

Parenting a child with a fetal alcohol spectrum disorder (FASD) is a journey. It can be challenging and rewarding all at the same time. You cannot parent a child with an FASD without having it change your life. You more than likely will meet some amazing people, make lifelong friendships, and see a child work really hard to be the best person they can be with your love and support. The information below can help guide you on this unique parenting journey.

On FASD

- There is a wide range of lifelong behavioral and intellectual effects caused by prenatal alcohol exposure.¹⁻² The effects of FASD can get more complex with age.³ It is hard to see your child struggle, and you may go through periods of grief, frustration, or confusion. This may hit you at times when you are least expecting it. This is normal and there is support available.
- Learn as much as you can about FASD. Read books, attend trainings and conferences, and connect with community resources and support groups; not just at the beginning of the journey, but throughout.
- Get accustomed to educating others on FASD, including friends, family members and professionals. It is often a misunderstood disorder and is commonly known as the invisible disability.⁴ FASD is a public health issue; everyone needs to know that drinking alcohol during pregnancy can cause birth defects.⁵
- Be aware that there are a number of characteristics your child might display as they grow. The different characteristics can present at different times of development, but in general you might see these effects of prenatal alcohol exposure during these particular stages:

Infants ⁶⁻¹²	Toddlers ¹³⁻¹⁶	School-Age ¹⁷⁻²¹	Teenagers ²²⁻²⁵
<ul style="list-style-type: none"> • low birth weight • sensitivity to light, noise, and touch • irritability • unable to suck effectively • slow to develop • ear infections • trouble sleeping 	<ul style="list-style-type: none"> • poor memory • hyperactivity • seems to have no fear • speech and language delays 	<ul style="list-style-type: none"> • poor social skills • easily distracted, short attention span • poor coordination • trouble with large and fine motor skills • difficulty in school 	<ul style="list-style-type: none"> • low self-esteem • involvement with the criminal justice system • poor impulse control • must be reminded of concepts on a daily basis

Remember²⁶

- FASD is a form of organic brain injury: it is permanent brain injury that causes inconsistency in behaviors and intellectual abilities on a daily basis.
- FASD is a spectrum disorder. Each person with an FASD is unique and special in their own way.
- Don't blame yourself (or the birth mother if you have adopted or are fostering a child). FASD is usually a result of misinformation, lack of knowledge, unplanned pregnancy, or alcohol use disorder. No person goes into their pregnancy willfully intending to harm their child.

Relationships²⁶

- Be aware that some relationships in your life may change. Work on educating family, friends, professionals, and community members about FASD, with hope that they will be patient and understanding.
- Connect with other families raising children with an FASD. This is one of the most common desires that caregivers have, to talk with another parent who "gets it".

Patience²⁶

- Be patient. Never blame the child for their brain injury. Children with an FASD may be able to repeat a rule but may not understand it or be able to apply it. This and other common cognitive symptoms of FASD can be very frustrating. Try not to get irritable or short tempered. Make respite and self-care for yourself a priority.
- Prepare to re-teach everything; even if they understand today, they may not tomorrow. Sooner or later they will likely get it.
- Know that conventional parenting techniques may not work for children with an FASD. Time-outs rarely work for kids with an FASD; the common symptom of inability to understand consequences may be the reason for this. We have to be creative and find alternative strategies like being proactive versus reactive and providing consistent supervision. Know that when we find one strategy that works, it might not work forever.

Routine & Structure²⁶

- Structure and routine can give children with an FASD a sense of calm. Keeping a daily routine and letting the child know ahead of time what the plan is for each day can be an effective strategy to regulate behavior.
- Consider using visual reinforcement of daily activities through written daily schedules or calendars. Try not to make the schedule too overwhelming.
- Prepare for transitions such as getting in and out of the car or bathtub, going to sleep, going to school, a change in television programs, etc. This preparation will look differently for each child; for some children a sand time or countdown timer seems to work well, for others timers may cause anxiety. Children with an FASD don't always have the ability to make transitions from one emotional state or one activity to another. Be prepared to support them find what works for them.
- When giving instructions, be concrete, specific and allow extra processing time. Children with an FASD may not be able to see the parts of a whole nor understand a sequence. Help them by breaking down tasks into smaller, more manageable steps, communicating one at a time and repeating as many times as needed.
- Learn to distinguish between flexibility and chaos. Allowing spontaneous change doesn't mean the whole schedule is done for that day. Structure can mean many things. Be understanding and supportive by being flexible or having a backup plan especially if the child is going to a new or high sensory place.

Health²⁶

- A healthy nutritious diet helps with physical and mental health. Consult your primary physician to see if there is a specific diet that could be more effective for your child.
- All children need exercise for muscle and motor development. Try out different activities to see what fits best such as swimming, rock climbing, biking, basketball, etc. For some children with an FASD, team sports can be a challenge but also prevent isolation. Being a part of a team or getting involved in a club or community group can also help with self-perception.
- Many children with FASD have poor sleeping patterns. To promote healthier sleep, establish evening routines before bedtime and use a visual schedule to depict the bedtime routine. Maintain a consistent bedtime and wake-up time throughout the week. If your child has sensory issues, you might try massage, white noise, ear plugs, turning pajamas inside out, or other ways of addressing sensory challenges.

School^{26, 27}

- Educate and work with your child's school to find what works best. Some examples are: one-on-one support, sensory breaks/tools, and/or reduced or no homework. This can reduce household tension in the evenings and respect the child's exhaustion level.
- Work with your child's teachers to have a flow of communication between home and school. This can create both a stronger home and school environment for the child.
- Ask your child's teacher to let you know if there are going to be any upcoming changes at school, such as a substitute teacher, a fire drill, or an activity that isn't usually part of the daily routine. Children with FASD thrive on consistency, and helping them prepare for a change can make the process less stressful for them.

Have Fun²⁶

- Have fun every day! The symptoms of FASD can create tension and stress within families so make sure you find something positive and fun each day. It can be simple and short, but it is really important to do.
- Make sure your child knows you love them. Reinforcing attachments ensures they know that, no matter what, you are there for them. This may look different for each child; it might be lots of cuddles, actively listening to them about their day or simply stating "I love you" during stressful situations.
- Remember that your child is a kid like any other who wants love and acceptance. Accept them for who they are and meet them where they are at each day. Ask yourself, "Where are they at today?" before setting expectations.
- Learn to expect chaos and celebrate when you are wrong!

Websites

- Proof Alliance: www.proofalliance.org
 - Calendar: www.proofalliance.org/calendar/
 - FASD Service Handbook: www.proofalliance.org/support-and-resources/fasd-service-handbook/
 - Resource Directory: www.proofalliance.org/directory/
 - Books and Videos: www.proofalliance.org/support-and-resources/resources/books-and-videos/
- National Organization on Fetal Alcohol Syndrome: www.nofas.org
- Center for Disease Control and Prevention: www.cdc.gov/ncbddd/fasd/index.html

Sources:

1. Rutman D. Becoming FASD Informed: Strengthening Practice and Programs Working with Women with FASD. *Substance Abuse: Research & Treatment*. 2016;10:13-20.
2. Girault V, et al. Prenatal Alcohol Exposure Impairs Autophagy in Neonatal Brain Cortical Microvessels. *Cell Death & Disease*. 2017; 8(e2610).
3. Moore EM, Riley EP. What Happens When Children with Fetal Alcohol Spectrum Disorders Become Adults?. *Curr Dev Disord Rep*. 2015;2(3):219-227.
4. Denys K, Rasmussen C, Henneveld D. The effectiveness of a community-based intervention for parents with FASD. *Community Ment Health J*. 2011;47:209.
5. Williams JF, Smith VC. Fetal Alcohol Spectrum Disorders. *Pediatrics*. 2015;136(5):e1395-406.
6. Sanvisens A, et al. Alcohol consumption during pregnancy: Analysis of two direct metabolites of ethanol in meconium. *International Journal of Molecular Sciences*. 2016;17(417).
7. Masotti P, Longstaffe S, Gammon H, Isbister J, Maxwell B, Hanlon-Dearman A. Integrating care for individuals with FASD: results from a multi-stakeholder symposium. *BMC Health Services Research*. 2015;15(1):1-12.
8. Centers for Disease Control and Prevention (CDC). Key findings: Neurobehavioral disorder associated with prenatal alcohol exposure. <https://www.cdc.gov/ncbddd/fasd/features/neurobehavioral-disorder-alcohol.html>
9. Hawaii Department of Health. Strategies for infants and toddlers with an FASD. <http://health.hawaii.gov/fasd/files/2013/09/Strategies-for-Infants-and-Toddlers-Handout-Rev-8-11.pdf>
10. Subramoney S, Eastman E, Adnams C, Stein DJ, Donald KA. The Early Developmental Outcomes of Prenatal Alcohol Exposure: A Review. *Frontiers in Neurology*. 2018; 9(1108).
11. Stephen JM, Kodituwakku PW, Kodituwakku EL, et al. Delays in auditory processing identified in preschool children with FASD. *Alcohol Clin Exp Res*. 2012;36(10):1720-7.
12. Hanlon-Dearman A, Chen ML, Olson HC. Understanding and managing sleep disruption in children with fetal alcohol spectrum disorder. *Biochem Cell Biol*. 2018 Apr;96(2):267-274.
13. Noor S, Milligan ED. Lifelong Impacts of Moderate Prenatal Alcohol Exposure on Neuroimmune Function. *Frontiers in Immunology*. 2018.
14. Young S, Absoud M, Blackburn C, Branney P, Colley B, Farrag E, & ... Mukherjee R. Guidelines for identification and treatment of individuals with attention deficit/ hyperactivity disorder and associated fetal alcohol spectrum disorders based upon expert consensus. *BMC Psychiatry*. 2016; 16(1):324.
15. Kozanian O, Rohac D, Bavadian N, Corches A, Korzus E, Huffman K. Long-Lasting Effects of Prenatal Ethanol Exposure on Fear Learning and Development of the Amygdala. *Frontiers in Behavioral Neuroscience*. 2018;12:200.
16. Centers for Disease Control and Prevention (CDC). Basics about FASDs. <https://www.cdc.gov/ncbddd/fasd/facts.html>
17. Carmichael Olson H, Montague RA. An innovative look at early intervention for children affected by prenatal alcohol exposure. In: Aduabato SA, Cohen DE, eds. *Prenatal Alcohol Use and FASD: Diagnosis, Assessment and New Directions in Research and Multimodal Treatment*. Bentham Books; 2011.
18. Flak AL, Su S, Bertrand J, Denny CH, Kesmodel US, Cogswell ME. The association of mild, moderate, and binge prenatal alcohol exposure and child neuropsychological outcomes: A Meta-analysis. *Alcohol Clin Exp Res*. 2014;38(1):214-26.
19. Taggart TC, Simmons RW, Thomas JD, Riley EP. Children with Heavy Prenatal Alcohol Exposure Exhibit Atypical Gait Characteristics. *Alcoholism: Clinical & Experimental Research*. 2017;41(9):1648-1655.
20. Masotti P, Longstaffe S, Gammon H, Isbister J, Maxwell B, Hanlon-Dearman A. Integrating care for individuals with FASD: results from a multi-stakeholder symposium. *BMC Health Services Research*. 2015;15(1):1-12.
21. Glass L, Moore EM, Akshoomoff N, Jones KL, Riley EP, Mattson SN. Academic difficulties in children with prenatal alcohol exposure: Presence, profile, and neural correlates. *Alcoholism: Clinical and Experimental Research*. 2017;41(5):1024-1034.
22. Duke University. Understanding FASD: Low self-esteem. <https://sites.duke.edu/fasd/chapter-6-the-fasd-student-and-behavioral-issues/low-self-esteem/>
23. Flannigan K, Pei J, Rasmussen C, Potts S, O'Riordan T. A Unique Response to Offenders with Fetal Alcohol Spectrum Disorder: Perceptions of the Alexis FASD Justice Program. *Canadian Journal of Criminology & Criminal Justice*. 2018;60(1):1-33.
24. Pei J, Leung WSW, Jampolsky F, Alsbury B. Experiences in the Canadian criminal justice system for individuals with Fetal Alcohol Spectrum Disorders: Double jeopardy?. *Canadian Journal of Criminology & Criminal Justice*. 2016;58(1):56-86.
25. Lewis SM, Vydrová RR, Leuthold AC, Georgopoulos AP. Cortical miscommunication after prenatal exposure to alcohol. *Experimental Brain Research*. 2016;234(11):3347-3353.
26. Community Living British Columbia. Supporting success for adults with fetal alcohol spectrum disorder (FASD). <https://www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf>
27. Duke University. Work as a team. <https://sites.duke.edu/fasd/chapter-4-the-fasd-student-and-the-classroom/work-as-a-team/>