Strategies for Infants and Toddlers with an Fetal Alcohol Spectrum Disorders (FASD)

Introduction

The information presented represents a collaborative venture of community agencies providing services to individuals and their families with Fetal Alcohol Spectrum Disorders (FASD) as well as foster and adoptive parents. The booklet is designed for parents, other caregivers, and professionals who in their everyday lives encounter children and youth affected by FASD.

Complex problems like Fetal Alcohol Syndrome and Alcohol-Related Neurobehavioral Disorders do not have simple or quick solutions. There is no single "right" way to parent a child with FASD. Each child is unique. The goal is to recognize each child's strengths and weaknesses in order to understand the best ways to teach, nurture, and parent the child. Parenting a child with FASD is likely to be a long-time effort with success measured in small increments.

Not all of the strategies listed will apply to your child. The strategies are suggestions and should not be regarded as hard and fast rules. At all times work with your pediatrician and other intervention specialists concerning your child's special needs.



[Content excerpted from: FASD Strategies not Solutions, City of Edmonton, Region 6 FASD Child and Youth Sub-Committee, 2004; and Parenting Children Affected by FAS, A Guide for Daily Living. Ministry for Children and Families, British Columbia, 1998]

Cover picture credit—Teresa Kellerman. www.fasstar.com

Feeding and Eating

Babies affected by FASD are often not big eaters. They may have poor coordination and weak sucking reflexes which contributes to nursing difficulties. They can easily become fussy because they can't get enough nourishment they need. Not all of the strategies listed will apply to your baby. At all times work with your pediatrician and early intervention specialists concerning your babies special needs.

- Reduce outside stimulation (noise, bright lights). Your baby may feed better in a darkened room.
- If the weather is not too hot, wrapping your baby in a blanket may help calm her while she is feeding.
- Hold your baby upright as much as possible so she doesn't swallow air. She may choke easily.
- Feed your baby slowly and burp him often.
- Limit feeding time to the baby getting tired. Try frequent small amounts of food throughout the day.
- Feed your baby as soon as he shows signs of being hungry.
- If you bottle feed, you may need to try different shaped or sized nipples until you find one that your baby prefers and feeds well with.
- Use the same bottle, same type of nipple, cloth, and bib every time!
- Make sure you have a good supply of the same nipple on hand including in your diaper bag.
- Infants may not "feel" the nipple or spoon in their mouth. Try to find a way to change the texture of the nipple or spoon (e.g. roughen the nipple with an emery board.)
- Gradually introduce new foods. One change at a time.
- Prepare and offer food with neutral flavors (not spicy, sweet, sour, or salty), heat and texture.
- Remove labels and put food in bowl so baby won't become attached to brand labels. Ignore labels that suggest particular age groups. As your baby gets older she/he may need and prefer to eat prepared foods that are smooth with minimal texture.
- Watch for reaction to tastes as babies may be orally hypo- or hyper-sensitive. (example, low light or more light).

Hygiene

- Try to follow the same routine for diaper changing (example, low light or more light).
- When bathing the baby, a face towel placed on the baby's body may provide some comfort.
- Make sure diaper wipes are warm and not cold.
- Use the same brand and type of diaper. Never use a scented diaper.
- Be aware of possible allergic reactions to creams. Ask your pediatrician about a good choice.
- Your infant may need changing often if she is particularly uncomfortable in a wet diaper.
- Due to possible skin sensitivities, use mild/no/phosphate free detergent.
- Limit the noise and number of people in the room during changing and bathing.

Sleeping

Infants and toddlers with FASD often have trouble falling asleep and waking. They may suffer from irregular sleep patterns, respiratory distress, trouble settling, arching their back, apparent discomfort if cuddled/being held, lack of eye contact, hypo- or hypersensitivity to touch, light, sounds, smells, being fussy, colicky, and trouble adapting to change.

- Where the baby sleeps should be in a quiet area, with low lights.
- Fleece throws (blankets) are very comforting and soothing to infants.
- Rock the baby or toddler gently up or down. A rocking chair may be useful. Rocking side to side may be over-stimulating.
- You will need to determine if your baby prefers to be wrapped snuggly or prefers to wear loose fitting clothing.
- When the baby starts to wake up, gently rock the bed or if your baby likes to be touched, gently rub his back to either help him fall asleep or to help transition him to being awake.
- Parents have found different types of "white noise" can be soothing to babies. These include: a ticking object, such as a clock, placed near your baby's bed, a fan, or music. Soft music such as Mozart or Bach has calming rhythms.
- Bedtime routines are important even for an infant. When at home put your baby to bed in the same bed every night.
- If your baby enjoys being bathed, a warm bath just before bedtime might help her fall asleep.

Parents' Needs - Taking Care of You

Parenting can be challenging at the best of times. Parenting a child with fetal alcohol spectrum disorders is even more demanding, frustrating, and exhausting. It's important not to lose sight of your needs when you are busy taking care of your child. Taking care of yourself is a crucial part of your job. After all, you are the most important person in your child's world!

- Get adequate sleep. Your baby may have difficulty sleeping, so you will likely have trouble getting enough rest for yourself. Rest when your baby is resting. Even a short nap is helpful.
- Make time for yourself to read, journal, get some physical activity. Maintain a sense of yourself beyond your child.
- Identify and practice stress reduction strategies.
- Maintain a sense of humor. Let yourself laugh.
- Establish reasonable expectations regarding what you can do for your child. Focus on what you can do and seek help for the things you can't.
- Tap into resources family, friends, church, federal, state, and county government, community agencies. You have an important, difficult job, and you don't have to face it alone.
- Keep on educating yourself about FASD. Books, magazines, newsletters, videos can provide practical information and serve also sources of support and inspiration.

RESOURCES

Early Intervention Programs in Hawaii (Children 0 – 3 years of age)

Hawaii Dept. of Health, Early Intervention Services

- Hawaii Keiki Information Service System (H-KISS)
- Oahu (808) 594-0066
- Neighbor Islands Toll Free 1-800-235-5477
- Easter Seals of Hawaii, Early Intervention Program
- Honolulu (808) 536-1015
- Kaimuki (808) 735-6981
- Kailua (808) 261-4999
- Kapolei (808) 678-3814
- Lihue (808) 245-7141
- Hilo (808) 961-3081

IMUA Family Services, Early Intervention Services

- Maui (808) 244-7467
- Kapiolani Medical Specialists, Hawaii Community Genetics FASD Diagnostic Clinic:

http://www.kapiolani.org/women-and-children/health-services-forchildren/genetics.aspx - (808) 973-3403

National Websites

(The sites listed are a small selection of websites addressing fetal alcohol syndrome)

- Great Lake FASD Regional Training Center, http://fasdeducation.org/
- Western Regional Training Center for FASD, http://www.semel.ucla.edu/fas
- National Organization on Fetal Alcohol Syndrome (NOFAS), http://www.nofas.org
- FASD Center for Excellence, information, fact sheets, videos and other free resource materials. http://www.fasdcenter.samhsa.gov/
- The FAS Family Resource Institute http://www.fetalalcoholsyndrome.org
- Fetal Alcohol and Drug Unit at University of Washington. http://depts.washington.edu/fadu/
- FASLINK (many articles and discussion forum)
- http://www.faslink.org/index.htm
- http://www.betterendings.org/. (Informative to increase understanding, make connections with families of high risk and special need individuals with a focus on FASD.

Books

- Kleinfeld, Judith and Wescott, Siobhan. (Ed.) 1993. Fantastic Antone Succeeds -Experiences in education Children with FAS. Anchorage: University of Alaska.
- Kulp, Liz and Jodee. The best I can be. 2000. A young teen with Fetal Alcohol Effects challenges the world to peer inside her life and brain. Through her own writings the reader is taken on a life changing journey that will impact their thinking about how to help and understand children with brain damage due to Fetal Alcohol. Better Ending New Beginnings, www.betterending.org.
- Malbin, Diane. Trying Differently Rather Than Harder. 2002. Book provide an understanding FASD; reducing frustration; developing interventions and strategies. To order: contact FASCETS, Inc. at (503) 621-1271 or www.FASCETS.org.
- Streissguth, Ann. Fetal Alcohol Syndrome: A Guide for Families and Communities. 1997. This guidebook explains how to identify and work with children and adults who have the disorder and how to educate prospective mothers and society at large. For parents, educators, pediatricians, psychologists, adoption workers, social workers, nurses, and child care providers.

Videos

- Worth the Trip: Raising and Teaching Children with Fetal Alcohol Syndrome. 2001. Vida Health Communications, Inc. The first comprehensive video resource about the health, development and learning styles of children affected by fetal alcohol. The program presents strategies for meeting the developmental and behavioral challenges faced by children with FAS and the parents and professionals who care for them. (Available on Amazon)
- Students Like Me: Teaching Children with Fetal Alcohol Syndrome. 2001. Vida Health Communications. Video gives parents, elementary and special educators a clear understanding of what Fetal Alcohol Syndrome is, how it affects children's learning and behavior, and what can be done to modify classroom environments and teaching methods to allow children with FAS to learn.
- The Story About Iyal- Uploaded on YouTube by CDC Streaming Health on Aug 25, 2009. A mother tells her compelling story about a family living with fetal alcohol spectrum disorders. Every family has unique experiences, challenges and successes. The intent is not to endorse specific interventions, but to share one family's story and hope.

Reference Materials

■ FASD Strategies not Solutions, City of Edmonton, Region 6 FASD Child and Youth Sub-Committee, 2004. For a copy of the complete document please contact: The Society of Special Needs Adoptive Parents (SNAP), Suite 1150, 409 Granville Street, Vancouver, British Columbia, V6C 1T2, Canada or email: snap@snap.bc.ca.



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www.health.hawaii.gov/fasd

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