



Diet & Nutrition



PRACTICAL FEEDING TIPS FOR PARENTS AND CAREGIVERS OF CHILDREN WITH NEUROMUSCULAR DISORDERS

BY RACHEL EZEKIEL-FISHBEIN

HMS's goal with the Coming to the Table series is to share concepts necessary to develop safe feeding support plans to help families and school personnel address the needs of children with complex feeding needs.

Sociologists and psychologists have long touted the benefits of family mealtime for child development. Research released by Oxford University in 2017 suggested that “communal eating increases social bonding and feelings of wellbeing, and enhances one’s sense of contentedness and embedding within the community.”

Creating family mealtimes can feel daunting for parents in the special needs community, according to Marianne Gellert-Jones, MA, CCC-SLP, a clinical feeding specialist and speech language pathologist at HMS School for Children with Cerebral Palsy in Philadelphia. HMS recently released the first two videos in its “Coming to the Table” series of free online videos and companion print materials to provide practical feeding tips for children with neuromuscular disorders.

“Everyone wants to eat with their children. It’s part of family life,” says Gellert-Jones. “Children with significant feeding needs can be at risk for aspiration, struggle with feeding efficiency, and become fatigued due to neuromuscular deficits. Many children also have significant underlying gastrointestinal or other medical issues that can impact their oral feeding ability and their enjoyment of feeding experiences. We want to help decrease families’ stress and make it safe and enjoyable for children with oral feeding challenges to be included in mealtimes.”

The school serves children and young adults with complex disabilities from across the country. Most students have identified oral

feeding issues. The school develops individualized feeding support plans for each student and provides training for staff, parents and caregivers.

Eight-year-old Sabina Heim of Glen Mills, PA, enrolled at HMS two years ago. Her feeding issues began in infancy. At six months of age, doctors inserted a gastrostomy tube (g-tube) to ensure Sabina was getting adequate nutrition. Due to Sabina’s significant issues with muscle tone, fatigue, and difficulty coordinating the suck/swallow/breathe sequencing necessary for safe oral feeding, her family was apprehensive about oral feeding. They feared she’d aspirate—a typical fear for parents and guardians of children with neuromuscular disabilities.

“Sabina’s eating has always been a source of fear and anxiety for us, because even if she chokes on something a little bit, it’s a big deal,” says Michelle Heim, Sabina’s mother. “I come from a huge Italian family that thinks a meatball can cure anything, and here was my daughter who couldn’t partake in family meals. It could change the whole dynamic of a family event or holiday.”

Last year, after a feeding assessment with Sabina’s team and her mother, HMS developed a new feeding support plan focused on improving Sabina’s comfort trying new foods, fostering greater independence, and promoting socialization during mealtimes.

GOOD COMPANY: (Opposite page) HMS student Sabina Heim is thrilled to be able to join her friends during mealtime. She is helped by HMS student feeder Maxine Fussell-Mills.

TABLE TALK : INDIVIDUALIZED FEEDING SUPPORT PLANS

Individualized feeding support plans for each student focus on many areas that are critical for safe and enjoyable feeding, including:



POSITIONING

Positioning is the most essential area to consider when engaging in oral feeding with children who present with neuromuscular challenges. The hips must be positioned all the way back in the chair. Once a stable base of support is established, the trunk, head and neck will be better aligned to promote safe swallowing.



TEXTURE

The texture of the food must match the oral-motor skills of the child to allow them to manage and swallow food and liquid safely. HMS prepares its daily menu in unmodified/regular, chopped or pureed textures. This allows students with varied needs to enjoy and taste the same foods as their peers and promotes the experience of a shared meal amongst staff and students.



MANUAL SUPPORT

Most students at the school require hands-on support to achieve lip closure, and jaw support, so they can swallow. (To get a feel for why this is important, try to chew and swallow a piece of food or swallow a sip of water with your mouth open. You’ll be surprised at how challenging this can be.)



PREFERENCES

It is easy to lose sight of preferences when creating a safe eating plan, but it’s important to remember that everyone wants a choice about what they eat and how they eat it (ketchup, mustard or relish on your burger? Soup first or as an entrée?). Part of building independence and making mealtime enjoyable is teaching students to communicate their preferences and ensuring that caregivers respect them.



PROPER UTENSILS

Utensil features (such as size, bowl depth and shape) are matched to meet the needs of each child to best promote successful oral feeding. Utensil selections are made based upon the size of the child’s mouth, where the food needs to be placed in the mouth, and the child’s specific oral motor challenges.



SOCIALIZATION

All staff training promotes mealtime as a social time. Often, when oral feeding is limited or challenging, all the talk surrounding the meal focuses on food and the volume the child ingests. HMS’s staff works to ensure that mealtimes are also opportunities for social engagement with peers and staff. Shared mealtime experiences really do support children in building relationships.



PERSONAL TASTE: HMS student Diana Rich enjoys a meal with feeding specialist Marianne Gellert-Jones. At home in Massachusetts, Diana likes to eat exactly what everyone else around the table is eating in exactly the same way they are eating it; At school, however, she is more comfortable having her food blended or chopped to make it easier to eat.

While Sabina still gets the majority of her nutrition from her g-tube, she is now also enjoying many of the same foods as her peers in the cafeteria, alongside her friends. Previously she had only enjoyed a few tastes of familiar foods provided from home. According to her mother, Sabina now loves mealtime and enjoys sharing stories with her family about what and how much she has eaten.

HMS's goal with the Coming to the Table series is to share concepts necessary to develop safe feeding support plans to help families and school personnel address the needs of children with complex feeding needs outside the HMS community.

Each video encourages caregivers to try experiential activities to drive home key concepts of positioning and manual support. The multi-media combination of written and video instruction, in the Coming to the Table series was designed to be accessible to individuals with varied learning styles. All of these materials are accessible for free on HMS's website: <https://hmschool.org/>.

"When a child gets their diagnosis, eating

together is the single activity most families feel is a 'must' to maintain some sense of normalcy," says Gellert-Jones. "There are so many things their child can't do and giving up on feeding is something about which families truly struggle. Our aim is to aid children with oral feeding and swallowing challenges to safely engage in some oral feeding experiences together with their families. It may not look the same as everyone else's mealtime and it may need to be different depending upon the environment, but mealtime and oral feeding experiences remain incredibly important in most families. We want to help children continue to participate in that activity in a safe and meaningful way."

Research has yet to identify any single therapeutic method to make all kids more successful feeders. However, training caregivers and families to feed children safely has been shown to improve outcomes. Untrained feeders can contribute to mealtime stress and fear for the child, and also unknowingly contribute to significant health issues.

"There are many opportunities for professional development in the area of feeding for speech and occupational therapists," says Gellert-Jones, "but there isn't much geared toward caregivers or paraprofessionals who are providing direct care outside of a therapy session. The Coming to the Table Series isn't designed to replace professional support, but may be referenced by other professionals and accessed by families to reinforce basic concepts for safe feeding across many environments."

Not every oral feeding experience can be transformed into a full meal, but with training, many families and caregivers can provide safe and enjoyable oral feeding experiences. Some children may only enjoy a "therapeutic taste," which means a light gloss of the food on their lips or a spoon dipped in food or liquid and placed in their mouth. Others may be able to enjoy a more significant meal with a modification in the food/liquid texture offered or they may only enjoy part of a meal orally before receiving their tube feeding.

Diana Rich, 21, who has cerebral palsy and fluctuating muscle tone, moved into the residence at HMS when she was 14. Her father, Carry Rich, describes Diana as a "foodie." Her favorite foods are sushi and steak.

"You try to make life as normal as you can with the special conditions you've been given," says Carry Rich. "We've always eaten meals together as a family. Diana's needs are always in the forefront and we have to be conscious of what we're giving her."

Diana comes from a large family that enjoys spending time together. When she's home in Massachusetts, Diana likes to eat exactly what everyone else around the table is eating in exactly the same way they are eating it. That can mean corn on the cob or chicken on the bone. At school, however, Diana is more comfortable having her food blended or chopped to make it easier to eat. Due to her difficulties with managing her muscle tone, Diana cannot independently manipulate a bolus of food in her mouth to move it back to her molars for safe chewing.

"Mealtime is a very social time for us because it takes so long for Diana to have a satisfying meal that goes from her mouth into her stomach. It's tiring and you can't

rush it,” explains Rich. “She loves the real food and I will often hold a piece of food on the side of her mouth for a very long time and she will just chomp on it and grind it.”

Diana, who uses an augmentative communication device to speak, often directs her mealtime routine using her device and her eyes. HMS student care supervisor Lauren Dukes, who works with Gellert-Jones to train HMS’s personal care attendants, emphasizes the importance of communicating with students throughout meals.

“I want students to have a choice about what they eat,” says Dukes. “This gives them dignity and teaches them to advocate for themselves.”

CONVERSATION PIECE

A mealtime conversation might sound like this with the student answering using a communication device:

Aide/Parent: You’re having chicken fingers and French fries for lunch today. Does that sound good?

Aide/Parent: Do you want ketchup on your chicken fingers (holding up choices so the student may eye gaze to their choice or use their device to respond)?

Aide/Parent: No? Okay. How about mustard? Would you like mustard on your chicken fingers?

Aide/Parent: Yes. Okay. A little or a lot? (The feeder mixes just a little in a small amount for the student to taste, knowing if they do too much or the student doesn’t like it the meal can be ruined for them.)

Ongoing communication is particularly important for students who are also visually impaired—as many students at HMS are—to help guard against any surprises during the meal. Even when you are not sure if a child can understand what you’re saying, assumed competence is important. Using language throughout meals also reinforces the concept of meals as a social opportunity and can support learning.

The social aspect of mealtime often goes by the wayside for children with oral feeding challenges. In most cultures, we celebrate with food, and the child who is left out because of medical issues, misses out on myriad opportunities to engage and connect with others.

Communication throughout the meal also reinforces students’ agency, encourag-

ing students to advocate for themselves and direct their mealtime experience. While a child may not be able to feed him- or herself, they can choose what they are going to eat, when they are ready for the next bite, and how they would like that food presented.

After 30 years in the field, Gellert-Jones has lost track of how many times she has reassured caregivers and parents that the definition of a successful meal is not an empty plate.

“Forget the old adage about cleaning your plate,” says Gellert-Jones. “The definition of a successful meal is when the child and the person feeding them have had an enjoyable mealtime experience, in whatever form that takes on for that child. There are always opportunities to engage and include children in mealtimes, even those who present with the most significant feeding challenges. The goal of our video series is to train people to provide support that allows each individual to safely participate in mealtime activities across multiple environments.”

“We are sometimes scared and very cautious, but we’re learning to not be afraid to try things,” says Michelle Heim, eight-year-old Sabina’s mom. “We’ve learned how much she’s really capable of and how much she loves to see what she can do and advance to the next level. Like a typical kid, she feels a huge sense of accomplishment that she can follow through and do something new.

Understanding each child’s individual needs will alleviate uncertainty and apprehension.

“The number one thing is understanding how your child manages food, and that is completely individual,” explains Carry Rich. “For my daughter, the most important thing is portion control—how much of a spoonful will go into her mouth. Next is providing the right support. I have to use both of my hands—one under her jaw with my fingers on her cheeks and the other to hold a spoon or whatever she is chewing on. I know that I have to get the food into

the right position in her mouth so she can reach it with her molars. And I need to make sure she is positioned correctly—that

she is not leaning to the side or forward or bent over, so she is in a good position to swallow.”

The key to creating a strong feeding relationship is to keep your focus fully on the child.

Lauren Dukes advises parents, family members and caregivers who are watching the videos:

“Think about how you’d want someone to feed you. You’d want them to focus fully on you and provide the care you couldn’t provide to yourself.”

“Think about how you’d want someone to feed you. You’d want them to focus fully on you and provide the care you couldn’t provide to yourself. Communicate throughout the whole meal, not just at the beginning and listen to the child in whatever way they can communicate. Don’t make assumptions, because their preferences may change from day to day. Remember this is about them, not you.”

Feeding can be challenging when the education and training isn’t provided to make it safe and enjoyable. When only a few close individuals are trained, comfortable, and safe feeding your child, the world in which your child can live is drastically limited.

“We hope to develop an entire series of Coming to the Table videos to provide training about a broad range of oral feeding issues for caregivers and families of children with neuromuscular disabilities,” says Gellert-Jones. “We believe these videos can expand the experiences in which children take part by imparting knowledge and increasing the confidence of parents and caregivers when engaged in feeding children with significant challenges across multiple environments.”•

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