

Discharge Home of Infants Requiring Ongoing Enteral Nutrition Supplementation



Implementation Date: April 10, 2019



Clinical Practice Guideline: Discharge Home of Infants Requiring Ongoing Enteral Nutrition Supplementation

Points of emphasis/Primary changes in practice:

This CPG is intended to guide feeding practices during an infant's transition to home period. Its focus is on the infant who is not fully orally fed (*per os*, PO) and who requires some ongoing gavage tube feeds (*per gavage*, PG). This includes nasogastric (NG) tube, gastrostomy (G) tube, and gastro-jejunal (GJ) tube feeding. Its creation was guided by the principles of evidence-based practice, individualized (cue-based) care, multi-disciplinary collaboration, and family-centered developmental care.

The working group consisted of representation from disciplines including: medicine (MDs and nurse practitioners), nursing (RNs), feeding therapy (SLP), nutrition (RDs), and care coordination.

Rationale for change:

This guideline was developed to assist in improving consistency of feeding approach and practice, discharge planning, and outpatient care coordination for infants who require enteral nutrition at the time of discharge. The goal is that implementation of this guideline will improve patient outcomes, parent confidence and competence in feeding their infant/s, and family satisfaction with their NICU care.

Also, see related Clinical Practice Guideline: "Feeding in the Weeks Leading up to Discharge".

Questions? Please contact:

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This is a clinical practice guideline. While the guideline is useful in approaching the planning and discharge coordination for the infant requiring NG, G-tube, or GJ tube feedings supplementation, clinical judgment and / or new evidence may favor an alternative plan of care, the rationale for which should be documented in the medical record.

- **I. Purpose:** The purpose of this clinical practice guideline is to establish standard practices for the care of infants who are not fully orally fed (*per os*, PO) and who require some ongoing gavage tube feeds (*per gavage*, PG) at the time they are otherwise medically stable and ready to transition to home. These guidelines have been developed to ensure that infants receive consistent and optimal care for management of PO feeding difficulties, discharge planning, and coordination of outpatient follow-up with the appropriate disciplines and teams.
- **II.** All CPGs will rely on the <u>NICU Nursing Standards of Care</u>. All relevant nursing PPGs are listed below.

III. Guideline



I. Background

Discharge of a high-risk infant from the Neonatal Intensive Care Unit (NICU) is dependent on several key considerations, including: infant medical and physiological stability, adequate growth, appropriate family education and training, and coordination of care with adequate outpatient follow-up in place (1). Historically, convalescent infants who continued to require PG feeds to meet their nutritional requirements would continue be cared for in the NICU, a step-down special care nursery, or in a pediatric hospital or rehabilitation facility. However, there is now a growing focus on transitioning infants home as soon as they are medically and physiologically stable, to minimize parent-child separation and support optimal neuro-developmental progress in the home environment. Hence, consideration is being given to transitioning to home otherwise medically and physiologically stable infants with a PG-tube in situ, to allow further maturation of feeding development in the home vs hospital setting.

The purpose of this clinical practice guideline is to assist a multidisciplinary clinical team to:

- 1) identify the optimal candidates that could benefit from discharge home with PG feeding supplementation
- 2) complete necessary pre-discharge arrangements
- 3) complete family education and training
- 4) arrange for outpatient care coordination necessary to address the medical and developmental needs of the infant and family post-NICU discharge.

As per American Academy of Pediatrics (AAP) policy statement (1), when planning the discharge of a medically complex (often former preterm) infant, the following criteria must be met prior to discharge:

- (a) the infant is otherwise physiologically stable and medically ready for discharge;
- (b) an active program of parental involvement and preparation for care of the infant at home is completed;
- (c) arrangements for health care after discharge have been made by a physician or other health care professional who is knowledgeable about the care and needs of high-risk infants post discharge;
- (d) follow-up with an organized program of tracking and surveillance to monitor growth and development post discharge is in place.

With regards to PG feeds, a decision must be made prior to discharge regarding whether it is most appropriate and suitable for the infant and family to transition to home with a temporary gavage tube (e.g. NG-tube) or whether to consider a surgical gavage tube (e.g. gastrostomy/ Gtube or gastro-jejunal/ GJ-tube). While both options (temporary and surgical enteral feeding tube) entail benefits and risks, there is no available high-quality evidence in the literature to guide practice (i.e. there are no randomized controlled trials), nor are there clearly delineated national guidelines to indicate which patients are best suited for each option.



NG-tube feeds involve the gavage tube being taped to the face. The tube is passed through the nose, on though the pharynx and esophagus, and into the stomach. Data supporting the safety of discharge home with NG-tube feeding supplementation is currently limited and based on observational, small studies (2, 3, 4). Potential safety concerns include the NG-tube becoming dislodged and feeds being delivered into the airway/lungs vs gut, or the tube coming out all together and the infant not receiving the required volume of fluid and nutrition until the NG tube is able to be safely replaced. In general, NG-tube supplementation is the preferred option for anticipated short-term feeding supplementation, as prolonged need for nasogastric tube feedings is associated with altered oral sensitivity and feeding aversion in infants and children (5, 6).

<u>G- or GJ-tube feeds</u> involve the enteral tube being surgically inserted into the stomach via the abdominal wall. In most cases, a low-profile button device is placed, to which a feeding tube is connected for each feed. A GJ-tube is placed in cases where the infant has demonstrated they cannot tolerate feeds directly into the stomach, and an extension is used to deliver continuous feeds into the small intestines (also referred to as post-pyloric feeds). Feedings via a gastrostomy tube appear more suitable for infants anticipated to require enteral supplementation for a period of time longer than several weeks to months. Downsides of this option include exposure to anesthesia and surgery in infancy. Some studies have suggested potential for more post-discharge complications, emergency room visits, and utilization of health care services post-discharge in children who have a G-tube vs NG-tube in situ (7), though it is recognized that children who receive G-tubes generally have a more medically-complex history (8-10). In the BWH NICU, we consider the expected need for tube feeding for greater than 3 months corrected age to justify consideration of a surgical gavage tube placement for supplementation of PO feedings.

II. Multidisciplinary approach of feeding difficulties in the infant nearing readiness for transition to home

Staff and families should anticipate that most former preterm infants will take most of their feeding quota PO by around 38 weeks' postmenstrual age (PMA).

Stage 1)

A pre-discharge family meeting/discussion should occur by 38 weeks PMA.

- o If infant is taking ≥ 50% quota PO with steady improvement: discuss discharge planning and outpatient follow-up.
- o If infant is taking <50% PO <u>and</u> trajectory of % PO progress is slow: discuss options for discharge planning, including possibility of PG tube feedings at home (via NG-tube or G-tube).
- If there are concerns (clinical signs or symptoms) of aspiration, consider MBS, per SLP team recommendations.
- o If there are concerns regarding gastro-esophageal reflux (GERD) or feed intolerance that is thought to interfere with ability to make PO progress, consider BCH GI consult.



Stage 2)

If infant is unable to take all or the majority of feeds PO by approximately 40 weeks PMA:

- o NICU multidisciplinary team (MD, NP/ PA, RN, feeding therapist, +/- nutritionist) should reconvene to review case
- o If there are concerns (signs/ symptoms) regarding aspiration, consider MBS (initial/ repeat), per SLP recommendations
- o Initiate BCH GI consult, if this hasn't already occurred
 - o NICU medical team will page BCH TUBE team (BCH contact clinicians are tube team NPs, who typically cover the pager), discuss rationale for consult, and provide BCH team with initial pertinent history and hospital course information.
 - o This step should occur *even if a general GI consult is already in place* for a specific GI problem (such as GERD or feeding intolerance), as BCH TUBE team will be the liaison for gavage tube teaching and scheduling multidisciplinary outpatient appointments with the appropriate clinicians.
 - NICU medical team (MD, NP/ PA) to schedule second family meeting/ discussion to determine if infant is candidate for discharge home with NG-tube vs G-tube feeds. This discussion should be multidisciplinary and include:
 - o NICU RN, feeding therapist, +/- nutritionist as appropriate
 - o BCH GI consult (TUBE team)
 - o BWH-BCH communication: once multidisciplinary team agrees on discharge plan with BCH GI TUBE team, the logistical scheduling of outpatient follow-up can be arranged via email with the following considerations:
 - BCH contact clinicians are GI TUBE nurse practitioners
 - BWH contact clinicians are SLP team
 - All communications should include the full clinical team involved in the case (attending, NP/PA, SLP, dietitian) to allow for multidisciplinary coordination of care

Possible outcomes at this stage:

- 1) If infant requires more time in hospital for optimization of medical/ feeding strategies (and/or maturation of feeding coordination):
 - Strategies should be implemented, as appropriate, with a clear definition of timeline to reassess progress (typically 1-2 weeks for each stage or feeding modification).
 - Subsequently, please proceed to **Stage 3**.
- 2) If infant is a candidate for discharge home with NG-tube feeding supplementation per multidisciplinary group decision:
 - Ensure that infant/family meet <u>criteria for qualification for discharge home</u> <u>with NG-tube feeds</u> (outlined under **Stage 3** section)
 - NICU medical team will write all necessary prescriptions for medical equipment.
 - BCH GI TUBE RN will meet with family for teaching/ education.
 - BCH GI TUBE RN and NICU feeding therapist will confirm necessary followup appointments have been scheduled.



- NICU RN champion will also meet with family for specifics of teaching/education/equipment use.
- NICU care-coordination will facilitate ordering of appropriate necessary supplies.
- 3) If infant is a candidate for discharge home with G-tube feeding supplementation per multidisciplinary group decision:
 - Ensure that infant/family meet <u>criteria for qualification for discharge home</u> with G-tube feeds (outlined under **Stage 3** section).
 - Consult BCH Surgery team for assessment and scheduling of procedure.
 - NICU medical team will write all necessary prescriptions for medical equipment.
 - BCH GI TUBE RN will meet with family for teaching/education.
 - BCH GI TUBE RN and NICU feeding therapist will confirm necessary followup appointments have been scheduled.
 - NICU RN champion will also meet with family for specifics of teaching/education/ equipment use.
 - NICU care-coordination will facilitate ordering of appropriate necessary supplies.

Stage 3

If infant is unable to take 100% of feed quota PO by <u>42-44 weeks PMA</u> and infant is physiologically and medically stable - with slow feeding progress being only reason infant is in NICU (i.e. infant not having apnea, bradycardia, or oxygen desaturation events, or another medical problem that requires inpatient stay), consider preparation for discharge home with enteral tube feeds supplementation.

- Criteria for qualification for discharge home with NG-tube feeds
 - Infant is able to take approximately 40-50% PO. This criteria is suggested in order to minimize risk of dehydration and/or need for emergency department (ED) visits should the NG-tube become dislodged outside of regular BCH GI clinic hours. This criteria is especially important in cases where parents are not trained/able to achieve competency in replacing NG-tube.
 - Family is in agreement with discharge plan and has favorable support in place to be
 able to sustain management of the NG-tube at home. This involves ability to go to
 outpatient GI clinic/ closest ED in case of dislodgement per GI provider advice, +/ability and desire to undergo training to place NG-tube themselves (which typically
 takes ~ 3 outpatient appointments with BCH GI clinic)
 - Family is able to spend sufficient time (recommend at least 1 day, including overnight if feasible) in the hospital pre-discharge and demonstrate competence in feeding their infant (PO and per enteral tube as applicable)
 - Infant's primary care physician (PCP) is involved in the discussion, and agrees with outpatient follow-up and contingency plan for how to replace NG-tube should it become dislodged after NICU discharge.



- Outpatient GI RN appointment scheduled, as well as appointments with multidisciplinary support team (GI, RDN, feeding therapy).
- A safe PO feed plan is in place (i.e. family has received instruction and demonstrated competency on which equipment, position, strategies, and liquid consistency is required for infant to feed safely).
- Follow-up steps:
 - BWH medical team will write all necessary prescriptions for medical equipment
 - BCH GI TUBE RN will meet with family for teaching/education
 - BWH RN champion will also meet with family for specifics of teaching/education/ equipment use
 - BWH care coordination will facilitate ordering of appropriate necessary supplies
- Criteria for eligibility for discharge home with G-tube (or GJ-tube, where necessary)
 - Infant is taking consistently < 50% PO with stagnant pattern/progress.
 - Infant has documented high aspiration risk.
 - Family does not wish for, or is unable to sustain contingency planning required for discharge home with NG-tube.
 - Family is in agreement with G-tube placement.
 - Family is able to spend sufficient time (recommend at least 1 shift) in the hospital pre-discharge and demonstrate competence in feeding their infant (PO and per enteral tube as applicable)
 - Safe PO feed plan is in place (i.e. family has received instruction on which equipment, position, strategies, and liquid consistency is required for infant to feed safely)
 - NICU Medical team, GI consult team, and Surgery consult teams all in agreement

Ultimately, the decision for discharge home an infant with enteral tube feeds supplementation, and the type of enteral tube utilized should align with the family goals and values, and should occur once a safe feeding plan is in place, and a reasonable contingency and follow-up plan is formulated and collectively agreed upon by the inpatient clinical team, pediatrician, and family.

<u>Alternatively</u>, if neither of the options above for discharge home with enteral tube supplementation are appropriate and/or preferable to the family, transfer to a step-down nursery (e.g. level II special care nursery close to family home) or pediatric hospital/rehabilitation facility should be considered for longer-term inpatient management of feeding difficulties.

Of note:

 NICU Medical team (attending physicians and NP/ PAs) should make every effort to coordinate multidisciplinary meeting with BCH TUBE team, a joint review of the case, and



formulation of a mutually agreed plan before offering recommendations to family. Meeting should include NICU RN, feeding therapist, and dietitian.

 BCH consultation notes are expected to be available in the baby's BWH medical record for review, to facilitate implementation of recommendations in a timely manner.

III. Outpatient GI follow-up multi-disciplinary programs to consider

Planning:

Appropriate outpatient multi-disciplinary follow-up should be discussed in NICU multi-disciplinary discharge planning rounds, and agreed upon between NICU medical, nursing, feeding therapy, dietetics, and other relevant disciplines involved.

NICU medical teams are also encouraged to review plans for outpatient follow-up with BCH GI consultant (by paging TUBE team, as per instructions below) for guidance.

- BCH point persons for outpatient care coordination are the TUBE team NPs, who will facilitate appointments in one of the programs below.
- NICU point persons for outpatient care coordination are the NICU feeding therapists (SLPs), who will facilitate email communications with BCH TUBE team, while including all pertinent NICU clinicians in all communications.
- Of note: For patients estimated to go home with NG-tube supplementation, please page TUBE pager at BCH assist in coordination of care (even if patient has a prior general GI consult).

To directly page 'TUBE' consult team pager: Call 617-355-7243

 \rightarrow Then enter pager ID (8823 = TUBE) then # \rightarrow then enter call back number then #

Outpatient Programs Available:

BCH Growth/Nutrition Program (GNP)

- Team:
 - Gastroenterologist (physician)
 - o Speech-language pathologist (feeding therapist)
 - o Registered dietitian
 - o Feeding psychologist
 - o Social worker
- Target Population: patients with feeding and growth issues, patients going home with enteral (NG or G-) tube feeds
- Administrator: Barbara Sargent Barbara.Sargent@childrens.harvard.edu
- NP: Kathleen Carr <u>Kathleen.Carr@childrens.harvard.edu</u>
- Phone: 617-355-7713



BCH Aerodigestive Clinic (ADC)

- Team:
 - o Pulmonologist (physician)
 - o Gastroenterologist (physician)
 - o Speech-language pathologist (feeding therapist)
 - o Registered dietitian (select visits)
 - o Otorhinolaryngologist (physician select visits)
- Target Population: patients with moderate-severe BPD, aspiration, feeding disorders
- Of note, nutrition is not present at each visit in ADC so if growth failure concerns needing close follow-up, specifically discuss this need with GI consult team.
 - As an alternative to ADC, team can consider referral to GNP and BPD clinic (CHILD) for patients with growth failure.
- Administrators: Alana Beaudreault <u>Alana.Beaudreault@childrens.harvard.edu</u> and Nairet Olivo - <u>Nairet.Olivo@childrens.harvard.edu</u>
- Phone: 617-355-0897

MGH Pediatric Multidisciplinary Feeding Team

- Team:
 - o Gastroenterology (physicians: Lauren Fiechtner MD, Victoria Martin MD)
 - o Speech-language pathologist (feeding therapist)
 - o Registered dietitian
 - o Feeding psychologist
- Target Population: patients with feeding and growth issues (equivalent to GNP at BCH)
- Administrator: Quantresa Goods QGoods@partners.org
- Phone: 617-724-0770

Note:

- It is preferable for infants who are discharged from the NICU on PG feeds to be referred to a multi-disciplinary team, for optimal inter-disciplinary coordination of care.
- However, it is acknowledged that there are cases where the distance of the family's home from a major children's hospital and/or their insurance makes this option prohibitive.
- In these cases, infant may be referred to the various follow-up providers required (generally GI and feeding therapy as a minimum) as separate visits. Wherever possible, these providers should be based in the same service/health care system, so that virtual multi-disciplinary care coordination can occur.



Appendix 1: Enteral Tube CPG Flowchart

Appendix 2: Discharge Checklist

Appendix 3: Parent Education Materials
Passport Home - NG Tube Goals for Discharge
Passport Home - G Tube Goals for Discharge
Family Education Sheet - Use and Care of a Nasogastric (NG) Feeding Tube

Appendix 4: Letter of Medical Necessity

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