

STRESS & MEALTIMES

Understanding Stress at Mealtimes

Many children and their parents experience high levels of stress in their lives. Physiological stressors such as surgery, illness, responses to medications, pain, and lack of sleep influence the body's ability to function at an optimal level. Emotional stress is derived from our perceptions and beliefs about the events and experiences that touch our lives. What is stressful for one person may not be stressful for another.

The Parent's Stress

Tube feedings offer a special set of potentially stressful situations for parents. Feeding tubes typically are recommended when infants or young children are simultaneously experiencing major medical challenges that limit their ability to swallow safely or to take in enough food and liquid to support adequate growth, nutrition and hydration. Parents frequently are mentally, emotionally and physically exhausted from their child's illness and the critical decisions that they have already made during this period. When the tube is recommended as part of the total medical solution during a period of hospitalization, the decision may be easier because it can be viewed as another medical solution that can save the child's life.

The meaning that parents attach to a feeding tube once the child is at home can be quite different and varied. The tube may be recommended when the child is not sick and is taking some foods orally. A mother may be spending hours at each meal trying to coax her child to eat more; and still the child does not gain enough weight. Feelings of guilt and a sense of personal failure may crop up when the doctor or dietitian recommends a feeding tube. Many young women learned from parenting their baby dolls as toddlers that "a good mother can feed her child". This contributes to feelings of inadequacy and stress when her child is unable to eat enough to grow and thrive.

Most parents are unfamiliar with the possibility that a child might be unable to eat by mouth. Before their baby is born they assume that their child will enjoy eating and have the skills and desire to eat a wide variety of foods. When they learn that their child needs to eat through a feeding tube, they are faced with a profound sense of loss. Most people go through a grieving process as they face loss, whether the loss is of a relationship, a job, a death, or the loss

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of a personal dream or assumption. The loss of eating and drinking is very powerful for many parents.

Tube feedings are accompanied by unfamiliar equipment and procedures. Learning to use feeding tubes, formulas, syringes, feeding bags and feeding pumps can initially feel overwhelming. This is particularly true if part of the system malfunctions or the child is uncomfortable during the meal.

Most parents understand when an orally fed child wants more food, needs a pause in the meal or has had enough to eat. There may be personal or cultural pressures to override the child's signals, but in most instances it is the child who makes the final decision. Reading the more subtle cues of an infant or toddler with a physical, sensory or gastrointestinal disability can be very challenging. As parents are trying to learn these cues and respect them, professionals may be telling them that their child must take in a specific number of calories at every meal. Their desire to regulate the timing and volume of the child's formula may be in conflict with their desire to follow the directions from the doctor or dietitian so that their child will grow.

All children and adults go through periods when they do not feel well. The natural response to unwellness is to eat less or to stop eating. Many children who have feeding tubes experience gastrointestinal discomfort. They may continue to retch and vomit even with tube feedings and cry or fuss when food is offered by mouth or by tube. Mealtimes can become highly stressful for parents who want to respect their child's signals of discomfort but feel that if they give the child less food, she will not grow.

Many parents worry about the added costs that tube feedings create. Special formulas are extremely expensive when compared with breast milk, infant formulas or the meals typically served to toddlers and young children. Payment for feeding tubes, syringes, formula bags and pumps increase costs exponentially. Although many families are able to get help with these costs through private insurance, Medicaid or other 3rd party payers, a substantial portion of the expenses still must be paid by the family. Insurance companies may limit the number of replacement feeding tubes that will be paid for each year or the number of syringes that will be supplied per month for bolus feedings. Many insurance companies will not pay for special formulas because they label them as food and not as a medical need. These financial pressures add to the stress that many families experience when their child has a feeding tube.

For all of these reasons, many parents want to wean their child from the tube as quickly as possible. They are drawn toward programs that promise rapid weaning or feel frustrated and angry when tube feedings appear to continue indefinitely.

Similar stressful situations may be present if the child eats and drinks entirely by mouth. Parents feel responsible for giving their child enough food and fluid to support adequate nutrition and hydration. When the child does not eat or drink enough to grow well or to prevent dehydration, pressure can increase to an almost intolerable level for many parents. They are afraid that their child will become physically or mentally delayed from marginal malnutrition. They dread visits to the pediatrician when the child will be weighed or to the dietitian who may recommend foods that they know their child will refuse. They hate mealtimes that deteriorate into family fights about eating or require massive effort to distract or reward a child who will not take a bite without being entertained.

The Child's Stress

Children may also feel stress at mealtimes. Some children received a feeding tube because they are ill or lack the coordination and endurance for safe swallowing and growth. These situations may continue to influence their tube feeding mealtimes. Reflux, vomiting, retching and other gastrointestinal discomfort often increase during both tube and oral meals. Because tube feedings frequently are offered in a very mechanical way, children may experience the added discomfort of formula that comes in too quickly or continues to arrive when the stomach is filled. Even though they may tell the person feeding them that they need to stop, they feel pressure from adults to eat more than is comfortable. Their communication signals may be ignored or misunderstood. The orally fed child may protest that he doesn't want the food. He may tell parents that he doesn't feel well or is full. These messages clash with the parent's fears about the consequences of not eating.

Individual Responses to Potentially Stressful Situations

Our society constantly reminds us that we are at the mercy of the people and events in our lives. We are taught verbally and by example that situations and people cause us to respond in predictable ways. We

could describe the specific situation as the stimulus, which could be perceived as a trigger for our feelings and our actions. This is a perspective that we can question when we look at the many different emotional responses and behaviors that different people experience with the same basic events.

The specific response that a person has to a situation is not a function of the stimulus. Another person or an event does not cause the response. Between the stimulus and response lie a complex group of personal meanings that are unique to each individual. For example, the doctor has just recommended a gastrostomy tube for a child who is not growing well. The stimulus is the recommendation for tube feeding. We know that different parents respond in very different ways to this recommendation. One may feel very happy because she believes that this will allow her child to grow; or she may feel relief because trying to get her child to eat enough by mouth has resulted in a constant battle and family conflict. Another parent may feel discouraged and upset because she believes she is a failure as a mother; or she may be unhappy and angry with her child for refusing to eat by mouth, and accepting the tube feels like a defeat. She may be afraid that a feeding tube will be permanent and her child will never be able to eat orally. She may even be angry about the tube because she is furious with the doctor, whom she believes never listens to her.

A child may experience uncomfortable physiological sensations from reflux and nausea. He may respond to these sensations by falling asleep; or he may react to the distress with upset, leading to gagging or retching. He may become frightened of the distressing sensations and feel that he is getting sick because his mother is giving him too much formula. He cries and tenses his abdomen even before the food is given because he believes that the food will make him sick.

Although we may have little control over the events in our lives, we always have the choice of how we will respond. We give a personal meaning to the event. We decide within ourselves whether the event is good for us or bad for us. When we choose a positive or optimistic meaning, we can approach the situation from a base of happiness. When we select the negative or pessimistic interpretation filter, we respond with unhappiness and increased stress. It all depends on what we believe—on the personal meaning that we give the experience.

Stress and Pain

Many children with gastrointestinal complications have chronic pain and discomfort during and between meals. When they have pain from gastroesophageal reflux, ulcers, poor digestion, abdominal dysfunction, and stomach pressures associated with mealtimes, it is hard to want the food next time. We know from carefully watching children (as well as from research) that when pain or discomfort is associated with eating (by mouth or tube), appetite is suppressed.

Chronic pain can create a stress cycle that is detrimental to appetite, growth and any type of enjoyment at mealtimes. This happens for several reasons. First, the pain itself takes away from the desire to eat. Who thinks about hunger and eating when they are in pain? Second, the process of eating just does not feel good and the children learn that! Instead of learning that eating is an enjoyable time, they learn the opposite—to try to get away from eating! Third, pain shifts the balance in the way the body regulates itself. It creates an excitable “arousal” response in the body. The heart beats faster; blood pressure increases; and there is disordered movement within the gastrointestinal system. The disorder in the GI system can include severe nausea, vomiting, slowed stomach emptying, no stomach emptying or too much movement in the intestines leading to cramping and diarrhea. Commonly, the pain leads to arousal, which leads to slowed gastric emptying. The slowed gastric motility can lead to pain, which again can lead to arousal and the cycle continues.

Over time, it seems to take less and less pain or discomfort to create the same level of arousal in children. For many children just the fear and anticipation of the upcoming pain event can cause actual pained reactions, even before the meal is presented. The amount of stimulation it takes to produce that pain reaction frequently becomes less and less over time.

The intensity of the pain response in relation to the perception of the pain is personal and different for each individual. It is influenced by the physical symptoms, the sensory perception of the symptoms, and the arousal, which is the body’s response to the pain and sensory perception. For example, the child has recurrent inflammation in the esophagus and vomiting with eating (i.e. pain or discomfort). These would be considered symptoms of disordered motility. The inflammation in the esophagus would

stimulate the pain nerve that travels between the GI tract and the spinal cord. The message is then passed on to the nerve that travels up to the brain (i.e. sensory perception). The child perceives this sensation based on intensity, past experiences with pain, parental reaction, and the arousal response. Over time it can take less pain to elicit the same response. Pain, slowed motility, sensory perception, emotions and the child's response are all interconnected, yet real for the child.

Gastrointestinal symptoms are influenced by the intensity of physical pain and discomfort, and sensory symptoms, degrees of arousal, emotions of past experiences and anticipation of the pain. Treatment to improve comfort at mealtimes, therefore, will be influenced by multiple factors. Some professionals work primarily to change the diet, meal sizes, and mealtime positions. Others treat the way the gastrointestinal system physically works through the modality of surgery and motility drugs. Still others focus on reducing or eliminating the gastric acid that creates so many of the symptoms of inflammation and pain. Many professionals help the individual develop skills in whole body relaxation, mental focus, breathing and distraction activities to reduce the anticipation of pain and increase the child's control during the meal. Some physicians focus directly on elimination of the pain response and anxiety through medications that help reduce the child's overall stress symptoms.

Stress and Growth

Although having a feeding problem and a feeding tube can create stress for many families, mealtimes themselves often become the major trigger of stress reactions for children and parents. Foods that contribute to gastrointestinal discomfort or metabolic, allergic or hypersensitive reactions create both physiological and emotional stress. Fear can create an easier threshold for gagging and vomiting. When the child vomits food or formula, many parents become worried and frustrated. They are afraid that their child will not receive enough calories and may even feel angry that they need to somehow get him to take an even larger amount of formula. The child's body has said "no more; something's wrong" and the parents' fears create pressure to take in more food. Children are often verbally or nonverbally chastised for the amount that they take in orally or by tube. The message is frequently "It's not enough" which the child often interprets as "You are not good enough".

Parents and professionals want children to grow well. Their bodies are programmed to take in nutrients and calories and use them for growth and health, but sometimes this program doesn't work well. We could compare this automatic part of a child's body to a computer running software for growing. This program operates the body's ability to digest, breathe, eliminate and protect itself internally through the immune system.

The body's computer also has a program for protection. The brain's computer system shifts its software from the growth program to the protection program whenever it feels threatened. Growing is no longer its highest priority when it perceives a situation as dangerous. Protecting itself becomes its main concern.

The body's protection system supports the ability to be strong enough to run away or stay and fight the attacker. In this "fight-or-flight" response the body directs its full energy and resources toward surviving. The body doesn't need to digest food and grow; it simply needs to survive. To do this, it must temporarily shut down the growth program. The brain does this by secreting a series of hormones that shift blood from the gastrointestinal system to the arms and legs. Digestion shuts down and stomach emptying is delayed. This increases the body's ability to get away from the dangerous situation or increase physical strength for fighting the danger.

The problem with this strategy is that it was designed for intermittent situations of acute stress where real danger to survival is involved. This system is counterproductive when the body is under chronic stress. We live in a world that promotes fear and anxiety. Chronic stress is a function of personal perceptions that see threat and potential disaster in many aspects of life. The meaning we attach to the event determines our response, not the event itself. Our body was designed to respond strongly when a tiger confronted it on the path; now it responds in the same way to situations that have nothing to do with immediate physical survival. The body doesn't differentiate between acute and chronic stress; it simply gets a message from the brain that advises it to prepare for danger. Thus, it gets ready to protect itself with a fight-or-flight response when we believe that we don't have enough money to buy what we want or that our child didn't complete his homework. The bottom line is that chronic stress is directed by our perceptions and beliefs that a situation is dangerous

or not in our best interest. The added physiological and emotional stressors of environmental toxins, pharmaceutical drugs, poor nutrition, a busy lifestyle, work-related challenges, and the task of raising and caring for children with special needs contribute additional stresses. This means that stress hormones flood the body with messages that constantly tell the body to protect itself. It also means that there is less energy available for digesting and absorbing food and growing. This is highly relevant to the feeding and mealtime issues of children who have feeding problems.

A large percentage of these youngsters have challenges with the growth system. Respiratory, digestive, elimination and immune system problems are common. Many have measurable difficulty gaining weight and growing, despite receiving an appropriate number of calories through tube feedings. Gastroesophageal reflux and other problems with the gastrointestinal system are common. Reflux contributes to nausea, vomiting and esophagitis. Infants and young children commonly associate this pain and discomfort with being fed, and they learn to protect themselves by refusing to eat or limiting the amount of food they take in. Constipation occurs frequently, both as a result of inadequate fiber from a liquid formula diet and from an overall reduction in efficient function of the gastrointestinal system. As part of the stress signal relay, specific hormones send a message to slow down digestion and stop stomach emptying. This contributes physiologically to the delayed gastric emptying that causes children to feel full all the time because the stomach actually is full of the food from the last meal. A constantly full stomach also increases the likelihood of reflux and vomiting. The same hormonal system that is activated by stress increases the movement of the lower intestines and can result in loose stools or diarrhea. Stress at mealtimes interferes with digestion and growth. It also makes it more difficult for children to learn that mealtimes can be pleasurable and that food itself can be satisfying and nurturing.

Creating a Nourishing Mealtime Environment

The Environment

The environment in which we offer the meal can either increase or decrease stress levels for both the child and the parent. When adults think about

creating a positive environment ahead of time, meals are easier for everyone because they are more positive and less stressful. When the environment provides nourishment rather than stress, children are able to learn more easily and grow and thrive.

Attitudes and Intention

The attitude of the feeder plays a critical role in creating the overall atmosphere of the meal. When adults approach the mealtime with the intention to be present, loving, non-judgmental and happy they become more receptive to the child's communication signals and desire to become a partner.

Location

The sensory input and physical characteristics of the location selected for the meal play a major role in the child's comfort and physical control. When the environment matches the child's needs, tube-feeding meals are more comfortable and successful.

Food and Liquid

The food itself plays a major role in a child's attitude toward the meal. Nourishment can be offered that meets the child's nutritional, sensorimotor, developmental and emotional needs. Parents and professionals can explore the potential role of foods that may trigger allergies, food sensitivities, reflux or general gastrointestinal discomfort. Food and liquid can be offered in a physical form that is easy and comfortable for the child to handle successfully. Homemade blended formulas may contribute to greater physical comfort for the child who is tube fed. Many parents report a higher level of personal involvement while feeding their child a formula that they have created. Both aspects contribute to the overall nourishment provided by a comfortable and interactive mealtime.

Timing

Tube feeding formulas may be given as bolus feedings with a syringe or through a feeding pump. Each child has specific needs for how much formula and the timing or speed with which the formula is offered. Orally fed children naturally may be hungrier and eat more at specific meals or times of day. It is worth taking the time to find the most comfortable way of offering the meal.

Communication and Control

The only person during the meal who knows whether the meal is creating comfort or discomfort is the

child. All children are able to communicate what is happening inside through their body movements or through signs or symbolic language. It is up to the feeder to learn the child's special communication system and respond in a way that honors the child's messages. Research suggests that adults and children experience more stress when they perceive they have little control over an aspect of their lives. Less control also is associated with higher levels of illness, depression and learned helplessness. When children are able to have some control during a meal, their stress is reduced.

Tools That Support Stress Reduction

Tools that contribute to stress reduction can help both children and parents participate in a happier and more relaxed meal. Many of these tools are highly effective in reducing pain. Just as stress has different triggering beliefs for different people, different tools may be effective for different adults and children. Often by asking ourselves some basic questions and observing the responses of both the child and adult, we will find the specific activities that we want to incorporate at mealtime.

Music:

Quiet, organizing music can help children and adults relax physically, mentally and emotionally. A specialized type of music called "Metamusic" contains an auditory guidance system known as Hemi-Sync that based on binaural beats. Metamusic is particularly effective in reducing overall stress and helping children focus their attention in a positive way on what is going on in their bodies.

- What type of quiet, organizing music seems to relax the child?
- What type of quiet, organizing music supports the parent's relaxation and focus of attention?

Imagery:

Imagery can create positive scenarios that both parents and older children can use to reduce stress. Research has shown that the brain is unable to tell the difference between an experience that occurs outside of the body and one that occurs inside. Whether we look at a flower growing in our garden or imagine that same flower with a picture created inside our head, the brain responds with the same patterns of electrical activity. Anytime we think of something in the future we are using our imagination, simply because none of us ever know the future – even a future that

is 5 minutes from now. We frequently make up or imagine a future that we don't really want. We create a make-believe scenario in our minds that might include our child being ill or refluxing and vomiting the meal. We could, however, make up something that we really want. We could go into a meal thinking about and creating feelings and pictures in our head that our child is happy and comfortable. We could imagine that we will recognize and respond to every communication cue that our child offered.

- Could the parent become aware of negative images that she creates before and during the child's meal? Can she simply notice these thoughts and imagery without judging them or herself?
- Could the parent consciously decide to imagine something that he really wanted for himself and his child during the meal? When his mind wanders to unhappy thoughts and images, could he let them pass and come back to images of what he would like for the present moment?
- Does the child enjoy listening to stories? If so, could the parent make up stories during the meal that are positive and interesting to the child? Many of these stories could feature the child as a main character in the story.

Breathing:

When children and adults are feeling stress or discomfort, they often hold the breath and briefly stop breathing. They frequently tighten the muscles of their abdomen. This can increase their perception of pain and discomfort. When we help children focus on their breathing and encourage them to keep their breathing movement easy and continuous, they are able to relax more easily and become calmer.

- What type of breathing pattern does the child use during the meal? Is there relaxed movement of the abdomen and the chest during breathing? Is there intermittent tension in the abdomen?
- Does the child hold her breath intermittently during the meal? Does this occur primarily with feelings of stress and anxiety?
- If the parent places her hand gently on the child's abdomen, is it easier to monitor the

child's breathing?

- Does the child respond with an easier, deeper or more continuous breathing pattern when the parent comments on the positive aspects of "keeping the breath moving"?

Caring for the Caregiver:

Many parents believe that all of their personal resources, including time, money and health priorities should be invested in the child. They frequently do not prioritize time to care for their own needs. Often this results from seeing themselves as separate from their child and then placing their child first. They may believe that any time spent nourishing themselves is selfish. In reality children and their parents are so interconnected that when a parent is stressed, tired and in poor health, it affects the child, in the same way that a child's stress and health issues affect the parent.

- What types of activity or non-activity does each parent find enjoyable and nourishing (i.e. reading, sleeping, walking, listening to music, taking bubble baths, spending time with a spouse or friends)?
- Would the parent be willing to take some time each day or several days a week to enjoy a personal activity that replenishes personal energy and health?

Sleep and Nutrition:

Both children and their parents need sleep and strong nutritional support. Many children sleep poorly; when children don't sleep well, neither do their parents. Busy parents often spend their waking hours tending to the needs of their children and feel that they don't have time to prepare nutritious meals for themselves and the rest of the family. The result is often tired parents and children who lack the nutritional reserves to deal effectively with stress and prevent stressful situations. Bedtime rituals and routines and sleep-promoting music played at bedtime and throughout the night are beneficial for many children. When children go to bed earlier, parents have more personal time for each other and for engaging in relaxing activities before they get into bed.

If a child is tube-fed, homemade blended formulas can make a strong contribution to improved nutrition for the whole family. When parents work with a dietitian to create nutritious blended meals for

their tube-fed child, they often become more aware of ways in which homemade meals can be cooked for the whole family. Balanced meals created from healthy ingredients can be prepared in less than 30 minutes. They typically cost less than prepared foods purchased at the grocery store or restaurant. Food supplements may be appropriate for some parents and children to build health at a cellular level of the body. The need and availability of good supplements can be discussed with the child's dietitian and health care providers. Healthy cells lead toward healthy tissues and organs and a higher level of wellness for the whole person. Stress weakens the immune system, often resulting in more frequent periods of illness for everyone in the family. Committing to a higher level of nutrition increases the body's resilience to stressful situations and can result in calmer meals.

- What resources are available to support the child's ability to go to bed at a reasonable hour, fall asleep easily and sleep throughout the night?
- What changes can the parents make in purchasing and preparing foods that are nutritious for everyone in the family?
- Would nutritional supplements be helpful in increasing the health and wellness of both the child and parents?

Stress Reduction in a Mealtime Program

Feeding therapists have often taken a narrow view of their role in developing a program to enhance a child's feeding and mealtime skills. The more traditional approach has been to address exclusively those skills involved with the sensorimotor development of safe and efficient sucking, swallowing, biting and chewing, and self-feeding. Very little attention has been paid to the child's tube feeding meals. Therapists now provide feeding therapy for many children with feeding aversion and refusal to eat. The interconnections among physical discomfort, fear and stress in relationship to eating has not been addressed adequately and progress is often slow and limited.

By reducing stress for both the child and parent, we increase the possibility of better health and growth. When we offer meals in a nourishing environment, we support the probability that the child will digest food more easily and will grow well. We build the child's comfort, confidence and competence that leads toward inner guided eating and drinking.

