinary group of healthcare professionals who care for people with Down syndrome

- Membership
- Project ECHO
- Webinars
- Free CME



# Resource Library



The screenshot shows the homepage of the Advocate Medical Group Adult Down Syndrome Center. At the top left is the logo with a cross icon and the text "Advocate Medical Group Adult Down Syndrome Center". To the right is a search bar with the placeholder text "Search for resources, events, and more" and a magnifying glass icon. Further right is a button labeled "Support Our Mission" with a heart icon. Below the header is a navigation menu with links for "Resources", "Events & Programs", "For Professionals", "About Us", and "FAQs". The main content area features a large photograph of a healthcare professional in a white lab coat high-fiving a young woman with Down syndrome. Overlaid on the photo is the text "Adult Down Syndrome Center" in a large white font. Below this is a paragraph: "Founded in 1992, the Advocate Medical Group Adult Down Syndrome Center (ADSC) has served the physical, mental, and social health needs of thousands of teens and adults with Down syndrome." At the bottom of the main area are three colored buttons: "Find a Doctor" (light blue), "Browse Resources" (light green), and "For Professionals" (orange).

[adulldownsyndrome.org](http://adulldownsyndrome.org)

# Questions?



[Resource Library](#)



[@adultdownsyndromecenter](#)



[Email List](#)

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# Support our mission

We are able to offer these webinars free of charge through the generosity of donors. If you would like to support the Adult Down Syndrome Center's Research and Education Program, please see our [Giving Page](#).

