

Enhancing Women's Health: Key Insights from the *Primary Care Provider's Guide to Women's Health and Down Syndrome*

with Hannah Graham, MD
October 8, 2024



NDSS Mission

NDSS empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions.

NDSS Core Programs

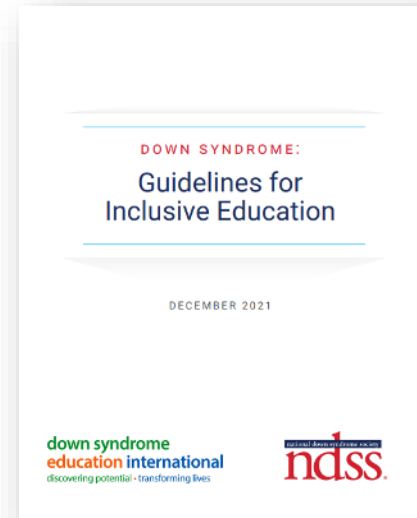
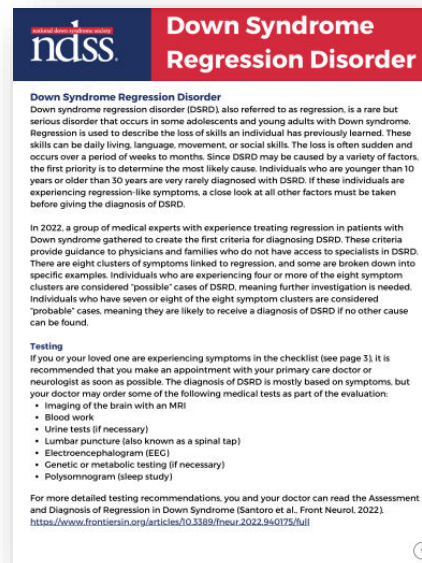
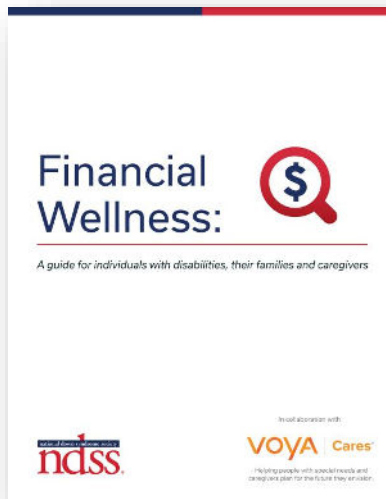
NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming:

- Resources & Support
- Advocacy & Policy
- Community Engagement

NDSS Resources and Support

Resources & Support

- 1-800 helpline and info email
- Resources and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving and more



NDSS Core Programs

Advocacy & Policy

- Federal, state, and local advocacy
- Develop and improve laws to positively impact people with Down syndrome across the country and affirm their human rights
- Legislative agenda spans the life experience of individuals with Down syndrome



NDSS Core Programs

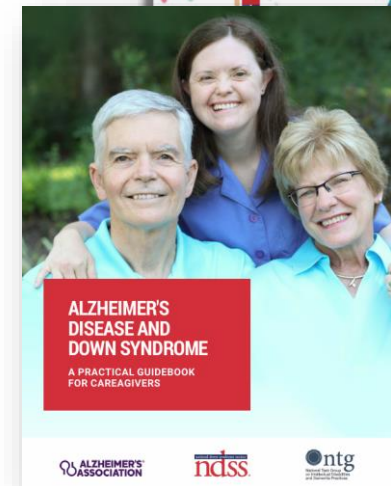
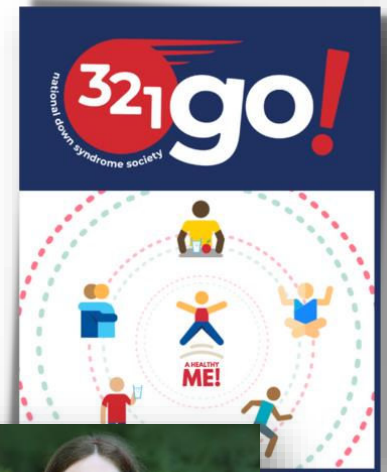
Community Engagement

- Scholarships, grants, and awards
- National Buddy Walk® Program
- Times Square Video presentation
- Athlete Ambassador Program
- DS-Ambassador Program
- Run for 3.21 relay
- Virtual Racing for 3.21 for World Down Syndrome Day
- Gala, golf, and more!

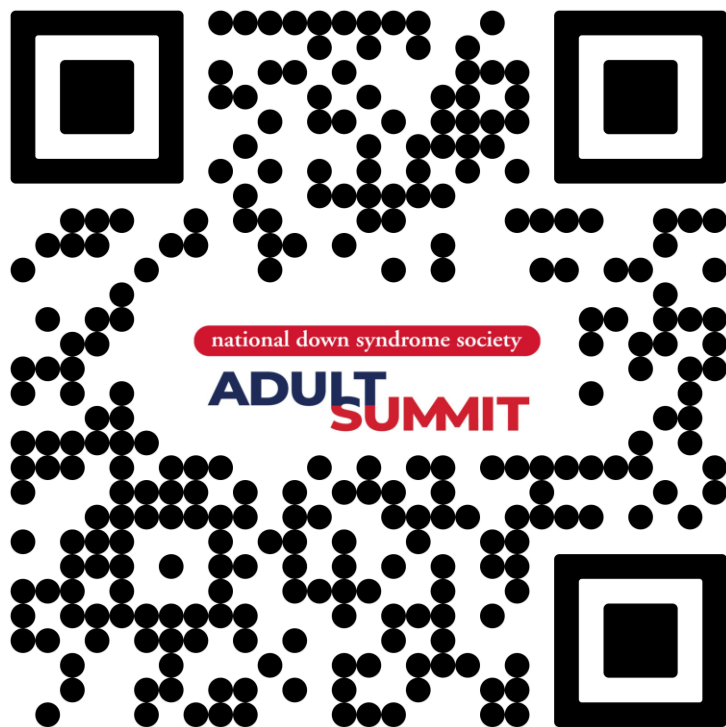


Health & Wellness

- Health-related webpages for website, informative resources, and guidebooks
- Health-related advocacy with Policy team
- [321go!](#)
- [Aging and Down Syndrome: A Health & Well-Being Guidebook](#)
- [Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers](#)
- [Self-Advocacy at Medical Appointments](#)



NDSS 2024 Adult Summit



Where: The Westin South Coast Plaza in Costa Mesa, CA

When: November 14-16, 2024

Session Topics: Health, finance, research, advocacy, employment, education, and self-advocacy

Get your tickets today:

<https://ndss.org/adult-summit>

Speaker Bio

Dr. Hannah Graham



- Hannah Graham, MD is a physician at the Advocate Health Care Adult Down Syndrome Center in Park Ridge, IL. The Center serves people aged 12 + with Down syndrome.
- Dr. Graham graduated from Loyola University Chicago Stritch School of Medicine. She completed her residency in Family Medicine at Advocate Aurora Lutheran General Hospital. Prior to working at the Adult Down Syndrome Center Dr. Graham practiced general family medicine.
- Currently a faculty member with the Family Medicine Residency Program at Lutheran General Hospital and the Assistant Education Director of Family Medicine at Rosalind Franklin University Chicago Medical School.
- She is also a mom to a young child with Down syndrome.

Please Note

- This presentation is intended for families, caregivers, health care professionals, and service providers of individuals with Down syndrome.
- The information in this presentation is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.
- We recommend that you bring specific questions about an individual with Down syndrome to their medical and/or therapy providers.

Objectives

1. Understand similarities and differences in the health needs of women with Down syndrome compared to women without Down syndrome.
2. Identify resources for medical providers to learn about women's health and Down syndrome.
3. Learn strategies to help patients understand women's health topics.

Support for the Guide

- Number of individuals with Down syndrome living in the United States has increased.
- Only 5% of individuals with Down syndrome ages 18 and older have access to a specialized clinic. Therefore, most adults receive medical care from their primary care physicians (*Santoro, Campbell, Balasubramanian, Haugen, Schafer, Mobley, 2021*).
- 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.

Primary Care Provider's Guide to Women's Health and Down Syndrome



**Primary Care Provider's Guide to
WOMEN'S HEALTH AND
DOWN SYNDROME**

INTRODUCTION

Down syndrome is the most common chromosomal condition diagnosed in the United States.¹ 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.² 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.³

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.⁴ 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.⁵

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!



© NATIONAL DOWN SYNDROME SOCIETY

Download the guide for free on the [NDSS website!](https://www.ndss.org)

Primary Care Provider's Guide to Women's Health and Down Syndrome

TABLE OF CONTENTS

Introduction.....	6
Importance of Learning about Women's Health and Down Syndrome.....	7
How Women with Down Syndrome Learn.....	9
Case 1.....	11
• Menarche	
• Period Hygiene	
• HPV Vaccination	
Case 2.....	14
• Menorrhagia	
• Dysmenorrhea	
• Birth Control	
• Period Suppression	
Case 3.....	19
• Oligomenorrhea and Amenorrhea	
• Polycystic Ovarian Syndrome (PCOS)	
Case 4.....	21
• PMS and PMDD	
Case 5.....	23
• Cervical Cancer	
• Pelvic Exams	
• Bacterial Vaginosis and Vulvovaginal Candidiasis Infections	
• STI Testing	
Case 6.....	26
• Sexual Exploitation	
• Disclosure	

Case 7.....	27
• Guardianship and Sexual Activity	
• Assessing for Consent	
Case 8.....	28
• Pregnancy	
• Sterilization	
Case 9.....	30
• Menopause	
• Osteoporosis	
• Breast Cancer	
Case 10.....	34
• Abnormal Uterine Bleeding	
• Fibroids	
• Ovarian Cancer and Endometrial Cancer	
Conclusion.....	36
Resources.....	37
• Resources for Providers	
• Resources for Women with Down Syndrome and Caregivers	
Appendix.....	39
• Visual Supports	
References.....	42

DISCLAIMER: This guidebook was created for the sole purpose of educating physicians and other health care providers on the differences and similarities that exist in the health care of women with Down syndrome. This resource is not intended to be used by any person in lieu of the patient-specific recommendations of their health care providers. The information contained in this guidebook is wholly owned by the National Down Syndrome Society and may not be copied or otherwise used for any purpose other than the educational advancement of the reader. The National Down Syndrome Society is not, and shall not be, liable for any damages associated with the use or misuse of the information outlined in this guidebook.

Down Syndrome Behavioral Phenotype

A Unique Learning Profile: Individuals with Down Syndrome

Hearing impairment

Some 50-70% of adults with Down syndrome experience hearing loss. Sensorineural and conductive hearing loss are common. Will have difficulty listening in noisy environments, processing spoken language, discriminating speech sounds, and learning phonics.

Verbal memory weakness

Difficulty learning from listening – maintaining attention, retaining instructions, memorizing sequences, and learning new vocabulary and information. Challenges in retaining and consolidating learning into long-term memory.

Delayed motor skills

Linked to low muscle tone, loose ligaments, and developing motor plans. Affects all physical activities. Delayed self-help skills and handwriting progress but will improve with practice. May have difficulty staying on task and multi-tasking. Easily distracted by other factors. Tires easily.

Speech & language delay

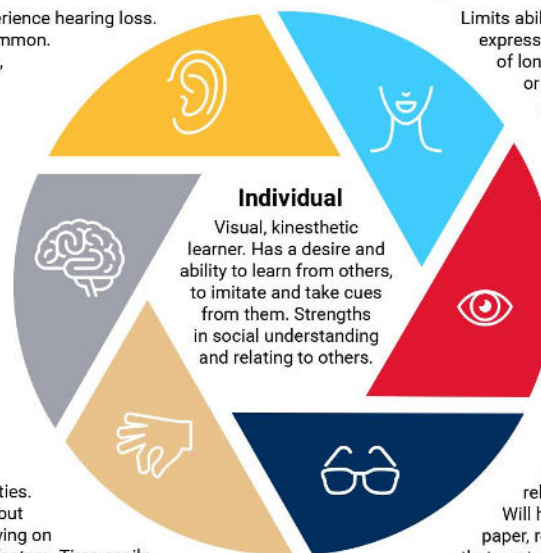
Limits ability to communicate. Understands more than can express – knowledge may be underestimated. Affects processing of long sentences, learning from listening, understanding new or subject-specific vocabulary, word finding, forming sentences, understanding instructions, reading comprehension skills, and thinking and reasoning.

Visual learning strengths

Ability to learn and use signs and gestures, to learn to read and use written words. Strengths in learning through imitation, from modeling and demonstration. Learns well from visual resources (pictures, photos, diagrams, symbols, concrete materials, digital technologies, and apps).

Visual impairment

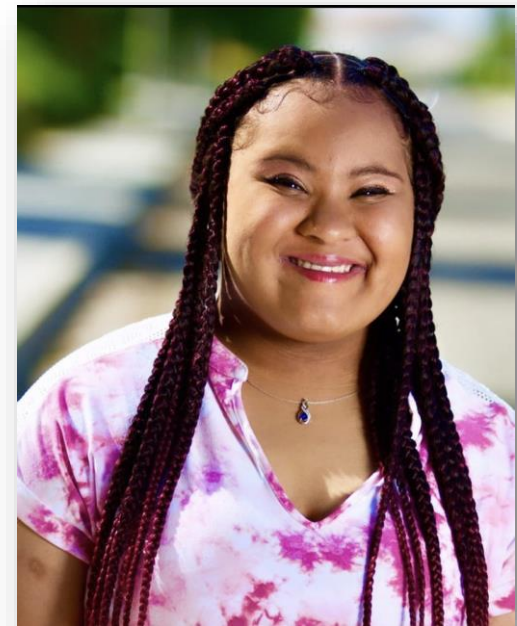
Common in adults with Down syndrome. Challenges with depth perception. Can experience early onset of age-related vision issues. Bifocals are routinely recommended. Will have difficulties with writing, using a pencil on blue-lined paper, reading <18 point font, coping with text/diagrams/pictures that are too cluttered, detailed, or have little contrast.



This graphic, adapted from *Down Syndrome: Good Practice Guidelines for Inclusive Education*, outlines strengths and challenges associated with the main aspects of the specific learning profile for people with Down syndrome, as well as the unique range of sensory, physical, and cognitive needs of this group of learners.

Common Characteristics in Women with Down Syndrome

- Visual learners
- Concrete thinkers
- The “Groove”
- Receptive vs expressive language
- The brain



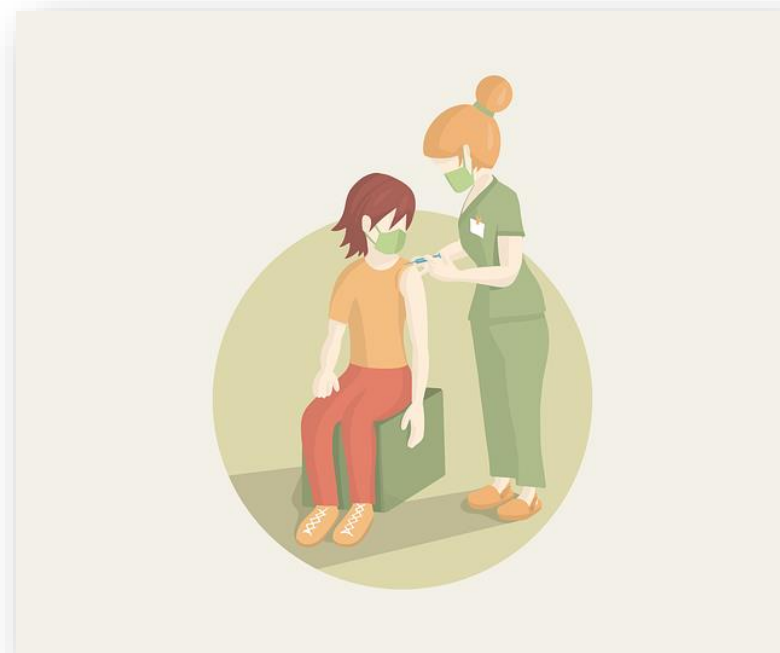
What Teaching Strategies Work for Most Individuals

- Visuals and videos
- Modeling
- Repetition
- Practice
- Social support
- Being as concrete as possible
- Establishing a routine



Human Papillomavirus (HPV) Vaccine

- No specific recommendations for people with Down syndrome.
- Vaccine is generally well-tolerated.




Menstruation

- **Menarche**
 - Average age of menstruation is around 12 (*Biro, Pajak, Wolff, et al., 2018*).
 - Similar to women without Down syndrome.
- **Period Hygiene**
 - With support, women can be independent or partially independent.
 - Period suppression does not need to be the first line of care.

Menstruation

[Menstruation \(Period\) Visuals | Adult Down Syndrome Center \(advocatehealth.com\)](https://www.advocatehealth.com)

Story About Getting My Period



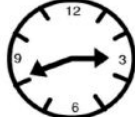








<p>I am growing up.</p> 	<p>My body is changing.</p> 	<p>I will start my period soon.</p> 	<p>I am not able to start or stop my period. My body is in control. This can be frustrating.</p> 	<p>Sometimes it may surprise me.</p> 
<p>It will happen one time a month for many years.</p> 	<p>It may last 4 to 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 still do most of my usual activities when I have my period.</p> 			

© 2023 Adult Down Syndrome Center

 Advocate Medical Group
Adult Down Syndrome Center

Period Hygiene

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> 	

© 2023 Adult Down Syndrome Center
















 Advocate Medical Group
Adult Down Syndrome Center

Period Hygiene

Story About How

<p>This is how I will change my sanitary pad.</p> 	<p>I will go to the bathroom for privacy.</p> 	<p>I can keep clean underwear in a bag so I can bring it to the bathroom with me.</p> 
<p>I will fold it in half so I do NOT see the blood. Then I will wrap it in toilet paper.</p> 	<p>I will throw the pad and toilet paper in the garbage can.</p> 	<p>I will NOT sit on the toilet.</p> 
<p>I will open the wrapper and take the pad out.</p> 	<p>I will remove the paper so I can see the sticky tape.</p> 	<p>I will put the sticky side of the pad on my underwear.</p> 
<p>I should also use the toilet and wipe to make sure I am clean.</p> 	<p>I will pull up my underwear and pants.</p> 	<p>I will take my supplies with me.</p> 

Story About How to Change My Period Panties

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

How to Change My Tampon

<p>I will keep my tampons and clean underwear in a bag so I can bring the supplies to the bathroom with me.</p> 	<p>When I go to the bathroom I will pull down my pants and my underwear.</p> 	<p>I will sit on the toilet.</p> 
<p>I will remove the new applicator from the packaging.</p> 	<p>I will put the applicator in my vagina and push the plastic to insert the tampon in my vagina.</p> 	<p>I may need to stand up to make it easier to insert.</p> 
<p>I should also use the toilet and wipe to make sure I am clean.</p> 	<p>I will pull up my underwear and pants.</p> 	<p>I will flush the toilet.</p> 
<p>I have questions or need help, I can ask a parent.</p> 		

© 2023 Adult Down Syndrome Center

© 2023 Adult Down Syndrome Center

© 2023 Adult Down Syndrome Center

Advocate Medical Group
Adult Down Syndrome Center

Advocate Medical Group
Adult Down Syndrome Center

Advocate Medical Group
Adult Down Syndrome Center

Heavy or Painful Periods

- Nonsteroidal anti-inflammatory agents (NSAIDs) are a first line treatment.
- Similar for women with Down syndrome and without Down syndrome.
- More difficult for a woman with Down syndrome to express discomfort.



Premenstrual Syndrome (PMS) and Premenstrual Dysphoric Disorder (PMDD)

- Up to 12% of women experience these disorders (*Hofmeister & Bodden, 2016*).
- There are no studies comparing the prevalence of these conditions in women with Down syndrome. They appear to be as common in women with Down syndrome as in women without Down syndrome.
- Treatment can include birth control and selective serotonin reuptake inhibitors (SSRIs).

Birth Control

- Different methods of birth control
- Period suppression
- Women with Down syndrome and blood clot risk?
- Other considerations
 - History of migraines
 - Congenial heart disease

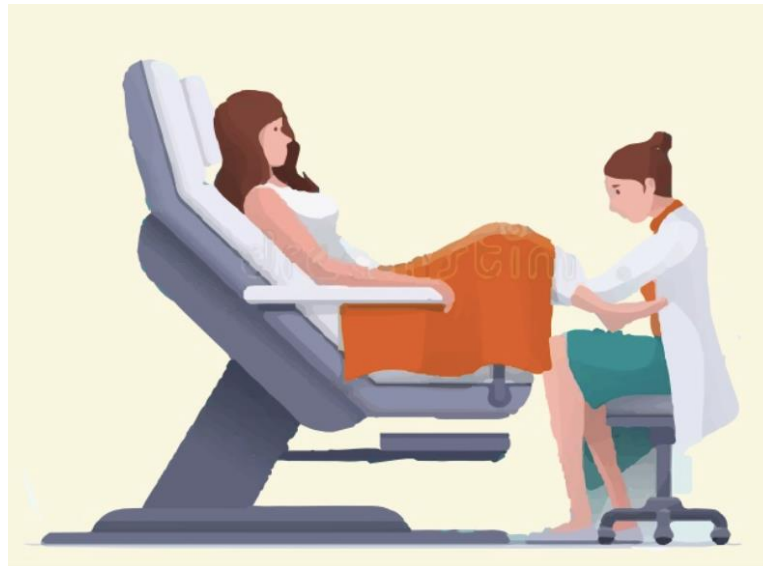


Polycystic Ovarian Syndrome (PCOS)

- Workup is the same for women with and without Down syndrome.
- Check thyroid!
- Treatment depends upon fertility goals.

Pelvic Exams

[Pelvic Exam Social Story | Adult Down Syndrome Center \(advocatehealth.com\)](https://advocatehealth.com)



Cancer

- **Cervical**
 - In a study of cancer mortality in people with Down syndrome, no mortality due to cervical cancer was reported (*Tomsa, Gutu, Cojocar, Gutiérrez-Bermejo, Flores, & Jenaro, 2021*).
 - No formal cervical cancer screening guidelines specific to women with Down syndrome.
 - Risk vs benefit.

Cancer

- **Breast**
 - A computer model shows it takes nearly 17,000 mammograms to save one life (compared to about 2,200 in women without Down syndrome). Due to false negative mammograms, the computer model also calculated it would take over 200 biopsies to save one life (*Alagoz, Hajjar, Chootipongchaivat, et al., 2019*).
 - There are no formal recommendations for breast cancer screening in women with Down syndrome. Notably, there are no separate data regarding the risk of breast cancer and screening for breast cancer in women with Down syndrome who also have a family history of breast cancer. (*Rethoré, Rouëssé, & Satgé, 2020*).

Sexuality

- **Sexually transmitted infections**
 - One study was found that reported on sexually transmitted diseases, and most were statistically less common in people with Down syndrome (*Maxwell, Watts Belser, & David, 2008*).
- **Sexual exploitation**
 - It is important to keep in mind that women with Down syndrome have lower rates of sexual activity but higher rates of sexual abuse.

Sexuality Education and Down Syndrome

- 73% of parents reported their child received sexuality education in the classroom setting, primarily a mainstream health class.
- 85% of parents reported previously initiating home-based sexuality education, however not with adapted materials.
- Parents understand the importance of sexuality education but lack the comfort and confidence in talking about it.
- Parents reported being more hesitant talking to their child with Down syndrome about sexuality topics compared to their other children.

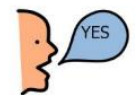





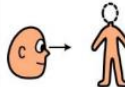

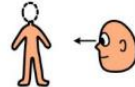








Consent

- A freely given “yes”.
- Giving permission.
- Components of consent
 - Information
 - Because opportunities for sexuality education are more limited or ineffectively adapted, people with Down syndrome may not understand the vocabulary typically used to assess consent.
 - Consider how you ask questions.
 - Voluntariness
 - The individual gets to decide who and how much someone touches and sees their body.
 - Ask permission before a physical exam or knock on closed door and wait for permission to enter.

Consent

[Story_About_Consent.pdf](http://advocatehealth.com)
(advocatehealth.com)

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> 			

© 2022 Adult Down Syndrome Center

 Advocate Medical Group
Adult Down Syndrome Center

Pregnancy

- Fertility rates for women with Down syndrome are reduced, but there have been many documented cases of women with Down syndrome giving birth (*Orthmann Bless, & Hofmann, 2020; Parizot, Dard, Janel, & Vialard, 2019*).
- Less than half of children born to a woman with Down syndrome have Down syndrome themselves (*Orthmann Bless, & Hofmann, 2020*).
- Women with mosaic Down syndrome are more likely to be able to become pregnant (*Orthmann Bless, & Hofmann, 2020*).
- Sterilization
 - There are legal and ethical nuances around sterilization.

Menopause

- The estimated average age of menopause in women with Down syndrome is between ages 44 and 46 (*Cosgrave, Tyrrell, McCarron, Gill, & Lawlor, 1999; Seltzer, Schupf, & Wu, 2001*).
- Many of the same symptoms for women with and without Down syndrome.
- The treatment of menopausal symptoms in women with Down syndrome is often very similar to the treatment of menopausal symptoms in women without Down syndrome.
- Women with Down syndrome have a relatively short interval between the age of menopause and the potential onset of dementia (*Schupf, Lee, Pang, et al., 2018*).



Menopause

[Menopause Visuals | Adult Down Syndrome Center \(advocatehealth.com\)](https://advocatehealth.com)

MENOPAUSE

<p>I am getting older. I am in my 40s.</p> 	<p>My body is preparing for menopause.</p> 	<p>Menopause is when I will stop having my period.</p> 	<p>This may take some time.</p> 	<p>My body will change.</p> 
<p>These changes can happen to all women as they get older.</p> 	<p>I will have days when I feel good!</p> 	<p>I will also have days when I do not feel so good.</p> 	<p>I may have some of the symptoms.</p> 	<p>Or I may not have symptoms at all.</p> 
<p>I may get hot during the day. This is called a hot flash.</p> 	<p>I may get hot when I sleep. This is called night sweats.</p> 	<p>My emotions may change throughout the day.</p> 	<p>I may feel tired during the day.</p> 	<p>I may not sleep well at night.</p> 
<p>I may gain weight.</p> 	<p>I may feel embarrassed by these body changes.</p> 	<p>I may get frustrated at times.</p> 	<p>I know I can get through it!</p> 	<p>If I have questions I can talk to a trusted adult.</p> 

Menopause

MENOPAUSE AND MY EMOTIONS

<p>My emotions may change throughout the day.</p>	<p>Sometimes this is called mood swings.</p>	<p>I can be happy.</p>	<p>Then I might become sad.</p>	<p>I may get frustrated at times.</p>
<p>I will be ok!</p>	<p>I can talk to someone about my feelings.</p>	<p>I can ask for some alone time.</p>	<p>I can go for a walk.</p>	<p>I can exercise or lift weights.</p>
<p>Yoga may also help me control my emotions.</p>	<p>I should keep doing all of the things I like to do!</p>	<p>Mood swings can happen to all women as they go through menopause.</p>	<p>If I have questions, I can talk with a trusted adult like my family, staff, or doctor.</p>	

MENOPAUSE AND MY WEIGHT

<p>I may gain weight.</p>	<p>My body shape will change and my clothes may fit differently.</p>	<p>It may be hard for me to lose the weight.</p>	<p>I may want to eat unhealthy foods.</p>	<p>But I should eat healthy foods.</p>
<p>I should drink plenty of water.</p>	<p>I should exercise.</p>	<p>Weight gain can happen to all women as they go through menopause.</p>	<p>If I have questions, I can talk with a trusted adult like my family, staff, or doctor.</p>	

MENOPAUSE AND HOT FLASHES

<p>I may get hot during the day. This is called a hot flash.</p>	<p>I may get hot when I sleep. This is called night sweats.</p>	<p>When I get hot, I may sweat.</p>	<p>My face may turn red.</p>	<p>Hot flashes can happen during the day.</p>
<p>Hot flashes can also happen at night.</p>	<p>Hot flashes can occur when it is hot out.</p>	<p>Hot flashes can occur even when it is cold out.</p>	<p>Hot flashes may only last a few minutes.</p>	<p>Hot flashes can happen several times a day.</p>
<p>I can wear thin layers of clothes to help when I get hot.</p>	<p>I can drink plenty of water.</p>	<p>I can use a fan to cool off.</p>	<p>I should NOT take a hot shower.</p>	<p>I should NOT drink too much coffee.</p>
<p>I should NOT eat too much spicy food.</p>	<p>Hot flashes can happen to all women as they go through menopause.</p>	<p>If I have questions, I can talk with a trusted adult like my family, staff, or doctor.</p>		

MENOPAUSE AND SLEEP

<p>It may be hard to fall asleep or stay asleep at night.</p>	<p>I may wake up to use the toilet.</p>	<p>I may wake up because of night sweats.</p>	<p>I may feel tired during the day.</p>	<p>It is ok to find time to relax during the day.</p>
<p>I may even take a nap during the day.</p>	<p>When it is time for bed, I should do something to help me relax.</p>	<p>I can read.</p>	<p>I can listen to music.</p>	<p>I could even meditate or pray.</p>
<p>I should go to sleep at the same time every night.</p>	<p>Trouble sleeping can happen to all women as they go through menopause.</p>	<p>If I have questions, I can talk with a trusted adult like my family, staff, or doctor.</p>		

Osteoporosis

- Osteoporosis is reportedly more common in women with Down syndrome than women without Down syndrome (*Chicoine, Rivelli, Fitzpatrick, Chicoine, Jia, & Rzhetsky, 2021*).
- DEXA scans may not be accurate in reporting bone density in women with Down syndrome (*Tsou, Bulova, Capone, et al., 2020*).
- There are few studies that report fracture risk in women with Down syndrome (*LaCombe & Roper, 2019*).
- “There is insufficient evidence to recommend for or against applying established osteoporosis screening guidelines” to adults with Down syndrome (*Tsou, Bulova, Capone, et al., 2020*).

Final Thoughts

- Life with Down syndrome is great!
- While there are differences, there are also a lot of similarities in the healthcare of women with Down syndrome.
- Lack of specialty clinics mean health care for women with Down syndrome is in the hands of primary care providers.
- Health care providers generally lack information to provide accurate health care for women with Down syndrome.

References

- Alagoz O, Hajjar A, Chootipongchaivat S, et al. Benefits and harms of mammography screening for women with Down syndrome: A collaborative modeling study. *J Gen Intern Med.* 2019;34(11):2374-2381. doi:10.1007/s11606-019-05182-5
- Biro FM, Pajak A, Wolff MS, et al. Age of menarche in a longitudinal US cohort. *J Pediatr Adolesc Gynecol.* 2018;31(4):339-345. doi:10.1016/j.jpag.2018.05.002
- Chicoine B, Rivelli A, Fitzpatrick V, Chicoine L, Jia G, Rzhetsky A. Prevalence of common disease conditions in a large cohort of individuals with Down syndrome in the United States. *J Patient Cent Res Rev.* 2021;8(2):86-97. doi:10.17294/2330-0698.1824
- Cosgrave MP, Tyrrell J, McCarron M, Gill M, Lawlor BA. Age at onset of dementia and age of menopause in women with Down's syndrome. *J Intellect Disabil Res.* 1999;43 (Pt 6):461-465. doi:10.1046/j.1365-2788.1999.00192.x
- Frank, K. & Sandman, L. (2019). Supporting parents as sexuality educators for individuals with intellectual disability: The development of the home B.A.S.E curriculum. *Sexuality and Disability, 37(3)*, 329-337. <https://doi.org/10.1007/s11195-019-09582-7>
- Frank, K. & Sandman, L. (2021). Parents as the primary sexuality educators for adolescents and adults with down syndrome: A mixed methods examination of the home B.A.S.E. for intellectual disabilities workshop. *American Journal of Sexuality Education.* <https://doi.org/10.1080/15546128.2021.1932655>
- Hasle H, Friedman JM, Olsen JH, Rasmussen SA. Low risk of solid tumors in persons with Down syndrome. *Genet Med.* 2016;18(11):1151-1157. doi:10.1038/gim.2016.23
- Hofmeister S, Bodden S. Premenstrual syndrome and premenstrual dysphoric disorder. *Am Fam Physician.* 2016;94(3):236-240.
- LaCombe JM, Roper RJ. Skeletal dynamics of Down syndrome: A developing perspective. *Bone.* 2020;133:115215. doi:10.1016/j.bone.2019.115215

References Continued

- Maxwell J, Watts Belser J, David D. The pelvic exam. In: *A Health Handbook for Women with Disabilities*. Hesperian Health Guides; 2008:130-134. Updated November 30, 2023. Accessed February 24, 2024. <https://en.hesperian.org/hhg/A Health Handbook for Women with Disabilities:The pelvic exam>
- Orthmann Bless D, Hofmann V. Pregnancies and births in women with Down syndrome – An analysis based on the Medical Statistics of Swiss Hospitals. *J Intellect Dev Disabil*. 2020;45(4):377-385. doi: 10.3109/13668250.2020.1767767
- Parizot E, Dard R, Janel N, Vialard F. Down syndrome and infertility: What support should we provide?. *J Assist Reprod Genet*. 2019;36(6):1063-1067. doi:10.1007/s10815-019-01457-2
- Rethoré MO, Rouëssé J, Satgé D. Cancer screening in adults with Down syndrome, a proposal. *Eur J Med Genet*. 2020;63(4):103783. doi:10.1016/j.ejmg.2019.103783
- Santoro SL, Campbell A, Balasubramanian A, Haugen K, Schafer K, Mobley W. Specialty clinics for adults with Down syndrome: A clinic survey. *Am J Med Genet A*. 2021;185(6):1767-1775. doi:10.1002/ajmg.a.62169
- Schupf N, Lee JH, Pang D, et al. Epidemiology of estrogen and dementia in women with Down syndrome. *Free Radic Biol Med*. 2018;114:62-68. doi:10.1016/j.freeradbiomed.2017.08.019
- Seltzer GB, Schupf N, Wu HS. A prospective study of menopause in women with Down's syndrome. *J Intellect Disabil Res*. 2001;45(Pt 1):1-7. doi:10.1046/j.1365-2788.2001.00286.x
- Smith AJB, Applebaum J, Tanner EJ, Capone GT. Gynecologic care in women with Down syndrome: Findings from a national registry. *Obstet Gynecol*. 2020;136(3):518-523. doi:10.1097/AOG.0000000000003997
- Tomsa R, Gutu S, Cojocar D, Gutiérrez-Bermejo B, Flores N, Jenaro C. Prevalence of sexual abuse in adults with intellectual disability: Systematic review and meta-analysis. *Int J Environ Res Public Health*. 2021;18(4):1980. doi:10.3390/ijerph18041980
- Tsou AY, Bulova P, Capone G, et al. Medical care of adults with Down syndrome: A clinical guideline. *JAMA*. 2020;324(15):1543-1556. doi:10.1001/jama.2020.17024

Questions?



Post-Webinar Survey



NDSS Resources

- Primary Care Provider's Guide to Women's Health and Down Syndrome
- Three P's
- Gynecological Exam
- Feminine Hygiene

The Three P's

Everyone does it and yet no one wants to talk about it.

Pee

- Urine should be clear and yellow. If it is not, you should tell someone.
- Use unscented toilet paper or unscented bathroom wipes. Wipe front to back.
- Use clean toilet paper with every wipe.
- Wash your hands while you sing "Happy Birthday" after you flush.

Period

Having a period is normal and a natural part of being a woman.

- Blood can be bright red, dark red or rusty red in color. Color can change.
- You can use a feminine product (maxi pad or tampon) or use period underwear. You may want to practice wearing a maxi pad, pantyliner or period underwear before you use it.
- Do not use a tampon if you are not having your period.
- It is very important to change your maxi pad or tampon every 2-4 hours, depending on the flow. Change period underwear every morning and before bedtime.
- Wrap your maxi pad or tampon in toilet paper and put it in the trash can. Never flush a maxi pad or tampon down the toilet. Period underwear can be rinsed, washed and reused.
- It is important to empty trash bin every two days.
- Wash your hands while singing "Happy Birthday" after changing your feminine product.
- Keep track of the first and last day of your period on a calendar or use a period tracker app. Flo, Period Tracker, Period Diary App and Apple Health are some examples of trackers. Your period should come every 21 to 35 days. This varies if you are on medication to change a period.
- Wear a pantyliner two days before your period and two days after your period. This prevents embarrassing moments.
- If you have bleeding in-between your periods, tell someone about it.

Gentle encouragement and consistency are key.

Information courtesy of Kate Nolan, NP, Director and Founder of The KIND Clinic. Revised by Hannah Graham, M.D., Physician at Advocate Medical Group Adult Down Syndrome Center.

Your Annual Gynecological Exam

Not one of our favorite things to do in life—but necessary. A calm and gentle conversation helps reduce fear and apprehension.

It is best for parents and caregivers to discuss having a pelvic exam, but please do not make it sound like a big deal. Having a pelvic exam is part of being a woman and staying healthy. It is okay for a doctor or nurse to do this, but no one should do it without permission. It can be medically necessary, but talk with your provider if you have concerns or are not comfortable.

Here is what will probably happen:

- You will meet the doctor or nurse practitioner.
- You will have your weight and blood pressure checked.
- You will be asked questions about any medications you are taking and any surgeries you have had. You may also be asked about your period, and about what your pee and poop look like. The last question will be about your exercise habits and the foods you eat.
- The doctor or nurse practitioner will leave the room and you will change into a gown with the opening of the gown in the front.
- Once they return, the doctor or nurse practitioner will listen to your heart and lungs with a stethoscope.
- Your neck will be touched to see if there are any lumps.
- Your breasts and under arms will be touched gently. This may tickle a bit.
- Your belly will be touched gently and this may tickle a bit too.
- You will be asked to place your legs in the stirrups and move your bottom to the edge of the exam table.
- The doctor or nurse practitioner will gently touch the skin outside the vagina (vulva) with a gloved hand.

More >

Feminine Hygiene

Routine and consistency are key.

This handout is intended to be a "script" for parents and caregivers to assist women with Down syndrome. It is written with the hope that it will be individualized in developing a long lasting routine of personal hygiene for the woman in your care.

Shower or Bath Daily:

Cather, wash, rinse and dry.

- Wash with a mild soap using a washcloth or loofa sponge.
- Use enough soap (unscented) so you see lots of bubbles.
- Gently clean from head to toes and then rinse.
- Thoroughly dry your body with a towel.
- Apply body lotion and deodorant after every shower or bath.
- It is important to clean your pubic area, your vulva and vagina, with a mild unscented soap. Less is best. Do not scrub.
- Avoid any scented soaps or bubble baths. They look good but they are NOT the best for your lady parts.
- Cotton underwear should be your standard underwear. Change daily or more frequently if it is soiled.

Shampooing:

Wash once, rinse twice.

- Wet hair.
- Put some shampoo on your hands and start rubbing the scalp.
- Keep rubbing all over your head until you get a hat of bubbles.
- Rinse with warm water, then rinse again until there is no shampoo.
- Use conditioner in the same way. Apply, rub through your hair and rinse twice.

Hair Care:

your crowning glory.

- Brush or comb your hair daily, or as often as is best for your hair type.
- Get haircuts regularly.

Thank You!

Additional Sexuality Resources

- [Advocate Health Care Adult Down Syndrome Center Resource Library](#)
- [Boyfriends & Girlfriends: A Guide to Dating for People with Disabilities](#). By Terri Couwenhoven
- [Relationships and Sex Education](#). Down Syndrome Association (UK).
- [Sex Ed for People with I/DD: Consent](#). National Council on Independent Living.
- [Sex Ed for People with I/DD: Pregnancy](#). National Council on Independent Living.
- *What is Sex?: A Guide for People with Autism, Special Educational Needs and Disabilities*. By Kate Reynolds

Email: health@ndss.org