# Autism Spectrum Disorder and Menstruation Research Guide



### University of New Mexico Center for Development and Disability Library

2300 Menual Blvd. NE Albuquerque, NM 87107



# Introduction

Autism Spectrum Disorder (ASD), which is often called autism, can make it hard for people to communicate and interact with others and can cause repetitive behaviors and interests<sub>1</sub>. Girls, women, and other people who were assigned female at birth are commonly misdiagnosed, not diagnosed, or may be diagnosed later in life with autism because healthcare providers don't know enough about how they show symptoms or how they "mask", or hide their differences<sub>2345</sub>. Because of this, many autistic people's needs are unmet and unexamined.

One important need that isn't always met for autistic people who have periods, also known as menstruators, is getting information and advice on how to deal with the unique challenges they may face around their periods. Recent research shows that menstruation can be harder for autistic people, who show high levels of sensory sensitivity, behavior dysregulation, bleeding issues, pain, and difficulty managing period care<sub>678</sub>. For example, one study found that while nonautistic menstruators usually figure out how to manage their periods within a year, autistic menstruators often take four to five years<sup>9</sup>. Understanding these differences is important so autistic menstruators can be better prepared for their periods and caregivers, healthcare providers, and even companies that make period products can find better ways to support autistic people.

This research guide provides many resources from the UNM Center for Development and Disability Library and other places. These resources can help you learn about these issues and find ways to deal with the challenges that come with menstruation for autistic people.

### Need Research Help? Contact us!



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# References



2 Driver, B., & Chester, V. (2021). The presentation, recognition and diagnosis of autism in women and girls. Advances in Autism, 7(3), 194–207. https://doi.org/10.1108/AIA-12-2019-0050

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conditions. Journal of Autism and Developmental Disorders, 47(8), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5

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7 Steward, R., Crane, L., Roy, E. M., Remington, A., & Pellicano, E. (2018). "Life is much more difficult to manage during periods": Autistic experiences of menstruation. Journal of Autism And Developmental Disorders, 48(12), 4297–4292. https://doi.org/10.1007%2Fs10803-018-3664-0

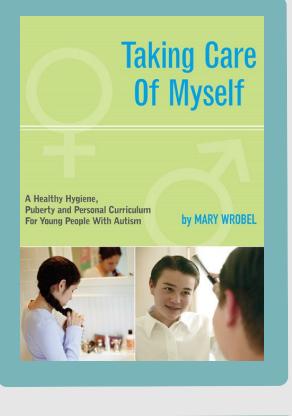
8 Toy, H., Herguner, A., Simsek, S., & Herguner, S. (2016). Autistic traits in women with primary dysmenorrhea: A case-control study. Neuropsychiatric Disease and Treatment, 12, 2319–2325. <u>https://doi.org/10.2147%2FNDT.S114439</u>

9 Jones, S., & Datta, S. (2022). How people on the autism spectrum experience and manage their periods. Intimina. <u>https://www.intimina.com/blog/wp-</u> <u>content/uploads/2022/03/Intimina-Autism-Report-V1f.pdf</u>









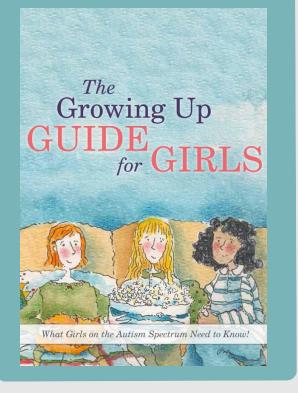
Taking Care of Myself: A Healthy Hygiene, Puberty and Personal Curriculum for Young People with Autism by Mary Wrobel

This is a curriculum for young autistic people to use on different aspects of puberty including hygienic demands, public and private behaviors, menstruation, masturbation, and physical development. Each lesson has a corresponding social story.



Published: 2003

Call Number: D-AUT 7 Wro 2003 C.



The Growing Up Guide for Girls - What Girls on the Autism Spectrum Need to Know! by

This book gives short explanations on physical maturation and the changes and demands that come with it such as cleaning clothes and bodies more frequently, understanding relationships/feelings, and navigating the internet safely.

Published: 2015

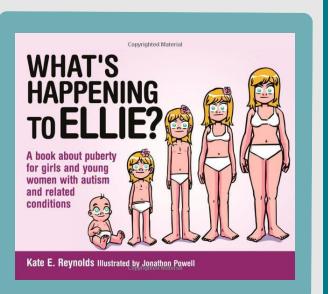
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### Books For Youth





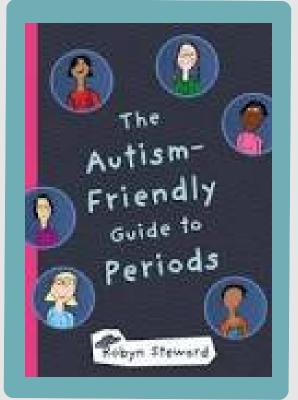
What's Happening to Ellie?: A Book About Puberty for Girls and Young Women with Autism and Related Conditions by Katie E. Reynolds

This book is meant to help explain puberty or bodily maturation to young autistic persons. It has short descriptions and corresponding visuals to better breakdown the experience.



Published: 2015

Call Number: D-AUT 3.5 Rey 2015



The Autism-Friendly Guide to Periods by Robyn Steward

This book provides an overview on puberty and periods specifically for young autistic individuals. It also has guides on how to use various menstrual product materials.



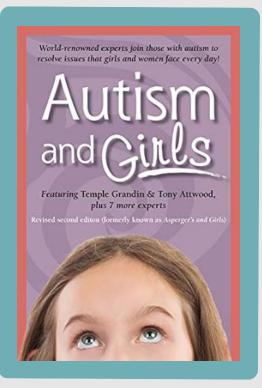
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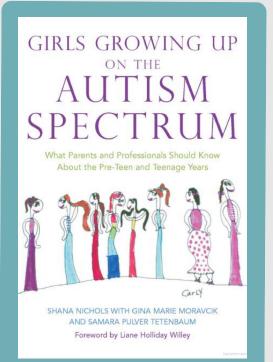
Autism and Girls: World Renowned Experts Join Those with Autism Syndrome to Resolve Issues that Girls and Women Face Every Day! Updated and Revised Edition

This book is for caregivers who are preparing for or are currently managing a child's physical, social, and emotional changes during puberty. It offers insights on how best to support their child at home and in their community.



Published: 2009

Call Number: D-AUT 7 Aut



Girls Growing Up On the Autism Spectrum: What Parents and Professionals Should Know About the Pre-Teen and Teenage Years by Shana Nichols

Written with input from autistic girls, this book is for caregivers. teachers and therapists who are preparing for or are currently managing a child's physical, social, and emotional changes, during puberty.

Published: 2009

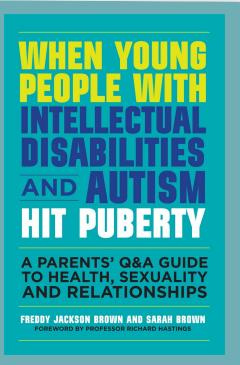


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### **Books** For Caregivers





When Young People with Intellectual Disabilites and Autism Hit Puberty: A Parents' Q&A Guide to Health, Sexuality and Relationships by Freddy Jackson Brown and Sarah Brown

This Q&A provides parents with information and resources to share with their children on the topics of changing bodies and emotions, personal hygiene and menstruation as well as personal relationships and sexual intimacy. Published: 2016



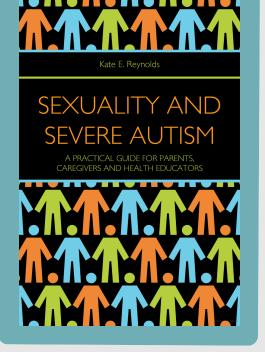
Call Number: D-AUT 7 Bro

Sexuality and Severe Autism: A Practical Guide for Parents, Caregivers and Health Educators by Kate E. Reynolds

This book lays out a framework for and insights into teaching young autistic people about sexuality. It is intended to help parents/caregivers and teachers/educators working with individuals on this and related topics.

Published: 2014

Call Number: D-AUT 3.5 Rey 2014



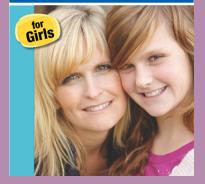






### Websites

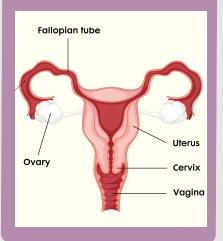
V VANDERBILT KENNEDY CENTER Healthy Bodies



### <u>Healthy Bodies Toolkit: A</u> <u>Parent's Guide on Puberty for</u> <u>Girls with Disabilities</u>

This guide is intended for caregivers of autistic females who are experiencing or preparing for puberty. There is a free interactive online course that caregivers can participate in, as well.

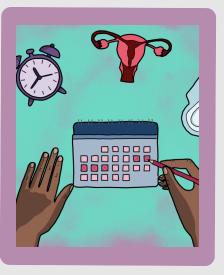
Last Updated May 2021, published by Kennedy Vanderbilt Center



### Periods and Neurodivergent children: a resource for parents and carers

This is a guide on how to explain menses to neurodivergent youth. It offers support on preparing for menstrual care independence, navigating possible period difficulties, and explores topics with additional resources.

Published in 2013 by the University of Edinburgh



### Sex Positive Families

On this website, families can find useful resources including a book, articles, websites, and blogs on various topics related to sexuality. It also has a self-paced course called Growing Into You! which offers comprehensive sex ed for families that they can do at home.

Copyright 2024, Sex Positive Families



https://vkc.vumc.org/healthybodi es/girls.html



https://www.ed.ac.uk/sites/default/file s/atoms/files/periods\_and\_neurodiver gent\_children\_.pdf



https://sexpositivefamilies.com/res ources/menstruation/



# **Online Resources**

### **Websites**

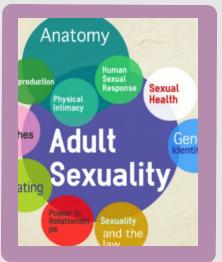




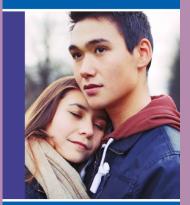
### **Sex Ed for Self-Advocates**

The OAR and other collaborators have developed modules on various aspects of pubertal, reproductive, and sexuality education. The lessons can be consumed in different formats (e.g., videos, podcast, text) and are accompanied by guizzes.

First published in 2018 by Organization of Autism Research (OAR)



#### Puberty, Sex, and Sexuality



An Introduction for Autistic Teens and Adults

### The Birds and the Bees

This is a project offers free sexuality education materials to caregivers and teachers of middle or high school-aged autistic students and autistic adults. It also has various resources to improve learning or dive further into sexuality-related topics.

First published in 2013 by Dr. Sarah Curtiss at the University of Delaware

### Puberty, Sex, Sexuality: An introduction for autistic teens and adults

This guide offers thorough descriptions of puberty, sex, and sexuality for autistic teens and adults using text and visuals. There is a free interactive online course that they can participate in, as well.

Last Updated June 2020, published by Kennedy Vanderbilt Center



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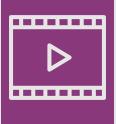


https://asdsexed.org



https://vkc.vumc.org/assets/files/resou rces/sexedtoolkit.pdf







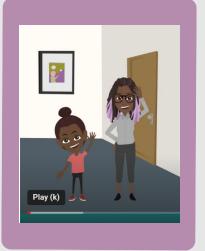
### Menstruation Introduction Video

from U-TTEC Lab, published Aug. 2, 2022 - 2:36 minutes

This video offers a short and explicit introduction to menstruation. It discusses what one may experience before, during, and after their period, as well as self-care recommendations.



https://www.youtube.com/watc h?v=WpeAoSYHmhU



### How to change a pad step-by-step

This video offers a step-by-step guide on how an individual may change a disposable pad without wings at home. It uses graphic illustrations to minimize any user's difficulty understanding abstract steps.

from U-TTEC Lab, published Aug. 2, 2022 - 2:15 minutes



<u>https://www.youtube.com/watch</u> ?v=UoVoUaEySfQ

Menstruation and ASD: Aunt Flo Doesn't Discriminate

#### Keely Lundy, M.Ed

### Menstruation and ASD: Aunt Flo Doesn't Discriminate

This webinar provides "up-to-date information on diverse puberty and menstrual experiences, and strategies to increase the comfort and autonomy with menstrual hygiene management for autistic peope. .

from U-TTEC Lab, published April 2, 2021 - 53:58 minutes



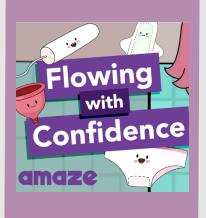
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# **Online Resources**

### Video Playlists





#### <u>Amaze</u>

This website provides a large number helpful and relatable animated videos on explaining complex topics like puberty, healthy relationships, personal safety, etc. The site is working on adapting these videos into other languages - including Spanish. Last updated May 30, 2024, published by Amaze



https://amaze.org

### every b<sub>o</sub>dy curious



### **Every Body Curious**

This website has videos on different sexuality education topics and is led by educators who talk about puberty, genitals, body image, etc., with children and teenagers.

Copyright 2024 by Every Body Curious



https://everybodycurious.com



Sex Ed for People With I/DD.

Sex Ed for People With I/DD

This playlist of videos were developed by and for neurodivergent adults discussing topics like healthy relationships, consent, how to use a condom, puberty, etc.

Last updated Sept. 30, 2019, published by National Council on Independent Living



https://www.youtube.com/playl ist?list=PLuEvYNNQdHeVhbyeJHx9s8oqsvBk621v



# **Academic Resources**

Journals, Databases and Websites

### To learn more, research using these sources

### **MedlinePlus**



An online health information resource for patients and their families and friend from the National library of Medicine

### **PubMed**



million citations for biomedical literature from MEDLINE. life science journals, and online books"

### **Google Scholar**



Allows you to use the power of Google to search for authoritative, scholarly books, articles and documents. A great starting point.

### **The Transmitter**



An editorially independent, online neuroscience magazine from SFARI.org written by journalists and scientists.

### Autism Spectrum News



An online-only publication that provides the autism community with a trusted source of evidence-based information

### The Spectrum Magazine



"One of the UK's largest collections of autistic art. poetry and prose."

### Autism



A peer-reviewed, journal focused on helping improve the quality of life for individuals with autism or autismrelated disorders.

### Journal of Autism and **Developmental Disorder**



focusing on all autism spectrum disorders and

### Autism Research



This journal "covers research relevant to ASD and closely related neurodevelopmental disorders."







### To learn more, check out these articles

Cummins, C., Pellicano, E., & Crane, L. (2020). Supporting minimally verbal autistic girls with intellectual disabilities through puberty: Perspectives of parents and educators. Journal of Autism and Developmental Disorders, 50(7), 2439–2448. https://doi.org/10.1007/s10803-018-3782-8

Klett, L.S. & Turan, Y. (2011). Generalized effects of social stories with task analysis for teaching menstrual care to three young girls with autism. Sexuality and Disability, 30(3), 319-336. <u>https://doi.org/10.1007/s11195-011-9244-2</u>

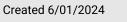
Corbett, B.A., Vandekar, S., Muscatello, R.A., & Tanguturi, Y. (2020). Pubertal timing during early adolescence: Advanced pubertal onset in females with autism spectrum disorder. Autism Research, 13(12), 2202-2215. <u>https://doi.org/10.1002/aur.2406</u>

Fei, Y.F., Ernst, S.D., Dendrinos, M.L., & Quint, E.H. (2021). Preparing for puberty in girls with special needs: A cohort study of caregiver concerns and patient outcomes. Journal of Pediatric and Adolescent Gynecology, 34(4), 471-476. https://doi.org/10.1016/j.jpag.2021.03.008

Lundy, K., Wenzbauer, A., Illapperuma-Wood, C., Fischer, A.F., Feng, M., Jensen, R., Maldonado, A.F., Mathis, S., Meservy, J., & Heller, H. (2022). Evaluating the acceptability and social validity of a caregiver-led technology-based menstrual hygiene management intervention for youth on the autism spectrum. Advances in Neurodevelopmental Disabilities, 1-16. <u>https://doi.org/10.1007/s41252-022-00261-x</u>

Veazey, S.E., Valentino, A.L., Low, A.I., McElroy, A.R., & LeBlanc, L.A. (2016). Teaching feminine hygiene skills to young females with autism spectrum disorder and intellectual disability. Behavior Analysis in Practice, 9(2), 184-189. <u>https://doi.org/10.1007/s41252-022-00261-x</u>

Wilbur, J., Torondel, B., Hameed, S., Mahon T., & Kuper H. (2019). Systematic review of menstrual hygiene management requirements, its barriers and strategies for disabled people. Plos ONE. <u>https://doi.org/10.1371/journal.pone.0210974</u>







### **Contact Us**



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Toll Free: 844-231-5003

Facebook:

https://www.facebook.com/unmcdd/

Cover Photo Provided by <u>Disabled and Here</u>. Disabled and Here is disability-led stock image and interview series celebrating disabled Black, Indigenous, people of color (BIPOC).

