



Body Changes and Hygiene: Pimples, Puberty and Privacy

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House Keeping

- To reduce background noise during the webinar, please put yourself on 'mute' through your phone or computer.
- Due to the size of our group, we will not be answering questions during the webinar. **Please type your questions** into the 'chat' box on your screen. We will review/answer questions during the Q & A at the end.
- If you experience any technical problems during the webinar, the problem is likely to be on your end. Please follow-up with your technology support person.
- The Webinar will end promptly at 5:00pm. If you would like to speak with us after the webinar, please send us an e-mail at rrcasd@urmc.rochester.edu.

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Learning Objectives

- Increase understanding of:
 - Factors affecting puberty for teens with autism and related disorders.
 - Common behavioral issues that occur with pubertal changes and adolescence.
- Be able to identify:
 - Key areas for the teen that may require instruction as it relates to body changes and puberty.
 - Some specific strategies to “teach” concepts and appropriate skills.

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Definition

- Puberty is : the condition of being or the period of becoming first capable of reproducing sexually marked by maturing of the genital organs, development of secondary sex characteristics, and in the human and in higher primates by the first occurrence of menstruation in the female
- Per Merriam-Webster

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Funny Video:
("TV Spot - Tide - Tide Sport - Gym Bag")



Factors affecting puberty

- Genetics
- General health and wellness
- Obesity
- Ethnicity

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Puberty

- Girls, the mean age for the first signs of puberty is about 10.5 years of age in girls, with a range from about 8 to 12 years.
- Boys, the mean age of pubertal onset is about 11.5 years, with a range from about 9 to 13 years.
- Precocious puberty is defined as breast development before the age of 9 years in girls, and testicular enlargement before the age of 9 years in boys

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Boys and girls - pubic hair

- Stage 1:
- Prepubertal (can see velus hair similar to abdominal wall)
- Stage 2:
- Sparse growth of long, slightly pigmented hair, straight or curled, at base of penis or along labia
- Stage 3:
- Darker, coarser and more curled hair, spreading sparsely over junction of pubes
- Stage 4:
- Hair adult in type, but covering smaller area than in adult; no spread to medial surface of thighs
- Stage 5:
- Adult in type and quantity, with horizontal distribution ("feminine")

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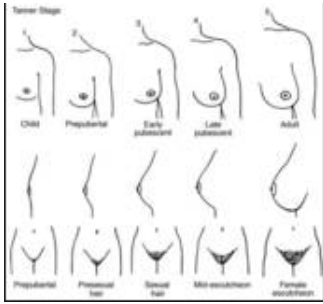
Girls - breast development

- Stage 1:
- Prepubertal
- Stage 2:
- Breast bud stage with elevation of breast and papilla; enlargement of areola
- Stage 3:
- Further enlargement of breast and areola; no separation of their contour
- Stage 4:
- Areola and papilla form a secondary mound above level of breast
- Stage 5:
- Mature stage: projection of papilla only, related to recession of areola



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Tanner Stages Female



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Boys - development of external genitalia

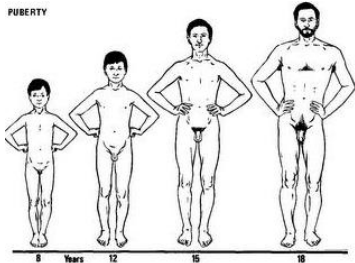


- Stage 1:
- Prepubertal
- Stage 2:
- Enlargement of scrotum and testes; scrotum skin reddens and changes in texture
- Stage 3:
- Enlargement of penis (length at first); further growth of testes
- Stage 4:
- Increased size of penis with growth in breadth and development of glans; testes and scrotum larger, scrotum skin darker
- Stage 5:
- Adult genitalia

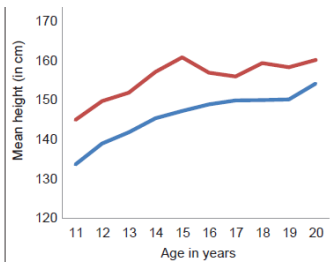


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Tanner Stages Males



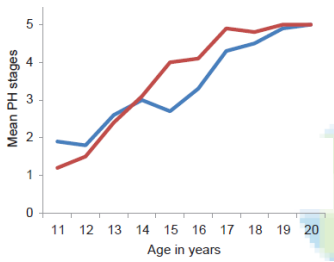
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Height Development

[Growth and sexual maturity pattern of girls with mental retardation.](#)
 Baidwan S, Paul MM, Chhatwal J, Deswal R.
 Int J Appl Basic Med Res. 2014 Jan;4(1):38-42

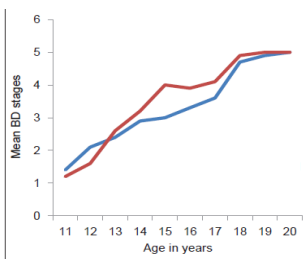
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Pubic Hair development

[Growth and sexual maturity pattern of girls with mental retardation.](#)
 Baidwan S, Paul MM, Chhatwal J, Deswal R.
 Int J Appl Basic Med Res. 2014 Jan;4(1):38-42.

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3: Comparison of breast development stages

Breast development

[Growth and sexual maturity pattern of girls with mental retardation.](#)
 Baidwan S, Paul MM, Chhatwal J, Deswal R.
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General medical issues for adolescence

- Iron deficiency and anemia
- Pubertal gynecomastia in males
- Acne
- Mental health issues
- Bone health and scoliosis
- Menses
- Myopia



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Medical issues for ASD

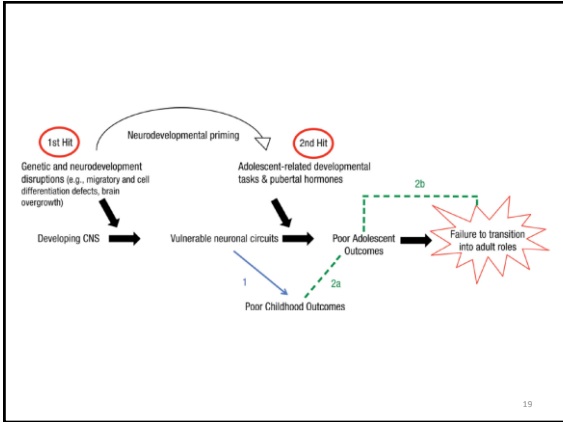
- Sleep problems-sleep cycle disturbances, apnea, restless legs, limit setting
- Seizures can occur in early childhood or adolescence for people with ASD, especially in girls and those with ID
- Increased GI symptoms, like constipation, selective eating and intolerances
- Higher rates of iron deficiency

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2 Hit Model Theory

- Children with ASD are born with a neurologic vulnerability that manifest the symptoms of ASD and can cause poor outcomes in childhood
- The 2nd hit is the hormonal changes in puberty and the developmental tasks can overwhelm the neural vulnerabilities leading to poor outcomes
- Multiple studies have shown a 30% decline in skills during puberty, but many others show a gradual improvement by adult in most areas

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Changes in brain development

- Certain parts of the brain change over time and do not develop in a typical manner
- Younger children with ASD tend to have more brain volume but this decelerates by late childhood with a plateau or decline into adolescence and there are areas of over and under development compared to peers

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Changes in brain development

- The changes in brain development can impact on the developmental task of shifting to peer orientation rather than parent which limits friendship and romantic relationships
- 50% of teens with ASD have been bullied
- Many teens/young adults do not date and may have atypical courtship skills
- No clear differences in risk taking, but people with more anxiety tend to take less risks
- Less likely to be peer pressure to take risks

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Puberty and female concerns

- Management of menses is often the primary concern of parents, lack of discretion/privacy, vulnerability and relationships, hygiene
- Behavior changes with menses, 18%; increased aggression, worsened “autistic behaviors”, increased repetitive movements, increased obsessive behaviors, dysmenorrhea (more with higher verbal skill teens)

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Behavior changes in girls with ASD

- Girls with ASD more likely to have mood and behavior changes than other girls with disabilities
- Girls with Asperger's reported more discomfort
- Track behavior and menses timing
- Did not cause absenteeism
- Most girls do better than expected

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Premenstrual syndrome

- Occurs in 80% of women of reproductive age and can cause difficulty for 20-40% of women and 5% significant impact of lifestyle, occurs in women with disabilities-18% in the study
- Characterized by behavioral and physical changes corresponding with clear hormonal cycle (luteal phase, days 14-28), improves with menses typically
- Track behaviors over a period of time to assess correlation with menses

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Treatment for premenstrual symptoms

- Similar to other females with over the counter ibuprofen or acetaminophen,
- Hormonal contraception
- SSRI medications for premenstrual dysphoria disorder (PMDD)

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Masturbation

- Generally the first nocturnal emissions (wet dreams) occur after the growth spurt is done.
- Core feature of ASD is self stimulatory behaviors and obsessive tendencies
- Watch for potential for unsuccessful masturbation and frustration
- Monitor and teach when it is an appropriate time/location
- Watch for inappropriate internet viewing

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Issues for teens with Down Syndrome

- Increased risk for obesity which increase risk for diabetes, sleep apnea issues and reduced bone density
- Specific screening guidelines for PCPs
- Need to screen for new behavior issues related to mental health issues, esp depression, anxiety, disruptive and repetitive behaviors. May present with different symptoms compared to peers.

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Sexual abuse

- Risk for sexual abuse estimates are 16-25% of people with ASD
- Very limited research
- Risk factors:
 - need to be accepted by others
 - limited communication
 - Trusting of adults, etc

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Mental health issue

- Depression and anxiety are the most common disorders that co-occur with autism
- 65% of individuals with autism are affected with depression, anxiety, or both
- Need to seek appropriate therapy/services
- Monitor for suicide in at risk individuals, limited research

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Mental health issues for teens

- Adolescence is often when one becomes aware of differences
- Limited communication skills to express self
- Limited insight into feelings
- Time of emerging mental health issues, “diagnostic overshadowing” can occur

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Treatment

- Seek out appropriate care for concerns
- Social connections
- Physical activity to boost mood
- Appropriate sleep hygiene
- Review school programs and engagement

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Commonly used medications

- Stimulant medications can suppress linear growth, but often will catch up when stopped and adult height generally not affected
- Atypical antipsychotics can cause weight gain and gynecomastia, sexual dysfunction in libido, arousal, and orgasm
- SSRIs can cause libido suppression and erectile dysfunction
- Propranolol rarely can cause libido suppression

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Growing Up

With the onset of puberty and related hormonal and physiological changes it will be important to increase the young person's awareness of good hygiene practices as well as social rules & expectations.

Working towards independence is key and it is never too early to start!

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Steps in Achieving Good Hygiene Practices

- Teaching Body Parts
- Teaching Hygiene Supplies
- Using Hygiene Schedules and Sequencing Associated Behaviors

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Teaching Body Parts

- Generally it is good practice to teach the correct names for body parts.
- For some individuals this can be made into a matching game (match label of body part with the body part in the picture)
- Using a diagram of the Tanner Stages can also help the child understand how their body parts are changing and how the hair will grow.

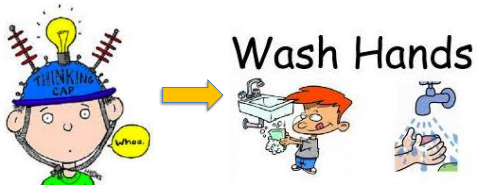
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Hygiene Supplies and How & When to Use Them

- More common items that the child is most likely already familiar with may include : toothbrush, toothpaste, hairbrush, shampoo, soap etc. However, moving the individual towards using these items independently may involve some additional instruction, adaptations and sequencing their use.
- Less familiar items such as conditioner, lotion, deodorant/antiperspirant, shaving cream or gel, razor/electric shaver, taking medication(s), skin cleansers, menstrual pads/tampons (when to use or change), when to change underwear/panties, when to change clothing, not squeezing pimples or picking at scabs etc. All may require additional instruction.

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From Thinking to Doing



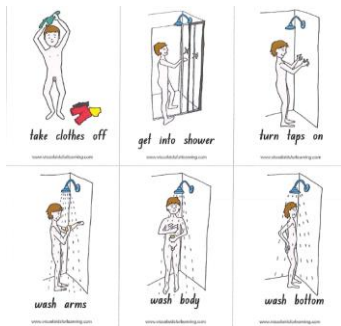
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Use of Stories, Visuals and Video Modeling

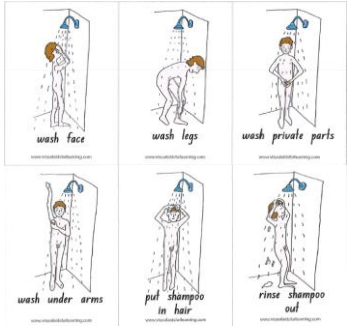
- Stories to explain how the body is changing and about concepts such as “body odor” and why it is important to smell clean/fresh versus dirty/stinky are often helpful.
- Sequencing a written list of steps/ icons/pictures of the steps in the correct order for the individual to perform to teach the order eventually fading out the need for visuals as prompts.
- Use of video modeling to teach the skill

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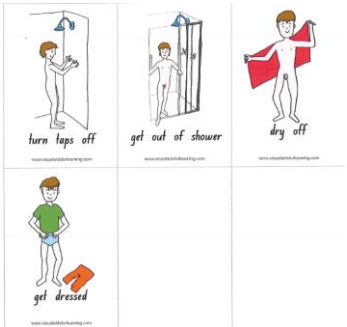
Visual Aids - Showering Sequence



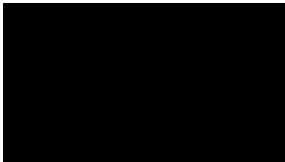
Visual Aids - Showering Sequence



Visual Aids - Showering Sequence



Video: Teaching a Child with Autism to Blow His Nose



Teaching Public versus Private Behaviors

It will be important for the young person and their family to identify where and when some behaviors can occur. For example, generally nose picking would be classified as a “private” behavior. Should someone pick their nose in “public” people may find it unpleasant but social ramifications would be minimal.

However, if an individual were to touch themselves in their private area (hands in pants) in public this would be significantly more concerning.

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Teach the Definitions

- It will be important to teach the definitions of each as a first step. Again visuals can be useful when instructing.
- **Public-** *is a place where other **people can see me.***
Public places: school bus, school, classroom, restaurants, stores, public bathrooms, library, museum, church/temple/mosque etc.
- **Private-** *is when I am **alone** in my bedroom, bathroom at home, in the shower or bathtub, *bathroom stall **and the door is closed.***

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Establish a List of Behaviors and Places

- Create activities to teach the places and behaviors.
- Be sure to include and teach **ALL behaviors** not just the ones that are private or acceptable.
- For example, talking to people versus swearing; scratching your arm versus your behind.
- It may necessary to teach some based on the **situation** and some **acceptable alternatives**. For example, passing gas. may involve instruction on asking to use the bathroom if in the classroom. Another example, eating although eating often occurs in public the way one eats in public may require different behaviors. Dressing/undressing and changing clothing in places such as home versus locker room etc.

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Touching Others and Being Touched

- It will be necessary to instruct where the young person can touch others and where it is okay to be touched as well as touching of self. This too can be done using visuals and instructional materials.
- This will include wave, high fives, fist bumps, touching someone's arm/shoulder, pats on the shoulder/back, hugs (frontal vs. side hugs), shaking hands, holding hands, kissing (cheek, forehead vs. lips) etc.

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Video: A Tad Too Close



Feelings and Self

- With the onset of puberty and many physical changes there also can be associated emotional fluctuations or mood lability and issues with regulating emotions.
- Moodiness can be normal during puberty.
- If the individual has not yet mastered emotions or been taught some of the higher level emotions (e.g., "excited", "curious", "fearful", "depressed", "embarrassed", "tired", "grumpy", "relaxed", "frustrated", "confused" etc.) it will be important to continue to teach emotions and also pair them with behaviors and acceptable coping strategies .

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Hormones and Behavior

Although moodiness can be a normal part of puberty sometimes it can result in other more serious issues that may require talking with a medical and/or behavioral professional:

- Severe fluctuations such as crying or laughing for no apparent reason.
- Aggression or intense behavior such as hitting others, self-injury, screaming, pacing, rocking etc.
- Significant changes in appetite or sleep (more/less).
- Complaints about chronic headaches, stomach aches, or body aches.
- Other concerns such as fatigue or over activity, difficulty focusing, unusual thoughts, significant disinterest in activities that typically were preferred etc.

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Teaching About Menses (The Period)

- Girls may experience fear at the onset of their periods when they notice blood. Using stories and visuals to explain where the blood comes from & that she is not hurt or injured. Explaining that this occurs every month (use of a calendar) and that other girls have their period too may help to alleviate the concern over time.
- Also explaining that it can be “messy” & “smelly” and that is why it so important to care for their clothing and importance of increased hygiene. Using a visual or written sequence and activities to teach the steps in caring for herself during her period as well as when to change the pad/tampon or clothing and perform other hygiene related activities such as showering.

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Determining the Impact of the Period

- Girls may experience other side effects such as stomach swelling, bloating, cramping and pain. Instruction and the use of a pain and/or mood scale may be helpful in determining how much discomfort she is experiencing and how her mood changes. This may aid in determining the need for medication or other medical intervention.
- Keeping track of sleep and appetite may also be useful when discussing how her period is impacting on her functioning and behavior with the medical personnel.

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Teaching About Erections

Boys during puberty may experience several erections throughout the day that are not in their control and require little if any stimulation.

It will be important to provide instruction on what to do when an erection occurs especially in public places and some preventative measures to decrease the occurrence.

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Teaching About Nocturnal Emissions

- Boys during puberty may experience “wet dreams” when they wake up in the morning.
- It will be important to reassure that nocturnal emissions are a normal part of growing up and provide instruction on what to do when this occurs.

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“Who Can I Talk to ?”

It will be important as a family to discuss with the young person who they can talk to if they have questions .

This too may require some instruction and helping the young person to understand who they can talk to & what they can talk about .

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Resources

- Kirch Developmental Services Center
 - Main Website:
<https://www.urmc.rochester.edu/childrens-hospital/developmental-disabilities/services/kirch.aspx>
 - Tele: 585-275-2986
 - Family Resource Directory Webpage:
<https://www.urmc.rochester.edu/childrens-hospital/developmental-disabilities/services/kirch/family-resource-directory.aspx>

Additional resources continued on the next few slides...

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Resources

- Rochester Regional Center for Autism Spectrum Disorder (RRCASD)
 - On-line educational resources, webinars, Information & Referral services.
 - Contact information:
 - Website: www.golisano.urmc.edu/rrcasd-nyautism
 - E-mail: rrcasd@urmc.rochester.edu
 - Tele: 1-855-508-8485
- Autism Speaks: website: www.autismspeaks.org
 - This site contains various toolkits and guides for home, school, work, safety, health/medical, etc.

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Resources

- Books/ Curriculums
 - Healthy Bodies: A Parent's Guide on Puberty for Girls/Boys with Disabilities. Materials and toolkits available at: <http://kc.vanderbilt.edu/HealthyBodies/>
 - Hygiene and Related Behaviors for Children and Adolescents with Autism Spectrum and Related Disorders: A Fun Curriculum with a Focus on Social Understanding <http://www.amazon.com/Behaviors-Children-Adolescents-Spectrum-Disorders/dp/1934575429>
 - Social Skills Stories: Functional Picture Stories for Readers and Nonreaders K-12 A.M. Johnson & J.L. Susnik , Mayer-Johnson (e.g., teaching appropriate proximity when interacting with others "Tad too Close") www.mayer-johnson.com/social-skills
 - More Social Skills Stories: Very Personal Picture Stories for Readers and Nonreaders K-12 A.M. Johnson , Mayer-Johnson. (e.g., social issues such as nose picking) www.mayer-johnson.com/social-skills

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Resources

- Websites
 - Teaching Nose-Blowing to a Child or Adult with Autism, Dr. Mary Barbera, You-tube video with step instruction <http://marybarbera.com/>
 - Social Skills Stories-Books, Games & Multimedia/Mayer-Johnson www.mayer-johnson.com/social-skills
 - Free Visual Sequences: www.visualaidsforlearning.com
 - Autism Speaks provides information on considerations for supporting your child in learning important life skills: <https://www.autismspeaks.org/family-services/community-connections/teaching-important-life-skills>

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Question & Answer

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