

FEEDING YOUR CHILD WITH WILLIAMS SYNDROME



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Society, the media, and even well-intentioned friends and family send messages to new parents about how to feed their children. Parents can usually take this information and figure out what to do to ensure their kids are getting good nutrition. But what if, as can be in the case of children with Williams syndrome (WS), your child requires a different approach to feeding and nutrition? Generally the message given is that you change or adapt foods according to a child's age. A better way to think of it may be progressing with the child's development and skill.

On the next page is a general guide to food types you may feed your child and the developmental skills your child should have when they may be introduced. For example, spoon-feeding should begin when your baby is strong enough to sit up in a high chair (supports may be used to keep them from leaning to one side). You will start with pureed foods and gradually add texture and complexity over time. As your start to notice your baby using chewing motions, chunkier and crunchier foods may be added. The time to get from one stage to the next is different for each child. It is common for a child to stay with one food type for a while before moving on to the next one, but by watching your baby during feeding time, you will know when he or she is ready to move on.



DEVELOPMENT/SKILL	FOOD TYPES	EXAMPLES
Gaining head/neck control	Breast/Bottle	Breast milk, standard infant formulas
Can sit in a supported recline	Breast/Bottle	
*Sitting unsupported in a high chair	Purees	Stage 1 baby foods, infant cereals
Munching with front teeth	Thicker puree/soft mashed Consider introducing some sort of cup; sippy, straw, open (free flow/no spill proof valve)	Stage 2 baby foods; mashed potatoes, sweet potatoes
Lateralizing food to molars (Moving food to the sides)	Meltable hard solid	Strips of toast, Veggie Stix™/Veggie Straws™
	Soft cubes	Canned or ripe, raw diced peaches/pears/mandarin oranges
	Single texture soft food	Cubed deli meats, pancakes, soft cooked pastas
	Mixed texture soft food	Baked beans, soft chicken nuggets, noodles and sauce, chunky applesauce
	Soft table foods to appropriate size	Avocados, bananas, black beans
Rotary Chew Jaw moves in a circular motion to grind food. ¹	Hard foods (dry crunchies)	Cereals (Cheerios, Life, Chex) Chips (pretzels, Fritos, tortilla chips) Hard crackers (Wheat Thins, Goldfish, Cheez-Its)

* **Unsupported** means without assistance from a person. Rolled up towels or bolsters can be used to assist with support in a high chair. If child is unable to sit unsupported by age 8 months, it will be time to seek assistance from Physical/Occupational Therapy.

¹ Source: Chart adapted from Kay A. Toomey, PhD; Denver, CO.

The American Academy of Pediatrics recommends the addition of complementary foods at 4-to-6 months of age. Because feeding readiness may come later for children with WS, it is ok to wait on spoon-feeding until your child is a little older. However, it is important for a child to begin having experience with solids by about age 7-to-9 months. Our experience has found that the longer a child goes without experiencing foods with texture, the more likely they are to develop an aversion to textured foods. If your child is not developmentally ready to sit in a high chair by 7 or 8 months, it may be time to work with a Physical Therapist/Occupational Therapist to work on this skill. This will assist them in being ready to progress with feeding.



Making your own baby food is an easy and inexpensive way to produce purees that can be thickened in consistency over time by adding less water/juice/breast milk/formula or blending them less. Many books and websites are available with tasty baby-food recipes. A blender, smoothie maker or food processor can be used in place of a food mill in many recipes.

HOW MUCH SHOULD I FEED?

The amount of breast milk/formula and foods your child eats depends on their age, size (how much they weigh now), and how active they are. Your pediatrician can give you advice about what is right for your child. If you or your doctor has additional questions, the team at the Williams Syndrome Center is available to help. Sometimes it may be helpful to work with a nutritionist or dietician. This person can help you select food combinations and amounts to meet your child's growth and nutrition needs. A dietician is sometimes available to those receiving other developmental services or a referral can be made by one of your doctors. Your doctor and dietician should plot your child on a WS growth chart (available on the Williams Syndrome Association website williams-syndrome.org and elsewhere online) to help make decisions about feeding goals.

SOME POSSIBLE CHALLENGES AT EACH STAGE

INFANCY: A common finding in infants with WS is irritability.

Irritability or “colic” in an infant does not necessarily mean the infant is in pain or physical distress. Current research suggests that colic may not be related to pain at all, but may just be the baby’s senses “coming on line.” Because of the developmental delays in WS, that period of irritability often lasts considerably longer. During this period, a baby can be irritable, have reflux symptoms or even spit up, but as long as they



are growing and gaining weight appropriately, there is no reason to stop trying to feed them by mouth. The book and DVD, “The Happiest Baby on the Block” by Harvey Karp, contains very helpful real-world tips for dealing with infant irritability/colic. A few suggestions include swaddling and shushing (making a soft “shh” sound in rhythm). Experiment with holding your baby in different comforting positions—some babies like to feel gentle pressure on their tummies, some like to snuggle and some would prefer less contact and enjoy being set

down in safe place. Depending on their age and disposition, they may enjoy simply observing you or hearing you sing.

If your baby is not gaining weight appropriately, it may be time to check with your pediatrician to make sure there aren’t other reasons for slower growth. Your pediatrician may refer you to a nutritionist or speech/language therapist who specializes in feeding to help you work with your child on feeding. Also, if your child is unable to suck from a bottle, has severe choking/gagging or develops pneumonias related to feeding, your doctor may want to do additional studies to assess the way they feed and swallow. In most cases, permanent feeding tubes are not needed in children with WS.

PUREES: It is developmentally appropriate for babies to thrust food out and even gag, when they are first beginning solids. This is due to the need to learn a new skill (different from sucking) to take in food. It is not uncommon in infants with WS for them to take longer to learn this new skill, refuse while learning this skill (because it is new or challenging) or fuss (because it feels different). Don't give up! Offer the new food before breast milk/formula at mealtime, so that your child will be most alert and hungry at that time. Keep trying a few bites at each meal and eventually most will master the skill. If after 3-to-4 weeks of trying to feed your baby pureed food (multiple attempts each day), your baby is still having difficulty, it may be time to consult your physician about a referral to Speech and Occupational Therapy.

SOFT SOLIDS AND BEYOND: With every transition to a new food type or texture, parents may experience resistance to change and difficulty transitioning from the familiar. This is especially true in children with WS. The familiar and "easier" choice is always more preferable. As with irritability and difficulty transitioning to solids, continue to offer these new foods to your child. If your child continues to have trouble progressing to the next level with solids, it may be time to seek a referral to Speech and Occupational Therapy. A knowledgeable therapist can offer tips that are specific to your child's needs to help them meet each milestone.

Similar to starting purees, when a child first tries any new food, they may have behaviors (gagging, thrusting food out) that look like they are having difficulty or something is wrong. Be assured, that in general, these behaviors are in all likelihood due to the newness of the experience or perhaps an individual difference in how the child perceives the sensations (smell, taste, texture, look) of this new feeding challenge. Many times it just takes multiple presentations of the new



food for the child to gain acceptance and mastery (We recommend 12 trials of a new food before fully taking it off your child's menu). If your child has difficulty with processing/ tolerating different sensations even after a good deal of trying (sometimes called oral aversion), this can be looked at by a pediatric Occupational Therapist, who may have ideas for helping your child tolerate sensations.

A NOTE ABOUT LIQUIDS

Transition from the bottle to a cup can also be a challenge for children with WS. As we have discussed with the food transitions, it can be hard for your child to give up what they know for something new. As such, we recommend starting the transition as soon as your child is developmentally able; this usually means when your baby is able to sit well in a high chair and hold their own bottle. There are different types of cups that you can try. Some children do well with a slow transition using a sippy cup with a soft spout (no spill-proof valve) before moving on to a harder spout. Pick one and start with a small amount of your child's favorite liquid (this is not the time to introduce a new taste). Offer the cup at all feedings and snacks.



Once they get the hang of it, increase the amount you offer in the cup. Make a goal of being off the bottle by 18 months to 2 years. Transitions to an open cup are similar (but more messy due to spills). Look for developing coordination with objects and playthings before making this change and start with only small amounts in the cup to limit the spills.

HEALTHY EATING AS A FAMILY

Establishing healthy food habits early in life is important for your child's health. Give them ample opportunities to try new things and remember that eating healthily is a family affair. Children and adults should aim for five fruits and vegetables per day, as well as whole grains, protein foods (meat, eggs and legumes) and some dairy (your



doctor will check the calcium level in your child's blood and urine and will help you determine the right amount of calcium for your child). While children with WS may have trouble gaining weight, adults with WS are at increased risk of obesity and diabetes. Starting in childhood, your doctor should check your child's body mass index (BMI), a value that compares a person's weight and height. If it is too high or too low, a visit with a dietician may be helpful to discuss portion size and food selection. Making good food choices will help your child maintain a healthy weight and may improve constipation.

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