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Prevention and Treatment of Tube Dependency in Infancy and Early Childhood

Marguerite Dunitz-Scheer, MD, Arie Levine, MD, Yehuda Roth, MD, Elisabeth Kratky, Hannes Beckenbach, PhD, Christian Braegger, MD, Almuthe Hauer, MD, Markus Wilken, PhD, Jean Wittenberg, MD, Thomas Trabi, MD, and Peter Jaron Scheer, MD

Abstract: *Tube dependency is recognized as an unintended result of long-term tube feeding in infants and young children. The condition involves disturbing side effects such as vomiting, gagging, and active food refusal. It prevents infants from making the transition from tube to oral feeding and from starting to learn to eat in the absence of any medical indication for continuation of enteral feeding. Tube dependency can have a destructive impact on the child's development, even in cases when the nutritional influence might be beneficial. The authors set up recommendations for the prevention of tube dependency and suggest guidelines for weaning tube-dependent children based on the results of the Graz program and satellite programs using a similar model. A sample of 221 tube-dependent patients aged 4 months to 15 years of age provided the clinical study group on which this article is based. Begun in 1987, a comprehensive tube-weaning program was developed on the basis of clinical experience and encounters with more than 430 tube-dependent children in 20 years, resulting in a success rate of 78/81 (96% for 2007) and 79/84 (94% for 2008). Placement must be preceded by clear criteria and a decision as to the indicated nutritional goal and time of use. The placement of a temporary tube must generate a plan covering maintenance issues, including time, method, and team for weaning. Aspects of tube feeding that go beyond purely medical and nutritional issues need to be considered to minimize the frequency and severity of unintended tube dependency in early childhood.*

Keywords: gastrostomy; enteral feeding; nasogastric tube; child; disability; dysphagia; infantile feeding disorders; food refusal

"Avoiding tube dependency starts first and foremost with the decisions physicians make when placing the tube and during follow-up."

Tube dependency is a distressing and unintended result of tube feeding in infancy. The condition of tube dependency can be defined as active refusal to eat and drink, lack of will to learn or the inability, and lack of motivation to show any kind of precursors of eating development and eating and drinking skills after a period of gastric feeding. It is characterized by overt disinterest, food avoidance and active refusal, gagging, vomiting, oversensitivity, fussiness, and other oppositional and aversive behavior. It may influence the quality of life of the affected infants and their families to such a degree that all other troubles fade into insignificance besides the nightmare of a child who will not eat or drink. Nevertheless, tube dependency is not recognized as a problem by many pediatricians.

Tube dependency is a new morbidity characterized by the need to remain tube-fed after the period of indicated use of enteral feeding, regardless of medical criteria. It can affect children with severe developmental delays and cerebral handicaps just as well as children who are highly intelligent and show age-appropriate development in all levels except eating and drinking. Tube dependency may be medically necessary for some patients—for instance, in wake coma patients and patients with dysphagia, recurrent episodes of

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aspiration, severe metabolic diseases, and the need for bad-tasting specific diets or any patient too ill to be stressed with oral feeding for diverse medical reasons. This is unavoidable and nonpreventable tube dependency. It is seen in all patients with permanent feeding tubes.

In this article, we discuss the topic of preventable tube dependency. Tube dependency develops in children who have the ability to ingest and digest food but cannot be weaned from tube feeding, so their lacking technique of oral intake becomes the sole reason for the tube to be left. The children should and could learn to eat and drink but resist doing so. Their growth might be well adapted with the help of tube-fed formula, but weight gain might in some cases also be poor despite tube-assisted enteral intake. Caregivers often develop an obsessive drive to feed the child orally and may indulge in frustrating and intrusive feeding attempts, causing further desperation.

There are 3 primary phases in tube feeding. The first phase is directed toward achieving defined nutritional and anthropometric targets. The second is the maintenance phase, in which these targets are maintained. The third phase—for children with temporary feeding tubes—is the weaning phase. A seemingly inescapable consequence of the first or second phase is tube dependency, which can occur as early as 1 week after initiation of gastric feeding. It can affect children of different ages and seems to be independent of the underlying medical diagnosis. Although more and more children are becoming tube dependent, there are no epidemiological data on this topic. Because this condition is not recognized as a diagnosis in itself, there exist no data on the number of affected children in any country. There is indeed some literature on sucking development in premature infants, including questionnaires identifying early feeding problems[1-10] and toddlers,[11-21] as well as studies dealing with the complexity of swallowing[22-31] in prematurely born, healthy, and handicapped children, but tube feeding as a medical intervention in itself and its functional impact on children's development has not been recognized yet as a powerful intervention and therefore has not been investigated adequately. Because the duration of tube feeding may affect the ability to wean children without specialized interventions, it is of great importance to detect disturbed eating patterns and tube dependency as early as possible. The recommendations presented here are based on the experience of an interdisciplinary group involved exclusively with tube-fed and tube-dependent children. The following paragraphs are divided into technical (T), nutritional (N), functional (F), developmental (D), and caregiver (C) aspects, although in practice, these issues intermingle strongly.

Pretube Staging

T: Avoiding tube dependency starts first and foremost with the decisions physicians make when placing the tube and during follow-up. The main aim of pretube staging is the diagnosis of the underlying problems and the decision about the type of tube and feeding strategy to be used. Apart from emergencies, tube placement should be preceded by thorough assessment by an interdisciplinary team. Depending on the specific diagnosis, the subspecialty of the main physician will vary as well as the subspecialty of the therapists involved. The preparatory team has several responsibilities: (1) to define goals and ensure the quality and quantity and duration of the recommended enteral nutrition[32-41]; (2) to maintain awareness of the developmental aspects, including safe swallowing; (3) to exclude all remedial causes of poor feeding, including food allergies and causes of painful swallowing such as by gastroesophageal reflux disease (GERD), and rule out diseases that lead to dysphagia and anorexia; and (4) to estimate the impact of interactive aspects, including assessment of the caregivers. Without goals, prolonged tube feeding is to be expected and might postpone the decision to initiate primary or complementary oral feeding, thus leading even more likely to tube dependency.

N: A nutritional program and tube feeding strategy should be prepared prior to tube placement. Bolus feeding, oral feeding followed by tube feeds during the day or by nocturnal supplementation, and continuous feeds are common options. As a general rule, oral feeding followed by bolus supplementation or nocturnal tube feeding with oral intake by day has the additional benefit of preserving oral activity and feeding habits, as well as hunger and satiety cycles. Patients intolerant to bolus feeding or with severe

malabsorption may benefit from continuous feeding.

F: Poor weight gain, protection from aspirations, metabolic needs (glucose delivery), and dysphagia are the most common indications for tube placement. Although growth and metabolic parameters as well as surgical arguments are more commonly recognized, symptoms of dysphagia might require additional expertise. In cases requiring long-term enteral feeding and a gastrostomy, it might be prudent to have a trial of nasogastric feeding for several days prior to gastrostomy placement to ensure feeding tolerance.

C: The question of psychological variables influencing feeding trials has been discussed. Parental reactive psychopathology is very hard to distinguish from prior existing psychological findings as long as the child is tube fed and or severely unwell.[42-44] A sensitive interview with the parents before the weaning process is started should try to address and respect the topic of additional psychosocial stressors and/or parental psychiatric imbalance. The integration of a psychologist or psychiatrist dealing specially with the parents is recommended in cases of severely traumatic experiences.[45-49] The distinction of primarily stressful parental feeding behavior with consecutive infantile food aversion versus the existence of a primary eating behavior disorder due to a functional or neurosensory impairment of the child is extremely difficult and basically useless because eating difficulties are by nature always interactively dependent and influencing both the child and the feeding caregiver mutually.[50-62] For coaching traumatized parents to learn to support their child more effectively, one should focus the intervention more on learning to change their perception and awareness of their child's cues than on starting a psychodynamic treatment on a psychiatric level.

Tube Placement

T, N, F: The need for short-term tube feeding is the main reason for nasogastric tube placement. Although the recommended length of tube feeding is arbitrary, by short term, we suggest a period up to 2 months; this would apply to premature infants, surgical corrections of inborn anomalies, and treatment of infants suffering from prolonged diarrhea. If, on the other hand, diagnosis includes an expected phase of prolonged insufficiency of oral intake (eg, lasting more than 2 months)—as seen in children with severe neuromuscular diseases, neurodegenerative diseases, metabolic disorders, regression of developmental milestones, recurrent aspirations, chronic lung disease, and so on—percutaneous endoscopic gastrostomy (PEG) insertion with subsequent placement of a gastrostomy button is recommended. Early PEG placement avoids facial irritation, nasal adhesions, oral and nasal irritation, and chronic infections and decreases the risk of aspiration due to migration of the nasogastric tube into the esophagus. Infants suffering from progressive failure to thrive require especially cautious assessment of nutritional and developmental aspects. Conflicts of interest between caregivers and infants, such as in infantile feeding disorders, should not be solved by tube feeding unless the nutritional state is precarious.

D, C: The choice of primary PEG must be justified. Children with metabolic disorders requiring specific diets will probably benefit from primary PEG placement, allowing them to use their mouth for additional oral intake but without the pressure of ensuring anabolic metabolism. A not proven clinical impression is that later tube weaning is far easier, is less traumatic, and risks less weight loss when weaning infants and toddlers from PEG tubes. They allow more sensitive and gradual reduction of volumes without the risk of recurrent traumatizations in cases of unexpected drawbacks. Prospective data analysis will need to prove this quite common clinical observation.

Tube Maintenance

T: Tube placement must involve responsibility for its impact on growth and development, including not only nutritional and medical but also ethical and legal issues. During the maintenance stage, professionals frequently do not take the time to plan the tube weaning stage. For this to occur, anthropometric goals must be set and monitored. Once they are achieved, weaning should be discussed by the team and with the parents.

N: Nutritional efficiency should be evaluated frequently during the period of nutritional restitution and at least monthly in the first few months following tube

placement in children requiring prolonged enteral feeding. If gastric feeding fails to result in growth improvement, compliance with the nutritional program, nutritional goals, and the reason for lack of improvement need to be reassessed, and removal of the tube might need to be considered as a possible option of choice.

F: Assessment of dysphagia or esophageal reflux, if existent, will indicate whether prior findings need reevaluation. Nonintrusive oral stimulation should always be encouraged before and during tube feeding. It might be advantageous to suggest continuous tube feeding during the night and smaller meals during the day. This allows for periods of hunger during the day, which can facilitate oral intake. As infants lose the instinctive connection between the sensation of full stomach and eating, even after a short period of tube feeding, the family should be provided with recommendations for safe oral stimulation. It cannot be assumed that an exclusively tube-fed child will suddenly begin to eat by mouth when tube feeding is reduced or terminated.

D: Feeding skills, from intake of liquids to semisolids and solids, develop step by step. To enable normal development in children with temporary tubes, safe oral stimulation with real food or toy food is recommended. Such activity should be supervised professionally. At home, the child should be involved in cooking activities and have the opportunity to touch and taste real food during tube feeding. Bolus tube feeding should take place during family meals and not in the crib, bathroom, or other isolated locations. For children with dysphagia, safe oral stimulation might include exercises without liquid or food. Therapy should also include positioning, increasing sensory input, and touching different textures of food.

C: Tube insertion generally results in some initial relief to caregivers. Any observation by parents about changed behavior or troubling side effects should be taken seriously. The question when to begin weaning is usually raised first by the parents; they want to know whether their child is ready for tube removal. The main task in tube maintenance should be to keep the child interested in touching and interacting with food without regard for intake volume. Force feeding and constant offering and urging must be prohibited because it hinders the progress of self-regulated feeding development. Discussions about tube feeding should not take place in the presence of the child because children feel ashamed about being different and often show oppositional behavior with respect to adult expectations. It is ethically unacceptable to make parents hope that tube weaning will be possible when it is unsafe or impossible because of the child's medical condition. It is also unacceptable not to wean a child with a self-feeding potential if the only problem is the nonavailability of appropriate treatment. Tube-fed children with the potential to eat should be helped to do so as soon and as effectively as possible; those who lack the potential of self-regulated oral feeding will need a permanent tube and should not be also traumatized by ineffective trials.

Assessment of Weaning and Priming

There is extremely little literature on the explicit topic of tube weaning. Some reports of force feeding and involvement of the child into behavioral sequences of directive feeding are highly distressing and not convincing in outcome.[63-68] The occurrence of serious medical complications of long-term tube feeding—such as infection, perforation, dislocation, chronic skin eczema, dumping syndrome, and, most commonly, recurrent daily vomiting[69-73]—suggests the need for effective tube-weaning programs for children. In addition, the increasing numbers of survivors of short bowel syndrome who are fed on continuous drip by central venous lines are another convincing group of patients needing effective models for learning how to eat, even if being delayed in this specific developmental item by years.

T: Before starting the weaning process, the child must be in a stable medical condition. The duration of tube feeding should have clearly passed the goals for the original indication. Children older than 2 years of age should be informed in advance about the intended project.

N: Fear of loss of weight is commonly the main argument against weaning. However, there are good arguments for weaning even in the presence of nutritional concerns. In a study sample of 221 tube-dependent infants, more than 90%

of the children had been tube fed for most of their lives.[74-77] Even though they had been exclusively fed by tube with a high caloric formula, the major part of this group was below average weight for length, with a body mass index (BMI) below the expected range. Apart from developmental and social advantages, oral nutrition is better used. Treatment of children with infantile feeding disorders and failure to thrive (FTT) often leads to initial weight loss when intrusive feeding behaviors are stopped, but children usually maintain or increase weight curves over time as oral intake and enjoyment of food increase.

F: All therapeutic activities should be reassessed routinely and terminated if the child fails to show good cooperation and progress.

D: A child able to sit should not be fed on a parent's lap. He or she should be allowed to interact frontally with the feeding person, who should also indulge in eating at the same time. Ideally, this occurs at the family meal. Swimming and any interaction with soap-free water is another way to enhance swallowing of water in a nonintrusive manner. Play therapy and psychological guidance can also be helpful in this phase. Allowing oral intake, even if minimal prior to weaning, may facilitate weaning down the stage. Children receiving continuous feeding or rigid bolus feeding should preferentially be placed on nocturnal continuous feeding with periods during the day when they are not fed to generate a hunger pattern.

C: Parents of tube-fed children feel unhappy about their plight. If the duration of tube feeding exceeds the predicted period of time, they will wish to start tube weaning but lack the means to do so. A vicious circle of insecurity and desperation may result. Pressure and adult expectation build, causing the child to resist any steps toward autonomy. Parents report feelings of anger, guilt, and sadness at the sight of other children eating normally. In earlier studies,[42,43] we reported that 86% of parents of tube-fed children suffered from overt depressive symptoms that disappeared after their children had begun to eat normally.

Figure 1.

- **Phase 1:** Pretube staging, choice of tube defined by the medical diagnosis/situation and estimated duration of tube feeding (temporary/permanent)
- **Phase 2:** Achievement and maintenance of nutritional and anthropometric goals with oral stimulation if possible by safe swallow function
- **Phase 3:** Tube weaning or reassessment of goals or set up of a long-term support system of aftercare

Procedure of Tube Weaning

T, N: Tube weaning is not possible without the presence of hunger. It is therefore necessary to reduce feeding volumes as drastically as possible and as gradually as necessary. No satiated infant will show oral activities, regardless of which and how food is offered. Depending on the occurrence of preweaning oral abilities, the Graz tube weaning protocol (a 3-week program) reduces the tube-fed volume by 20% to 40% on day 1, 40% to 60% on day 2, and—depending on the child's physical state and exploratory oral behavior—the remaining 40% to 60% either completely on day 3 or gradually over the following days. During this period, the child must be exposed to a world of attractive food and drink, all served in small and colorful dishes during all therapeutic sessions (Figure 1) but not offered by anyone specifically. The number of daily individual sessions varies from 1 to 4, and the group intervention called play picnic becomes a repetitive daily routine that the infants look forward to. The resulting weight loss varies from child to child. It should not exceed 10% of the initial body weight, unless the child has been nutritionally primed prior to the weaning project. As soon as any oral activity is observed (babbling, sucking, licking, tasting), the nasogastric tube should be removed, at least during the day, or G-tube feeding should be stopped during the day. If drinking takes place, even if only in sips, tube feeding should be interrupted for as long as the child is in a stable condition, as assessed professionally.

If parents and the responsible team are comfortable with the idea of continuing without the tube, or if the child removes the tube by himself or herself, weaning can be continued. In this transition phase, sufficient support is crucial. Parents must be able to have the child checked at any time if they have any concerns about insufficient intake or potential harm. Body weight should be measured daily; an initial phase of weight loss must be expected. In our study,[74-77] the average weight loss was 5.3% (range, 1%-18%), with a maximum in the second week. Depending on the child's initial ability to drink, the weight loss may be negligible. This option of reducing volume gradually is distinctly easier in a child with a G-tube. As soon as the child starts drinking well, tube feeding can be terminated. Nutritional needs must be assessed in terms of immediate versus long-term needs. We do not generally recommend daily blood checks because daily urine production provides a reliable clinical parameter. Immediate intake needs are dependent on the child's state. If there is no additional loss of fluid through fever, diarrhea, or vomiting, daily needs are covered by the child's own physical reserves. In this phase, infants may become inactive and fussy; this can be tolerated for 1 or 2 days if all vital parameters are stable. The child must be seen at least twice daily by the responsible pediatrician. Minor weight variations are acceptable, provided the patient is well. If the medical history affects any specialized team, as in children after kidney transplantation, cardiac and lung transplantation, oncological diseases, or metabolic disorders, the related specialists also

must be involved in the weaning course on a daily basis. The faster tube volume is reduced, the less tired the children become. The child needs to discover that eating is the solution to hunger. For tube-dependent children, the process of learning to eat can happen in an extremely condensed way; the transition from exclusive long-term tube dependency to self-sustaining eating can take place in as short a time as 1 week in a well-trained and supportive environment. Such transition requires basic confidence of the caregivers and involved professionals that learning to eat can and will happen. The duration of exclusive tube feeding does not seem to correlate with the difficulty or ease of weaning, although clinical evidence shows that weaning before the age of 12 months is easier and happens more frequently by itself than afterward.

F: An environment providing food in a relaxed and natural way is essential. After the phase of individuation, any active offering of food by adults reduces autonomy and self-motivated food seeking by the child, especially if expectation, pressure, urge, or even harassment is linked to the offering. Parental intrusiveness is never meant to harm or hinder the infant, but anxious-insecure attachment patterns increase the occurrence of fussiness and the tendency for refusal in the child. Parental sensitivity in reading their child's cues is paramount. If the food comes too fast, it may provoke the impression of intrusiveness, leading to facial aversion and food avoidance. If the food comes too late, the infant will not make the link between cue and answer and will not learn his or her own role in the food-seeking and food-offering dialogue.

When tube-weaning attempts fail, it is often because the adults involved try too hard. Because tube-fed children are likely to be traumatized by well-meant but counterproductive adult behavior, guidance must concentrate on minimizing adult interference.

We do not wish to provide a simple list of do's and don'ts here. Any attempt to do so would involve the risk of harming tube-fed children and upsetting their families unnecessarily. The concept published as "the Graz model"[74-83] forbids any kind of force feeding and is as autonomy supporting and nondirective as possible. In the Graz program, children receive daily 4 to 5 hours of individual speech, occupational, and movement therapy and a joint psychoanalytical coached picnic in the group. The weekly program is embedded in a pediatric surrounding, including intensive care on an inpatient or outpatient basis. The program is open to learning visitors from all over the world and of all interested professions. Teaching focuses on understanding the impact of tube feeding on the child's development and supervises various models of treatment that will enhance autonomy in existing centers.

C: Communication between parents and children during the weaning phase is important and should be kept as smooth as possible. It differs by age, developmental status, and personality. Children who are able to talk can express their wishes and needs by asking for food or drink or help to achieve whatever they want. Advice to parents should center on learning to wait until the child expresses his or her needs and wishes. Communication with infants and toddlers requires some additional rules: no offering of food without a cue from the baby, and make food visible and have it available, but never take the first step. The infant's cues are divided into clear "yes" signals, clear "no"s, and noninterpretable ones. A yes should lead to the next step of helping the baby to approach the food, if necessary. A no should lead to removal of food. A noninterpretable cue should simply be noted.

A final point concerns the tendency of professionals to involve parents and other primary caregivers in the role of cotherapists. In pediatric hospitals, this happens all the time. Professionals are not aware of this when giving orders such as, "Well, just try, I'm sure you will do the right thing." Confident parents of a healthy child will gladly take this as a sign of trust and will know intuitively to do the right thing at the right time in the right way. However, parents of tube-fed children are unlikely to be so self-assured. They are often traumatized, ambivalent, insecure, and even terrified about the weaning process, even though they wish fervently for it to happen. Professionals must be aware of the special emotional needs of the affected parents. They should expect to see reactions of all kinds: crying, weeping, anger, insecurity, doubt, depression, aggression, resentment, accusation, and sadness. Tube weaning is often perceived as a relief after months of fear, anxiety, and stress, and the overall topic of "letting go" becomes a central and painful theme in the parent-child relationship, which needs to be worked on in therapeutic sessions. Besides, this situation can also provoke a crisis in the marital relationship of the strained parents. All

Table 1.

Characteristics of Patients and Classification of Main Pathology

	n		%
Number of patients included	221		100
Male	118		53.4
Female	103		46.6
Type of tube			
PGT	102		46.2
NGT	119		53.8
	Mean	**Range**	**SD**
Age at admission, d	791.13	134–2791	552
Weight at admission, kg	9.76	3.92–23.5	3.84
Gestational age at birth, wk	35.07	23–41	4.98
Duration of tube feeding before weaning, d	650.75	60–2700	476.87
Duration of tube feeding, % of lifetime	83.5	14.4–100	21.91
Group of Main Pathology	**n**		**%**
Complicated prematurity	48		21.7
Congenital malformation of the heart	41		18.6
Congenital metabolic disease	54		24.4
Malformation or disease of the gut	46		20.8
Neurological diseases	18		8.2
Psychiatric disease of child or parents	12		5.4
Healthy; no diagnosis on Axis III of ZTT	2		0.9

PGT, percutaneous gastrostomy tube; NGT, nasogastral tube; ZTT, Zero to Three.

these reactions are normal in the course of tube weaning and must be addressed with sensitivity and understanding.

Posttube Weaning

The primary aim must be to achieve confidence that the child is able to sustain his or her biological needs by self-regulated eating and drinking. After a phase of weight loss in the first 2 to 3 weeks after tube weaning is completed, weight will stabilize and gradually start gaining in the course of 2 to 3 months. If the child starts to develop greater motor skills in this phase and therefore uses more energy, the period of weight stagnation might last even 4 to 5 months, as is also known in healthy children around the age of 12 months. The variation of oral skills and the range of selected favorite foods with which the child managed to wean himself or herself will gradually grow as less expectation is put onto this topic. Eating rules such as table manners, structured mealtimes, and preselected food should be established only when the feeding situation has become more relaxed and the child has become a confident and easy self-sustained eater and drinker.

In our study, videoconference consultations via Internet with colleagues abroad have become a helpful tool between our center, pediatricians, and the therapists who continue to work with the child and his or her family after the weaning phase is completed. In most cases, great improvement in speech and play activities is reported, as well as ceasing of vomiting habits and an overall better quality of life, including complete normalization of eating patterns within 6 months. However, some formerly tube-fed infants and children remain picky and difficult eaters. The topic of eating will then remain the sensitive issue in the family, but the transition to oral eating patterns will certainly make a big difference in normalizing the child's developmental and social options.

Graz Tube Weaning Data

From 1987 to this day, more than 490 children (aged 3 months to 15 years) have undergone treatment geared to wean them from long-term tube feeding and unintended tube dependency. Initially, a specific program was developed to wean tube-dependent children referred only from Austria. A specific data collection sheet (eat-doc) and tube-feeding questionnaire were set up that included the *ICD-10*, *DSM-IVR*, or ZTTDC: 0-3[53-55] diagnosis. Results of this work (1987-1998) have been presented at numerous international pediatric, child surgical, and psychiatric meetings and conferences and have been published in German, English, and French.[74-83] Since 1998, the growing number of referrals also has included patients from all European Union countries, Switzerland, Israel, the United States, Canada, Australia, and New Zealand. All patients had undergone repeated but ineffective efforts to enhance oral feeding

Table 2.

Causes for Not Weaning 18 of 221 Children

Case #	Cause for Impracticality of the Weaning Protocol
1	Chromosome defect, trisomy 18, severe disorder, died at home 6 months later
2	Parents decided to drop out of the protocol because of acute infection
3	Citrullinemia, partially weaned, tube feeding only during sleep
4	Persisting neonatal hyperinsulinism, partially weaned, tube feeding during sleep
5-9	Severe dysphagia, recurrent aspirations and pneumonias, change from NGT to PGT
10	Down syndrome, trisomy 21, malnutrition, partially weaned, night feeds kept
11, 12	Esophageal atresia, severe psychological dependency, partially weaned
13	Francescetti syndrome, choanal atresia, insufficient oral intake
14	Diagnosis of an astrocytoma, transferred to oncology unit
15, 16	Infantile larynx, tracheomalacy, tracheostoma, night feeds kept
17, 18	Subtotal stenosis of esophagus, transferred to surgical department for operation

PGT, percutaneous gastrostomy tube; NGT, nasogastral tube.

before referral. Table 1 shows the characteristics of the 1999-2006 study group (n = 221 tube-dependent children) and the large range of underlying medical diagnoses covering all known pediatric diagnoses, including children with metabolic disorders, after transplantations, after neonatal surgery, cardiac surgery, short bowel syndrome, and all common complications of infants after extreme prematurity. Most children had more than one organ system affected by a primary diagnosis, most had been treated at intensive care units for months, and in most cases, the placement of the feeding tube had been a clear decision of secondary priority in view of other more threatening complications. In this study sample, 49% were fed by prolonged nasogastric or nasojejunal tubes, whereas 51% were fed by G-tubes or mickey button. The mean age at referral was 2.1 years (range, 4 months to 15 years), and 53% were female. All patients had been tube dependent for more than 4 months (mean 83% of their lifetime; range, 14.4%-100%) and had been on continuous and exclusive tube feeding before referral, with no oral activities aside possibly licking food. As the program evolved, we identified techniques and methods that improved the structure and the success of the program. Over this period, weaning failed or was not completed in only 18 of 221 cases, as shown in Table 2. In 2007, 81 exclusively tube-fed children were referred for tube weaning, and 78/81 (96.2%) were successfully weaned.

Conclusions

This article is not intended to be the final statement on tube dependency and tube weaning. It does not claim to offer a recipe for centers planning to start work in this field. Rather, it is intended to encourage discussion among different professional disciplines about a category of patients who have been somewhat neglected in terms of clinical attention and medical literature. Recommendations distillated directly from our clinical focus include early G-tube placement if tube feeding is expected to last more than 2 months, as well as weaning of all neonatal temporary tubes if possible within 1 month after discharge and, at the latest, by the end of the first year of life.

The main preventive factor is continuous oral and tactile stimulation if possible with organic tastes and various natural textures. Further research is necessary to investigate the range of issues related to tube dependency and tube weaning and to continue the development of more directive guidelines.

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The International Feeding Intervention Group (IFIG) was founded in 2004 in Graz and includes pediatricians, paramedic therapists, psychiatrists, and surgeons of the Sick Children's Hospital in Toronto; the Charité Hospital in Berlin; Kinderklinik Darmstadt; Kinderspital Zürich, Ospedale Burla, Triest, Italy; Wolfson Medical Center; and the Belinson Schneider Children's Hospital, Tel Aviv. The goal of the group is to share and evaluate experiences with the specific program of the Graz University Children's Hospital, which began its standardized tube-weaning program EAT (Early Autonomy Training) systematically in 1999 (see www.notube.at). We are grateful to the Styrian government and the Austrian Ministry of Health and Research for funding during the past decade in the phase of establishing the specific weaning program, making it possible to achieve prominent international reputation. At the same time, we thank all children and their families for their trust, feedback, and donations and all colleagues who have referred patients, shared critical concerns, and helped us to present the guidelines at their current stage.

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References

1. Cooke RJ, Embleton ND. Feeding issues in preterm infants. *Arch Dis Child.* 2000;83:F215-F218.
2. Daley HK, Kennedy CM. Meta analysis: effects of interventions on premature infants feeding. *J Perinat Neonatal Nurs.* 2000;14:62-77.
3. Einarsson-Backes LM, Deith J, Price R, Glass R, Hays R. The effect of oral support on sucking in preterm infants. *Am J Occup Ther.* 1994;48:490-498.
4. Field TM, Ignatoff E, Stringer S, et al. Nonnutritive sucking during tube feedings: effects on preterm neonates in an ICU. *Pediatrics.* 1982;80:381-384.
5. Singer LT, Davillier M, Preuss L, et al. Feeding interactions in infants with very low birth weight and bronchopulmonary dysplasia. *Dev Behav Pediatr.* 1996;17:69-76.
6. Jones MW, Morgan E, Shelton JE. Dysphagia and oral feeding problems in the premature infant. *Neonatal Network.* 2002;21:51-57.
7. Lau C, Hurst N. Oral feeding in infants. *Curr Problems Pediatr.* 1999;29:105-124.
8. Mizuno K, Ueda A. The maturation and coordination of sucking, swallowing and respiration in preterm infants. *J Pediatr.* 2003;142:36-40.
9. Morris BH, Miller-Loncar CL, Landry SH, Smith KE, Swank PR, Denson SE. Feeding, medical factors, and developmental outcome in premature infants. *Clin Pediatr.* 1999;38:451—457.
10. Shanler RJ, Shulman RJ. Feeding strategies for premature infants: randomized trial of gastrointestinal priming and tube-feeding methods. *Pediatrics.* 1999;103:434-439.
11. Archer LA, Rosenbaum PL, Streiner DL. The children's eating behavior inventory: reliability and validity results. *J Pediatr Psychol.* 1991;16:629-642.
12. Birch LL, Fisher JO, Castro CN, Grimm-Thomas K, Sawyer R, Johnson SL. Confirmatory factor analysis of the child feeding questionnaire: a measure of parental attitudes, beliefs and practices about child feeding. *Appetite.* 2001;36:201-210.
13. Burklow KA, Phelps AN, Schultz JR, Rudolph C. Classifying complex pediatric feeding disorders. *J Pediatr Gastroenterol Nutr.* 1988;27:143-147.
14. Chatoor I, Getson P, Menvielle E, et al. A feeding scale for research and clinical practice to assess mother-infant interactions. *Infant Mental Health J.* 1997;18:76-91.
15. Gisel EG, Patrick J. Identification of children unable to maintain a normal nutrition state. *Lancet.* 1988;1:283-286.
16. Kedesky J, Budd K. *Childhood Feeding Disorders: Biobehavioral Assessment and Intervention*. Baltimore: Paul H. Brookes; 1998.
17. Schwarz SM, Corredor J, Fisher-Medina J, Cohen J, Rabinowitz S. Diagnosis of feeding disorders in children with developmental disabilities. *Pediatrics.* 2001;108:671-676.
18. Skuse D, Stevenson J, Reilly S, Mathisen B. Schedule for oral motor assessment (SOMA): methods of validation. *Dysphagia.* 1995;10:192-202.
19. Thiel A, Paul T. Deutschsprachige Version des Eating Disorder Inventory (EDI). *Zeitschrift für Differentielle und Diagnostische Psychologie.* 1989;9:267-273.
20. Wardle J, Guthrie CA, Sanderson S, Rapoport L. Development of the Children's Eating Behaviour Questionnaire. *J Child Psychol Psychiatry.* 2001;42:963-970.
21. Adran GM, Kemp FH. Some important factors in the assessment of oropharyngeal function. *Dev Med Child Neurol.* 1970;12:158-166.
22. Hughes T. Neurology of swallowing and oral feeding disorders: assessment and management. *J Neurol Neurosurg Psychiatry.* 2003;74:48-53.
23. Lau C, Alagugurusamy R, Schanler RJ, Smith EO, Schulman RJ. Characterization of the developmental stages of sucking during bottle feeding. *Acta Paediatrica.* 2000;89:845-852.
24. Mathew OP. Regulation of breathing pattern during feeding: role of suck, swallow, and nutritions. In: Mathew OP, Sant'Ambrogio G, eds. *Respiratory Function of the Upper Airway.* New York: Marcel Dekker; 1988:535-560.
25. Palmer MM. Identification and management of the transitional suck pattern in premature infants. *J Perinat Neonatal Nurs.* 1993;7:66-75.
26. Stevenson RD, Allaire HH. The development of normal feeding and swallowing. *Pediatr Clin North Am.* 1991;38:1439-1453.
27. Sullivan PB, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffith P. Prevalence and severity of feeding and nutritional problems in children with neurological impairment. *Dev Med Child Neurol.* 2000;42:674-680.
28. Wolf SL, Glass RP. *Feeding and Swallowing Disorders in Infancy: Assessment and Management.* San Antonio, TX: Therapy Skill Builders; 1992.
29. Reilly SM, Skuse DH, Poblete X. Feeding problems and oral motor dysfunction in children with cerebral palsy. *J Pediatr.* 1996;129:877-882.
30. Reilly SM, Skuse DH, Wolke D. Oral-motor dysfunction in children who fail to thrive. *Dev Med Child Neurol.* 1999;41:115-122.
31. Welch K, Pianta RC, Marvin RS, Saft EW. Feeding interactions for children with cerebral palsy and mothers contributions. *J Dev Behav Pediatr.* 2000;21:123-129.
32. Wudy SA, Hagemann S, Dempfle A, et al. Children with idiopathic short stature are poor eaters and have decreased body mass index. *Pediatrics.* 2005;116:e52-e57.
33. Andrassy RJ, Patterson RS, Ashley J, Patrissi G, Mahour GH. Long-term nutritional assessment of patients with esophagus atresia and/or tracheoesophageal fistula. *J Pediatr Surg.* 1983;18:431-435.
34. Corbett SS, Drewett RF, Wright CM. Does a fall down a centile chart matter? The growth and developmental sequelae of mild failure to thrive. *Acta Paediatrica.* 1996;85:1278-1283.
35. Drewett R, Wolke D, Asefa MM, Tessema F. Malnutrition and mental development: is there a sensitive period? A nested case-control study. *J Child Psychol Psychiatry.* 2001;42:181-187.
36. Birch LL, Johnson SL, Andresen G, Peters JC. The variability of young children's energy intake. *N Engl J Med.* 1991;111:232-235.
37. Parkinson KN, Drewett RF. Feeding behaviour in the weaning period. *J Child Psychol Psychiatry.* 2001;42:971-978.
38. Gardner SL, Hagedorn MI. Physiological sequelae of prematurity: Part V. Feeding difficulties and growth failure. *J Pediatr Health Care.* 1991;5:122-134.
39. Latal-Hajnal B, von Siebenthal K, Kovari H, Bucher HU, Largo RH. Postnatal growth in VLBW infants: significant association with neurodevelopmental outcome. *J Pediatr.* 2003;143:163-170.
40. Pohlandt F, Mihatsch WA. Wichtige Aspekte der enteralen Ernährung von sehr kleinen Frühgeborenen. *Monatsschrift Kinderheilkunde.* 2001;143:163-170.
41. Pollitt E, Gorman KS, Martorell R, Rivera J. Early supplementary feeding and cognition. *Monogr Soc Res Child Dev.* 1993;58:1-99.
42. Dunitz M, Scheer P, Trojovsky A, Kaschnitz W, Kvas E, Macari S. Changes in psychopathology of parents of NOFT (non-organic failure to thrive) infants during treatment. *Eur Child Adolesc Psychiatry.* 1996;5:93-100.
43. Dunitz M, Scheer P, Kvas E, Sulzer V, Azizi A. Psychopathologie des Parents d'enfants

atteints de retard de croissance sans organique détectable. *Devenir.* 1996;3:17-25.

44. Cooper PJ, Whelan E, Woolgar M, Morrell J, Murray L. Association between childhood feeding problems and maternal eating disorder: role of the family environment. *Br J Psychiatry.* 2004;184:210-215.
45. Deloian BJ. Feeding Outcomes and parenting experiences as premature infants transition to home from hospital. *NCAST Natl News.* 1990;15:1-8.
46. Fraiberg S, Adelson E, Shapiro V. Ghosts in nursery: a psychoanalytic approach to the problem of impaired infant-mother relationships. *J Am Acad Child Adolesc Psychiatry.* 1975;14:387-422.
47. Keren M, Feldman R, Eidelman AI, Sirota L, Lester B. Clinical interview for high-risk parents of premature infants (CLIPS) as a predictor of early disruptions in the mother-infant relationship at the nursery. *Infant Mental Health J.* 2003;24:93-110.
48. Pierrehumbert B, Nicole A, Muller-Nix C, Forcada-Guex M, Ansertmet F. Parental post-traumatic reactions after premature birth. *Arch Dis Childhood.* 2003;88:F400-F404.
49. Redshaw ME. Mothers of babies requiring special care: attitudes and experiences. *J Reprod Infant Psychol.* 1997;15:109-120.
50. Satter E. The feeding relationship. *J Pediatr.* 1990;117:187-189.
51. Stern DN. *The Motherhood Constellation.* Stuttgart, Germany: Klett-Cotta; 1998.
52. Zeanah CH. Psychopathology in infancy. *J Child Psychol Psychiatry.* 1997;38:81-99.
53. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders.* 4th ed. Washington, DC: American Psychiatry Press; 1994.
54. Zero to Three. *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood.* Rev. ed. Washington, DC: Zero to Three; 2005.
55. Dunitz M, Scheer PJ, Kvas E, Macari S. Psychiatric diagnosis in infancy: a comparison. *Infant Mental Health J.* 1996;17:12-24.
56. Dunitz-Scheer M. Psychotherapeutische Liaison für die Neonatologische Intensivstation. *Paediatric Paedol.* 1997;32:219-223.
57. Dunitz-Scheer M, Scheer PJ, Dunitz-Scheer NA. Interaktionsdiagnostik. In: Keller H, ed. *Handbuch der Kleinkindforschung.* 2 vols. Bern, Germany: Huber; 1997:209-234.
58. Dunitz-Scheer M, Scheer PJ. *Psychotherapie in der frühen Kindheit.* Göttingen: Vandenhoeck & Ruprecht; 1998.
59. Chatoor I. Feeding disorders in infants and toddlers: diagnosis and treatment. *Child Adolesc Psychiatry Clin North Am.* 2002;11:163-183.
60. Chatoor I, Ganiban J, Harrison J, Hirsch R. Observation of feeding in the diagnosis of posttraumatic feeding disorder of infancy. *J Am Acad Child Adolesc Psychiatry.* 2001;40:595-602.
61. Handen BL, Mandell F, Russo DC. Feeding induction in children who refuse to eat. *Am J Dis Childhood.* 1986;140:52-54.
62. Levy Y, Levy A, Zangen T, et al. Diagnostic clues for identification of non organic food refusal and poor feeding. *J Pediatr Gastroenterol Nutr.* In press.
63. Illingworth RS, Lister J. The critical or sensitive period, with special reference to certain feeding problems in infants and children. *J Pediatr.* 1964;65:839-848.
64. Benoit D, Wang EEL, Zlotkin SH. Discontinuation of enterostomy tube feeding by behavioral treatment in early childhood. *J Pediatr.* 1999;137:498-503.
65. Benoit D, Wang EE, Zlotkin SH. Characteristics and outcomes of children with enterostomy feeding tubes. *Pediatr Health Care.* 2001;6:132-137.
66. Benoit D, Coolbear J. Post-traumatic feeding disorders in infancy: behaviours predicting treatment outcome. *Infant Mental Health J.* 1998;19:409-421.
67. DiScipio WJ, Kaslon K, Ruben RJ. Traumatically acquired conditioned dysphagia in children. *Ann Otolaryngol.* 1978;87:509-514.
68. Geertsma MA, Hyams JS, Reiter S. Feeding resistance after parenteral hyperalimentation. *Am J Dis Children.* 1985;139:255-256.
69. Mittal RK, Stewart WR. Effects of catheters in the pharynx on the frequency of transient lower esophageal sphincter relaxation. *Gastroenterology.* 1992;103:1236-1240.
70. Nelson SP, Chen EH, Syniar GM, Kaufer CK; PPRG. One year follow-up of symptoms of gastroesophageal reflux during infancy shows that regurgitation resolves and feeding problems emerge. *Pediatrics.* 1998;102:e67.
71. Puntis JW, Ritson DG, Holden CE, Buick RG. Growth and feeding problems after oesophageal atresia. *Arch Dis Childhood.* 1990;65:84-88.
72. Sleigh G, Brocklehurst P. Gastrostomy feeding in cerebral palsy: a systematic review. *Arch Dis Childhood.* 2004;89:534-539.
73. Strauss D, Kastner T, Ashwal S, White J. Tubefeeding and mortality in children with severe disabilities and mental retardation. *Pediatrics.* 1997;99:358-362.
74. Dunitz-Scheer M, Hauer A, Wilken M, et al. "Essen oder nicht, das ist hier die Frage": Sondenentwöhnung mit dem Grazer Modell. *Pädiatrie Pädologie.* 2004;39:28-38.
75. Dunitz-Scheer M, Wilken M, Schein A, Walch G, Scheer P. Wie kommen wir von der Sonne los. *Kinderkrankenschwester.* 2000;19:448-457.
76. Dunitz-Scheer M, Wilken M, Lamm B, et al. Sondenentwöhnung in der frühen Kindheit. *Monatsschrift Kinderheilkunde.* 2001;149:1348-1359.
77. Scheer P, Dunitz-Scheer M, Schein A, Wilken M. DC0-3: in pediatric liaison work with eating behavioral disorder. *Infant Mental Health J.* 2003;24:428-436.
78. Scheer P, Dunitz-Scheer M. *Handbook of Infant Mental Health.* New York: John Wiley; 1999.
79. Scheer P, Dunitz-Scheer M. Psychotherapie auf einer Intensivstation. *Zeitschrift für Intensivmedizin & Anästhesie.* 2000;8:167-171.
80. Scheitenberger S, Stadler A, Dunitz-Scheer M, Scheer P, Grossmann K. Tube weaning in infancy, the Graz model. Presented at: 7th WAIMH, World Congress, July 26-30, 2000; Montreal, Canada.
81. Wilken M, Scheer P, Dunitz-Scheer M. Posttraumatische Fütterungsstörung bei Früh- und Risikogeborenen. *Zeitschrift für Psychotraumatologie.* 2004;2:8-18.
82. Wilken M. Kann es auch ohne gehen? Praxis und Evaluation der ambulanten Sondenentwöhnung. In: Teeffelen A, Jacobs P, eds. *Ernährung auf eine andere Art.* Heilbronnn, Germany: SPS Verlagsgesellschaft; 2006:65-104.
83. Wilken M, Jotzo M. Ambulante Sondenentwöhnung: Therapie für Kinder mit besonderen Bedürfnissen. *Die Kinderkrankenschwester.* 2007;26:102-108.