

Autism Spectrum Disorder and Menstruation Research Guide



University of New Mexico
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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 interests¹. 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^{2 3 4 5}. 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^{6 7 8}. For example, one study found that while non-autistic menstruators usually figure out how to manage their periods within a year, autistic menstruators often take four to five years⁹. 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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- 9 Jones, S., & Datta, S. (2022). How people on the autism spectrum experience and manage their periods. *Intimina*. <https://www.intimina.com/blog/wp-content/uploads/2022/03/Intimina-Autism-Report-V1f.pdf>

Books For Youth

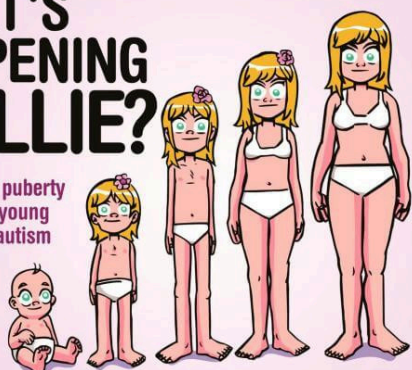


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WHAT'S HAPPENING TO ELLIE?

A book about puberty
for girls and young
women with autism
and related
conditions



Kate E. Reynolds Illustrated by Jonathon Powell

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: YA D-ASD Rey 2015



Books for Youth

Taking Care Of Myself

A Healthy Hygiene,
Puberty and Personal Curriculum
For Young People With Autism

by MARY WROBEL



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

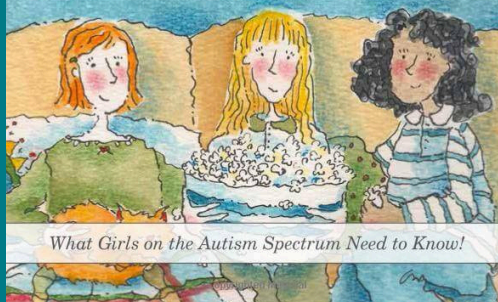
This is a curriculum for young autistic people to use on different aspects of puberty including hygienic demands, public and private behaviors, menstruation, masturbation, and physical development. Each lesson has a corresponding social story.



Published: 2003

Call Number: D-AUT 7 Wro 2003 C. 1

The Growing Up GUIDE for GIRLS



What Girls on the Autism Spectrum Need to Know!

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

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

Call Number: CHILD D-AUT Har 2015



Books

For Caregivers

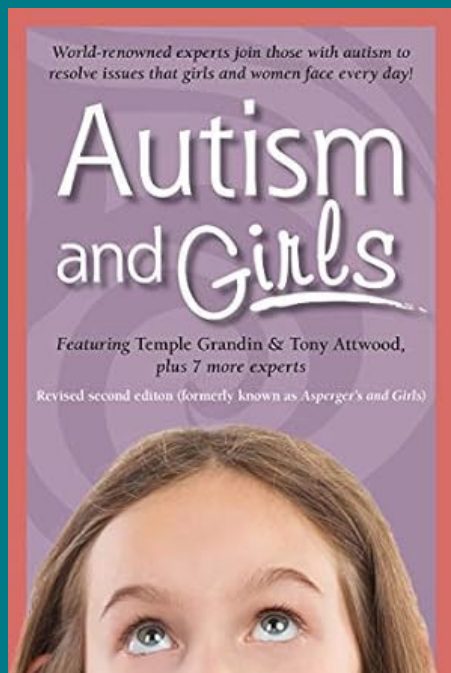
Autism and Girls: World Renowned Experts Join Those with Autism Syndrome to Resolve Issues that Girls and Women Face Every Day! Updated and Revised Edition

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



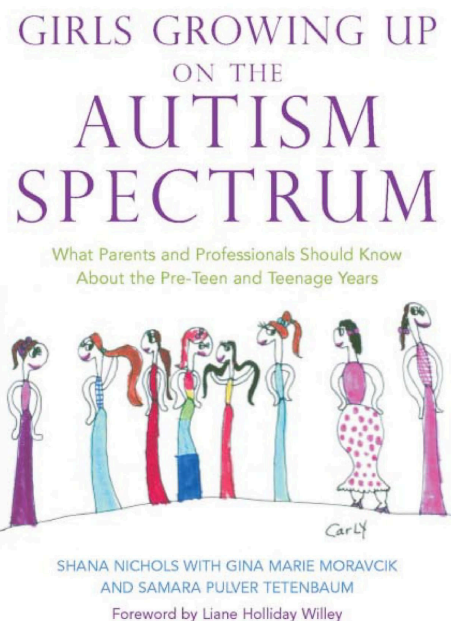
***Girls Growing Up On the Autism Spectrum: What Parents and Professionals Should Know About the Pre-Teen and Teenage Years* by Shana Nichols**

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

Call Number: D-AUT 3.5 Nic 2009



Books

For Caregivers



WHEN YOUNG PEOPLE WITH INTELLECTUAL DISABILITIES AND AUTISM HIT PUBERTY

A PARENTS' Q&A GUIDE
TO HEALTH, SEXUALITY
AND RELATIONSHIPS

FREDDY JACKSON BROWN AND SARAH BROWN
FOREWORD BY PROFESSOR RICHARD HASTINGS

When Young People with Intellectual Disabilities 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



Kate E. Reynolds

SEXUALITY AND SEVERE AUTISM

A PRACTICAL GUIDE FOR PARENTS,
CAREGIVERS AND HEALTH EDUCATORS



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.



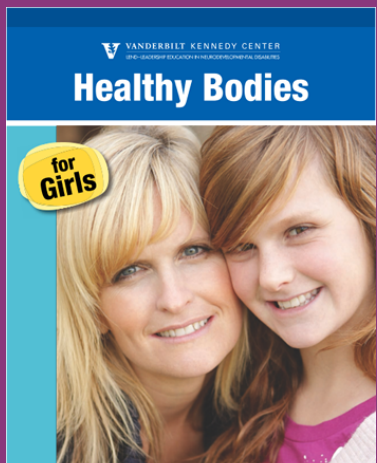
Published: 2014

Call Number: D-AUT 3.5 Rey 2014



Online Resources

Websites



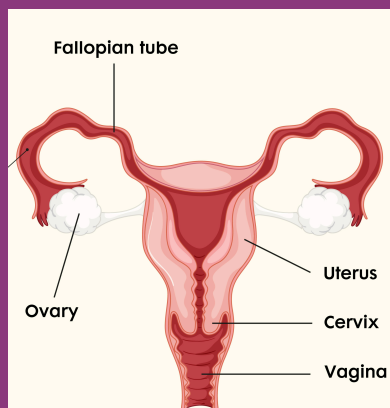
Healthy Bodies Toolkit: A Parent's Guide on Puberty for Girls with Disabilities

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



<https://vkc.vumc.org/healthybodies/girls.html>



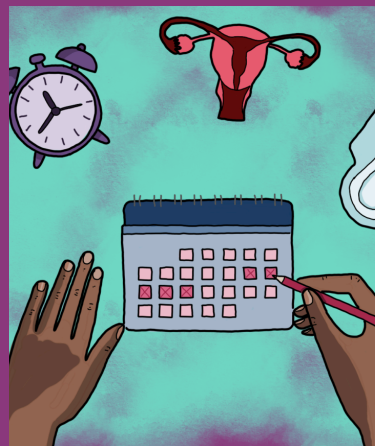
Periods and Neurodivergent children: a resource for parents and carers

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 2013, University of Edinburgh



https://www.ed.ac.uk/sites/default/files/atoms/files/periods_and_neurodivergent_children.pdf



Sex Positive Families

Offers families 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://sexpositivefamilies.com/resources/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 quizzes.

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



<https://researchautism.org/self-advocates/sex-ed-for-self-advocates/>



The Birds and the Bees

This 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



<https://asdsexed.org>

Puberty, Sex, and Sexuality



An Introduction for Autistic Teens and Adults

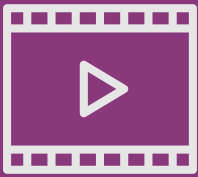
Puberty, Sex, Sexuality: An introduction for autistic teens and adults

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



<https://vkc.vumc.org/assets/files/resources/sexedtoolkit.pdf>



Online Resources

Videos



Menstruation Introduction Video

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.

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



<https://www.youtube.com/watch?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



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

Menstruation and ASD: Aunt Flo Doesn't Discriminate

Keely Lundy, M.Ed

Menstruation and ASD: Aunt Flo Doesn't Discriminate

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

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



<https://www.youtube.com/watch?v=k85ukOUypYc>

Online Resources

Video Playlists



Amaze

Provides a number of helpful and relatable animated videos 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 body curious



Every Body Curious

This website has videos on different sexuality education topics 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

Playlist of videos 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/playlist?list=PLuEvYNNQ-dHeVhbyeJHx9s8oqsvBk621v>



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



This "comprises more than 37 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 autism-related disorders.

Journal of Autism and Developmental Disorder



A journal focusing on all aspects of autism spectrum disorders and related disabilities.

Autism Research



This journal "covers research relevant to ASD and closely related neuro-developmental disorders."

Academic Resources

Bibliography



To learn more, check out these articles

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