Home Enteral Nutrition Support Program for Children

Parents’ Welcome Guide for Bolus and Gravity Feeding

Refresh™

HOME ENTERAL NUTRITION SUPPORT


A program of APRIA HEALTHCARE®

(844) 260-1788 • apria.com/Refresh
Welcome to Apria’s Refresh™ Home Enteral Nutrition Support Program

We want to give you and your child a warm welcome to Apria’s Refresh Home Enteral Nutrition Support Program. In this program, you will be provided with the tube feeding formulas, equipment, and supplies prescribed by your child’s physician. You will also be provided the top level of service and compassionate care. Apria will contact you monthly to monitor your child’s progress with the therapy and answer any questions you might have.

You should always make sure that you have a minimum of 5 days of supplies and formula on hand. If you become low on supplies at any time, please call us to reorder.

As our customer, you will have access to:

• Registered Dietitians: Our Nutrition Support Dietitians screen all patients, develop nutrition plans, manage home tube feeding, and provide education. Our dietitians are available for 24 hours a day, 7 days a week to address any therapy questions.

• Routine Monitoring: All patients are re-screened routinely to monitor response to therapy and identify any signs of problems, such as dehydration or weight loss.

• Our dedicated customer service team is here from 8:00 am to 10:00 pm EST Monday through Friday, and on Saturdays 8:00 am to 5:00 pm EST.

Your first 3 days of supplies will be provided at the time of your equipment set up. The remainder of your first month’s supplies will be shipped to your home shortly thereafter. Additional supplies will be shipped to your home on a monthly basis. Please be sure to inspect all supplies upon receipt and contact us if you have any questions.

Please accept our personal welcome to Apria Healthcare and our Refresh Home Enteral Nutrition Support Program. We look forward to serving you.

Kindest regards,
Your Refresh Home Enteral Nutrition Support Team
(844) 260-1788
Parent/Caregiver Acknowledgement

Your Apria representative will review the items on this checklist with you. After you have reviewed each item, please check the appropriate box. Then sign and date at the bottom, remove the checklist from your manual, and return it to Apria.

- Welcome to Apria’s Refresh Home Enteral Nutrition Support Program
- Apria’s Staff and Services
- Managing Your Child’s Supplies
- Safe Practices for Home Tube Feeding
- Fire Safety
- Notice of Privacy Practices
- Patient’s Rights and Responsibilities
- ENFit Transition Checklist

Additional Resources
- How to Administer Your Child’s Feeding
- Syringe or Bolus Feeding
- Gravity Feeding
- Opt-In Enteral Refill Program Enrollment Form (enrollment is optional)
- Refresh Welcome Guide

The parent or caregiver acknowledges that he/she has received, been instructed in, and understands the items on the checklist above. In addition, the listed Additional Resources have been provided.

Parent/Caregiver Signature ___________________________ Date __________

Parent/Caregiver Signature ___________________________ Date __________

Please PRINT Name ____________________________________________

Please PRINT Name ____________________________________________
# Table of Contents

Welcome to Apria’s Refresh Home Enteral Nutrition Support Program ........................................ 1  
Apria’s Staff and Services .............................................. 5  
  Apria’s Dedicated Team of Professionals .............. 5  
Feedback on Our Services ........................................... 5  
Managing Your Child’s Supplies .......................... 6  
  Initial Delivery .................................................. 6  
  Recurring Orders and Clinical Follow-Up .......... 6  
  Delivery of Supplies ........................................... 6  
Safe Practices for Home Tube Feeding ............... 6  
  Help Stop the Spread of Germs ...................... 8  
Fire Safety .............................................................. 8  
  An Ounce of Prevention ................................. 8  
  Planning Can Prevent Panic ......................... 9  
  If a Fire Occurs ............................................... 9  
Notice of Privacy Practices ........................................ 10  
Patient’s Rights and Responsibilities ...................... 15  
  Patient/Client Bill of Rights ........................... 15  
  The Patient’s Responsibilities ......................... 16  
Medicare DMEPOS Beneficiary Statement ........... 17  
Interpretation Service Available .......................... 18  
**Enteral Therapy Additional Resources** ............... 20  
  Getting Started with Home Tube Feeding ............ 21  
  Feeding Methods .......................................... 22  
  How to Administer Your Child’s Feeding .......... 22  
    Syringe/Bolus Feeding .................................... 22  
    Gravity Feeding .......................................... 23  
  Positioning Your Child ..................................... 24  
    Feeding Position Tips .................................. 25  
  How to Care for Your Child’s Nasogastric Tube .... 25  
    When to Call Your Healthcare Team ............. 26  
    NG Tube Care Tips .................................... 26  
    Securing the NG Tube .................................. 26  
  How to Care for Your Child’s G-Tube or J-Tube .... 27  
    Daily Cleaning ......................................... 27  
    Flushing Feeding Tubes and Extension Sets .... 28
Apria’s Staff and Services

Apria’s Refresh Home Enteral Nutrition Support Program will provide the supplies, equipment, and formula necessary for your child’s home tube feeding therapy.

Apria’s dedicated team of professionals

Our highly-skilled team of Nutrition Support Specialists is here to help you and your family adjust to home tube feeding, providing resources and personalized care that includes:

• Educational tools, materials, and resources that can help you with your child’s home tube feeding
• Our registered dietitians are available for 24 hours a day, 7 days a week to address any therapy questions.
• Our dedicated customer service team is here from 8:00 am to 10:00 pm EST Monday through Friday, and on Saturdays 8:00 am to 5:00 pm EST.

Nutrition Support Dietitians will help manage your child’s home tube feeding and will work with your doctor and healthcare team to develop a plan to follow so that your child takes in enough calories and other nutrients.

Our dietitians are available to answer any questions you have or help with problems that may arise. Our enteral nutrition support team simplifies the nutrition management process and is dedicated exclusively to the support of tube feeding patients.

Feedback on our services

Apria is among America’s most experienced and respected homecare providers, and our patient satisfaction scores are consistently high. It is possible, however, that you may have a concern and we always welcome feedback. To voice a concern, you should take these steps:

• Call our Enteral Nutrition Support Customer Service at (844) 260-1788
  OR
• Contact us by email at: Patient_Satisfaction@apria.com
  OR
• Visit our website at apria.com and select from the menu under tab for Contact Us.
Managing Your Child’s Supplies

Initial delivery
A member of the Apria team will most likely provide your child’s initial delivery of supplies to your home or to your hospital room before discharge. The delivery will vary depending on your child’s specific needs. Your first delivery will be enough for 3 days, and the remaining supplies will be shipped to your home.

Recurring orders and clinical follow-up
You will receive a reminder call approximately 10 days prior to your resupply date. Please call in your order in a timely fashion to ensure you do not run out of supplies. During your resupply conversation the resupply team will ask you questions about your child’s current health status and how things are going with your child’s home tube feedings. These questions may take a few minutes to answer, but please remember, they are very important for the proper management of your child’s care.

Delivery of supplies
Don’t run out of supplies. You will receive a reminder call to contact us regarding your resupply needs. We encourage you to call us when you are down to 5 to 7 days’ worth of formula and supplies in order to prevent you from running out. Deliveries will arrive by UPS or a similar carrier.

If you have any concerns about a delivery you have received, please call us immediately. You can also contact us toll-free with any questions regarding supplies, service, or nutrition therapy at (844) 260-1788.

Safe Practices for Home Tube Feeding
Just like food, tube feeding formula needs to be handled carefully to prevent spoilage and food-borne illness. Follow the tips below to help make your tube feeding safe.

- Formula should be stored in a cool, dry place.
- Wash your hands vigorously with soap and warm water for at least 20 seconds before preparing or
giving any tube feeding formula or touching any tube feeding equipment. Simple hand washing is the easiest way to prevent the spread of bacteria.

- If you do not thoroughly wash your hands before touching the tube feeding equipment or formula, the bacteria on your hands can cause food-borne illness. People with food-borne illness often experience stomach upset, nausea, vomiting, diarrhea, and/or infection. If your child experiences any of these symptoms, it is important to contact your healthcare professional.

- Take a damp paper towel and wipe off the top of the can of formula before opening. This will prevent any dust or debris from getting into the formula.

- Once a container of liquid formula has been opened, it needs to be refrigerated. Discard any refrigerated formula that has not been used within 24 hours.

- Once powder formula is mixed, store in refrigerator and use or discard within 24 hours. Once a container of powder formula has been opened, store at room temperature and use contents within 1 month.

- Do not mix new formula with old formula that has been hanging.

- If sterile water is required, boil the water and let it cool to room temperature. You can also purchase sterile water from your local pharmacy.

- Be aware that like any food, tube feeding formula may become contaminated with bacteria if left at room temperature for too long. To reduce the risk of food-borne illness, your formula should not be left at room temperature for more than 12 hours. If using breast milk or powdered formula that is mixed with water, add just enough formula for 4 hours.

- When using a gravity feeding bag with formula that has been at room temperature for the maximum time (4 or 12 hours, depending on your formula), rinse the feeding bag with water before adding more formula. Never add fresh formula to a bag of existing formula.
Help stop the spread of germs

Cover your cough

• Cover your mouth and nose with a tissue when you cough or sneeze.
• Put your used tissue in a waste basket.
• You may be asked to put on a mask to protect yourself and others.

Wash your hands after coughing or sneezing

• Wash your hands for 20 seconds with soap and warm water.
• If soap and water are unavailable, clean your hands with antimicrobial hand sanitizer.

Fire Safety

Take the time now to prepare — it can save lives!

An ounce of prevention…

Smoke alarms

• Install a smoke alarm outside of each sleeping area and on each additional level of your home.
• Install smoke alarms INSIDE sleeping areas if people sleep with their doors closed.
• Test smoke alarms once a month by pressing test buttons.
• If an alarm fails the test or starts making beeping noises, replace batteries immediately.
• Replace ALL smoke alarm batteries at least once a year.

Fire extinguishers

• Consider purchasing one or more fire extinguishers to keep in your home.
• Read the instructions to understand how your fire extinguisher works, and make sure all family members understand how to use it.
• Read the instructions to find out how to check if your extinguisher is in working order, and how frequently it needs to be checked.

**Escape ladders**
• Consider installing escape ladders for upstairs rooms.
• Learn how to use your escape ladder.
• Store ladders close to windows.

**Flashlights**
• Keep flashlights throughout your house and make sure everyone knows where they are located.
• Check batteries regularly.

**Planning can prevent panic**

**Escape routes**
• Figure out at least two ways for escaping for every room in your home.
• Everyone living in your home should be familiar with these escape routes.

**Practice**
• At least twice a year, practice using your escape plans.
• Practice crawling because you may need to escape by crawling under smoke, where the freshest air will be.

**Meeting place**
• Decide on a location where everyone will meet outside your home after escaping from a fire.
• A meeting place is important so that you can quickly see if everyone has escaped.

**If a fire occurs...**

**Making your escape**
• If there is smoke or fire in one escape route, use another route.
• If there is no way to avoid smoke, remember to stay low and crawl under the smoke, where the freshest air will be.
• If you want to escape by opening a closed door, FIRST check to see if the door feels warm before opening it. If it is warm, do NOT open the door. Instead, use another route.
Blocked escape routes
If all of your escape routes are blocked by smoke, heat or flames:

• Stay in the room and keep any doors closed.
• Keep out smoke by piling rugs, blankets or pillows along the bottom of any doors.
• If there is a phone in the room, call 911 and tell them where you are.
• Signal out a window for help using a brightly colored cloth, sheet, towel, or flashlight.
• Stay as close to the floor as possible, near a window or door.

After escaping
• Go to a neighbor’s house and call 911 as soon as possible.
• NEVER go back inside a burning house. Once you’re outside, stay outside!
• When firefighters arrive, tell them if you think anyone is still inside.

Notice of Privacy Practices

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

I. Who We Are
This Notice describes the privacy practices of your home healthcare company.

II. Our Privacy Obligations
We are required by law to maintain the privacy of your protected health information (“PHI”), to provide you with this Notice of our legal duties and privacy practices with respect to your PHI, and to notify affected individuals following a breach of unsecured PHI. When we use or disclose your PHI, we are required to abide by the terms of this Notice (or other notice in effect at the time of the use or disclosure).

III. Permissible Uses and Disclosures Without Your Written Authorization
In certain situations, which we will describe in Section IV below, we must obtain your written authorization in order to use and/or disclose your PHI. However, we do not need any type of authorization from you for the following uses and disclosures:

A. Uses and Disclosures for Treatment, Payment, and Healthcare Operations. We may use and disclose PHI, but
not your “Highly Confidential Information” (defined in Section IV. D below), in order to treat you, obtain payment for equipment and services provided to you, and conduct our “healthcare operations” as detailed below:

- **Treatment.** We use and disclose your PHI to provide treatment and other services to you—for example, to treat your injury or illness. In addition, we may contact you to provide appointment reminders or information about treatment alternatives or other health-related benefits and services that may be of interest to you. We may also disclose PHI to other providers involved in your treatment.

- **Payment.** We may use and disclose your PHI to obtain payment for equipment and services that we provide to you—for example, disclosures to claim and obtain payment from your health insurer, HMO, or other company that arranges or pays the cost of some or all of your healthcare (“Your Payor”). We may also use and disclose your PHI to verify that Your Payor will pay for healthcare, including disclosures to Your Payor’s eligibility database.

- **Healthcare Operations.** We may use and disclose your PHI for our healthcare operations, which include internal administration and planning and various activities that improve the quality and cost-effectiveness of the care that we deliver to you. For example, we may use PHI to evaluate the quality and competence of our clinicians and other healthcare workers. We may also disclose PHI to your other healthcare providers when such PHI is required for them to treat you, receive payment for services they render to you, or conduct certain healthcare operations, such as quality assessment and improvement activities, reviewing the quality and competence of healthcare professionals, or for healthcare fraud and abuse detection or compliance.

**B. Disclosure to Relatives, Close Friends, and Other Caregivers.** We may use or disclose your PHI to a family member, other relative, a close personal friend, or any other person identified by you when you are present for, or otherwise available prior to, the disclosure, if we: (1) obtain your agreement; (2) provide you with the opportunity to object to the disclosure and you do not object; or (3) reasonably infer that you do not object to the disclosure. If you are not present, or the opportunity to agree or object to a use or disclosure cannot practicably be provided because of your incapacity or an emergency circumstance, we may exercise our professional judgment to determine whether a disclosure is in your best interests. If we disclose information to a family member, other relative, or a close personal friend, we would disclose only information that we believe is directly relevant to the person’s involvement with your healthcare or payment related to your healthcare. We may also disclose your PHI in order to notify (or assist in notifying) such persons of your location, general condition, or death.
C. Public Health Activities. We may disclose your PHI for the following public health activities: (1) to report health information to public health authorities for the purpose of preventing or controlling disease, injury, or disability; (2) to report child abuse and neglect to public health authorities or other government authorities authorized by law to receive such reports; (3) to report information about products and services under the jurisdiction of the U. S. Food and Drug Administration; (4) to alert a person who may have been exposed to a communicable disease or may otherwise be at risk of contracting or spreading a disease or condition; and (5) to report information to your employer as required under laws addressing work-related illnesses and injuries or workplace medical surveillance.

D. Victims of Abuse, Neglect, or Domestic Violence. If we reasonably believe you are a victim of abuse, neglect, or domestic violence, we may disclose your PHI to a governmental authority, including a social service or protective services agency, authorized by law to receive reports of such abuse, neglect, or domestic violence.

E. Health Oversight Activities. We may disclose your PHI to a health oversight agency that oversees the healthcare system and is charged with responsibility for ensuring compliance with the rules of government health programs such as Medicare or Medicaid.

F. Judicial and Administrative Proceedings. We may disclose your PHI in the course of a judicial or administrative proceeding in response to a legal order or other lawful process.

G. Law Enforcement Officials. We may disclose your PHI to the police or other law enforcement officials as required or permitted by law or in compliance with a court order or a grand jury or administrative subpoena.

H. Decedents. We may disclose your PHI to a coroner or medical examiner as authorized by law.

I. Organ and Tissue Procurement. We may disclose your PHI to organizations that facilitate organ, eye, or tissue procurement, banking, or transplantation.

J. Research. We may use or disclose your PHI without your consent or authorization if an Institutional Review Board or Privacy Board approves a waiver of authorization for disclosure.

K. Health or Safety. We may use or disclose your PHI to prevent or lessen a serious and imminent threat to a person’s or the public’s health or safety.

L. Specialized Government Functions. We may use and disclose your PHI to units of the government with special functions, such as the U. S. military or the U. S. Department of State under certain circumstances.

M. Workers’ Compensation. We may disclose your PHI as authorized by and to the extent necessary to comply with state law relating to workers’ compensation or other similar programs.
N. As Required by Law. We may use and disclose your PHI when required to do so by any other law not already referred to in the preceding categories.

IV. Uses and Disclosures Requiring Your Written Authorization

A. Use or Disclosure with Your Authorization. For any purpose other than the ones described above in Section III, we only may use or disclose your PHI when you grant us your written authorization (“Your Authorization”). For instance, you will need to execute an authorization before we can send your PHI to your life insurance company or to the attorney representing the other party in litigation in which you are involved.

B. Marketing. We must also obtain your written authorization prior to using your PHI to send you any marketing materials (“Your Marketing Authorization”). However, we may communicate with you about products or services relating to your treatment, case management, or care coordination, or alternative treatments, therapies, providers, or care settings without Your Marketing Authorization unless we receive financial remuneration from a third party whose product or service is being described in exchange for making the communication. Further, we can provide you with marketing materials in a face-to-face encounter without obtaining Your Marketing Authorization. We are also permitted to give you a promotional gift of nominal value, if we so choose, without obtaining Your Marketing Authorization.

C. Sale of PHI. With certain exceptions, we must also obtain Your Authorization for any disclosure of PHI if we receive remuneration from or on behalf of the recipient of the PHI in exchange for the PHI.

D. Uses and Disclosures of Your Highly Confidential Information. In addition, federal and state laws require special privacy protections for certain highly confidential information about you (“Highly Confidential Information”). We will comply with such special privacy protections which may cover the subset of your PHI that is about: (1) mental health and developmental disabilities services; (2) alcohol and drug abuse prevention, treatment, and referral; (3) HIV/AIDS testing, diagnosis, or treatment; (4) venereal disease(s); (5) genetic testing; (6) child abuse and neglect; (7) domestic abuse of an adult with a disability; (8) sexual assault; or (9) abortion.

V. Your Rights Regarding Your PHI

A. For Further Information; Complaints. If you desire further information about your privacy rights, are concerned that we have violated your privacy rights or disagree with a decision that we made about access to your PHI, you may contact our Physician and Patient Relations Department. You may also file written complaints with the Director, Office for Civil Rights of the U.S. Department of Health and Human
Services. Upon request, the Physician and Patient Relations Department will provide you with the correct address for the Director. We will not retaliate against you if you file a complaint with us or the Director.

B. Right to Request Restrictions. You may request restrictions on our use and disclosure of your PHI: (1) for treatment, payment, and healthcare operations; (2) to individuals (such as a family member, other relative, close personal friend, or any other person identified by you) involved with your care or with payment related to your care; or (3) to notify or assist in the notification of such individuals regarding your location and general condition. While we will consider all requests for restrictions carefully, we are not required to agree to a requested restriction, except that we must agree to a request to restrict disclosure of PHI to a health plan if:

1. the disclosure is for the purposes of carrying out payment or healthcare operations and is not otherwise required by law; and
2. the PHI pertains solely to a healthcare item or service for which the healthcare provider involved has already been paid out of pocket in full. If you wish to request restrictions, please submit a written request to our Physician and Patient Relations Department. A form to request restrictions is available upon request from the Physician and Patient Relations Department.

C. Right to Receive Confidential Communications. You may request, and we will accommodate, any reasonable request for you to receive your PHI by alternative means of communication or at alternative locations.

D. Right to Revoke Your Authorization. You may revoke Your Authorization, Your Marketing Authorization, or any written authorization given to us by you in connection with your Highly Confidential Information, except to the extent that we have taken action in reliance upon it, by delivering a written revocation statement to the Physician and Patient Relations Department identified below. A form of written revocation is available upon request from the Physician and Patient Relations Department.

E. Right to Inspect and Copy Your Health Information. You may request access to your medical record file and billing records maintained by us in order to inspect and request copies of the records. Under limited circumstances, we may deny you access to a portion of your records. If you desire access to your records, please submit a written request to the Physician and Patient Relations Department. You may obtain a record request form from the Physician and Patient Relations Department. Requests for a copy of a limited amount of your medical or billing records (e.g., a prescription) maintained by us may be made orally. We may, however, require that you submit a written request to the Physician and Patient Relations Department.
F. Right to Amend Your Records. You have the right to request that we amend PHI maintained in your medical record file or billing records. If you desire to amend your records, please send a written request for the amendment, including the reason for the amendment, to the Physician and Patient Relations Department. You may obtain a form to request an amendment from the Physician and Patient Relations Department. We will comply with your request unless we believe that the information that would be amended is accurate and complete or other special circumstances apply.

G. Right to Receive an Accounting of Disclosures. Upon request, you may obtain an accounting of certain disclosures of your PHI made by us during the six-year period prior to the date of your request.

H. Right to Receive Paper Copy of This Notice. Upon request, you may obtain a paper copy of this Notice even if you have agreed to receive it electronically.

VI. Effective Date and Duration of This Notice
A. Effective Date. This Notice is effective as of September 16, 2013.

B. Right to Change Terms of This Notice. We reserve the right to, meaning we may, change the terms of this Notice at any time. If we change this Notice, we may make the new notice terms effective for all PHI that we maintain, including any information created or received prior to issuing the new notice. If we change this Notice, we will post the new notice in waiting areas at our facility and on our Internet site. You also may obtain any new notice by contacting the Physician and Patient Relations Department.

VII. Physician and Patient Relations Department
You may contact the Physician and Patient Relations Department at:

Physician and Patient Relations Department
26220 Enterprise Court
Lake Forest, California 92630
Telephone Number: (800) 260-8808
Facsimile Number: (949) 587-0089

Patient’s Rights and Responsibilities

PATIENT/CLIENT BILL OF RIGHTS
As a patient/client of Apria Healthcare, you have the rights which include, but are not limited to the following:

1. Be given information about your rights for receiving homecare services.
2. Receive a timely response from Apria Healthcare regarding your request for homecare services.
3. Be given information about Apria Healthcare policies, procedures and charges for services.
4. Choose your homecare providers.
5. Be given appropriate and professional quality homecare services without discrimination against your race, color, creed, religion, sex, national origin, sexual preference, handicap, or age.
6. Be treated with courtesy and respect by all who provide homecare services to you.
7. Be free from physical and mental abuse and/or neglect.
8. Be given proper identification by name and title of everyone who provides homecare services to you.
9. Be given the necessary information regarding treatment and choices concerning rental or purchase options for durable medical equipment so you will be able to give informed consent for your service prior to the start of any service.
10. Be given complete and current information concerning your diagnosis, treatment, alternatives, risks and prognosis as required by your physician’s legal duty to disclose in terms and language you can reasonably be expected to understand.
11. A plan of service that will be developed to meet your unique service needs.
12. Participate in the development of your plan of care/service.
13. Be given an assessment and update of your developed plan of care/service.
14. Be given data privacy and confidentiality.
15. Review your clinical record at your request.
16. Be given information regarding anticipated transfer of your homecare to another healthcare facility and/or termination of homecare service to you.
17. Voice grievance with and/or suggest change in homecare services and/or staff without being threatened, restrained, and discriminated against.
18. Refuse treatment within the confines of the law.
20. Have an advance directive for medical care, such as a living will or the designation of a surrogate decision maker, respected to the extent provided by the law.
21. Participate in the consideration of ethical issues that arise in your care.

THE PATIENT’S RESPONSIBILITIES

Apria Healthcare and its personnel have the right to expect from you, our patient, your relatives and friends, reasonable behavior which takes into consideration the nature of your illness or predicament.
These responsibilities include, but are not limited to the following:

1. Give accurate and complete health information concerning your past illnesses, hospitalization, medications, allergies, and other pertinent items.
2. Assist in developing and maintaining a safe environment.
3. Inform Apria Healthcare when you will not be able to keep a homecare visit.
4. Participate in the development and update of your homecare plan of service/treatment.
5. Adhere to your developed/updated homecare plan of service/treatment.
6. Request further information concerning anything you do not understand.
7. Contact your physician whenever you notice any unusual feelings or sensations during your plan of service/treatment.
8. Contact your physician whenever you notice any change in your condition.
9. Contact Apria Healthcare whenever your insurance company or plan changes.
10. Contact Apria Healthcare whenever you have an equipment problem.
11. Contact Apria Healthcare whenever you have received a change in your homecare prescriptions.
12. Contact Apria Healthcare whenever you are to be hospitalized.
13. Give information regarding concerns and problems you have to an Apria Healthcare staff member.
14. Contact Apria Healthcare prior to any change of address.
15. Contact Apria Healthcare if you acquire an infectious disease during the time you are receiving services and/or care from Apria Healthcare, except where exempted by law.

Medicare DMEPOS Beneficiary Statement

DMEPOS suppliers have the option to disclose the following statement to satisfy the requirement outlined in Supplier Standard 16 in lieu of providing a copy of the standards to the beneficiary.

The products and/or services provided to you by (supplier legal business name or DBA) are subject to the supplier standards contained in the Federal regulations shown at 42 Code of Federal Regulations Section 424.57(c). These standards concern business professional and operational matters (e.g., honoring warranties and hours of operation). The full text of these standards can be obtained at http://www.ecfr.gov. Select Title 42: Public Health in the drop down box. Then browse Parts 414–429, Part 424, Subpart 424.57(c). Upon request we will furnish you a written copy of the standards.
**Interpretation Service Available**

**English translation:** Point to your language. An interpreter will be called. The interpreter is provided at no cost to you.

<table>
<thead>
<tr>
<th>Language</th>
<th>Translation</th>
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<tbody>
<tr>
<td>Arabic</td>
<td>أبشر إلى لغتك. وسيتم تعلم الترجمة فوندي لك. سيتم تأمين الترجمة الفوري مجانا.</td>
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<tr>
<td>Armenian</td>
<td>ֆորերենուային</td>
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<tr>
<td>Cantoneses</td>
<td>廣東話</td>
</tr>
<tr>
<td>French</td>
<td>Pointez vers votre langue et on appellera un interprète qui vous sera fourni gratuitement.</td>
</tr>
<tr>
<td>German</td>
<td>Zeigen Sie auf Ihre Sprache. Ein Dolmetscher wird gerufen. Der Dolmetscher ist für Sie kostenlos.</td>
</tr>
<tr>
<td>Hindi</td>
<td>अपनी भाषा पर इनाम करें और एक दुर्भाषिया बुलाया जाएगा। दुर्भाषिया का प्रस्तुत अप पर बिना किसी खर्च के किया जाता है।</td>
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<td>Hmong</td>
<td>Hmoob</td>
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<tr>
<td>Italian</td>
<td>Puntare sulla propria lingua. Un interprete sarà chiamato. Il servizio è gratuito.</td>
</tr>
<tr>
<td>Japanese</td>
<td>あなたの話す言語を指して下さい。無料で通訳を提供します。</td>
</tr>
<tr>
<td>Khmer (Cambodian)</td>
<td>ខ្មែរ (Khmer)</td>
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<td>Language</td>
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<td>Korean</td>
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Charts on pages 18–19 provided by Language Line Services ©2007
The materials provided in this section include resources for your use. If your child experiences any physical symptoms or changes in medical condition, or if you have concerns about your child’s specific therapy, contact your child’s physician.

If you have questions about your equipment or wish to speak with our dietitians, please contact Apria’s Enteral Nutrition Support at (844) 260-1788.
Getting Started with Home Tube Feeding

What type of feeding tube your doctor believes is best for your child will include many factors including how long the tube feedings will be needed and how well the stomach and intestines are working.

Short-term
• **NG-tube:** For children who will need feedings for less than 6 weeks, it is common to place a small tube that goes through the nose and esophagus into the stomach. This tube is called a *nasogastric* tube, or NG-tube for short.

Long-term
If a child requires tube feeding for longer than 6 weeks, a more permanent type of tube is generally recommended.

• **G-tube:** A tube placed in the stomach is called a *gastrostomy* tube, or G-tube for short.
• **J-tube:** A tube placed in the intestinal tract, below the stomach, is called a *jejunostomy* tube, or J-tube.

Feeding tubes are soft and flexible and can be placed directly through the abdominal wall into the stomach or intestinal tract through a surgical incision called a stoma. Part of the tube is inside the stomach or intestine and another part extends to the outside of the body. The outside part of the tube has an opening at the end where formula will be delivered. This opening is called the feeding port.

Many children have a low profile gastrostomy tube placed instead of a standard feeding tube. This type of tube is often referred to as a “button,” since it is small and round and sits right on top of the stomach. Special tubes called extension sets are attached to the button.
Feeding methods

1. **Syringe/Bolus Feeding:** A syringe is used to push formula directly into the stomach.

2. **Gravity Feeding:** Formula is poured into a feeding bag, which is hung from a pole. The force of gravity pulls the formula from the bag, through the tube.

These feeding methods will be reviewed in detail in the next section of this booklet, “How to Administer Your Child’s Feeding.”

It is of great importance that you follow the instructions provided by your healthcare team. The information in this guide is provided to supplement the instruction you have received from your healthcare team.

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**How to Administer Your Child’s Feeding**

There are 3 ways that you can home tube feed your child, and the method is determined by your healthcare team:

- Syringe/bolus feeding
- Gravity bag feeding
- Pump bag feeding (this method is reviewed in a separate booklet)

**Syringe/bolus feeding**

This method is the most common and the easiest. All you need is the formula and a syringe. And a bolus feeding only takes 15 to 30 minutes. When your child is new to bolus feeding, it is good to start with a smaller amount of formula to let his or her body adjust. If there are no problems, gradually increase until you are up to the full amount of formula prescribed.

1. Wash your hands vigorously with soap and warm water for at least 20 seconds.
2. Clean the top of the formula can with a damp paper towel. Shake the can and then open it. For children prescribed with powder formula, only prepare enough for a 24-hour period and immediately refrigerate any unused formula.

3. Open the feeding port cap, or if your child has a feeding button, attach a bolus extension set.

4. Administer the feeding:
   - Pull the syringe plunger out. Connect your syringe to your feeding tube. Position the syringe upright so formula will not spill out. The syringe acts as a funnel. Fold/pinch the feeding tube to prevent fluid from running out.
   - Insert the syringe tip into the feeding tube port or extension set.
   - Unfold or unclamp the feeding tube.
   - Slowly pour a small amount of formula into the syringe. The formula will then go through the tube into the stomach. Let the formula run through the tube by gravity.  
     - If desired, you can put the plunger back into the syringe, and then slowly push down to force formula into the feeding tube.
     - Repeat until the prescribed amount of formula has been given.

5. Flush the feeding tube with at least 30 mL (1 ounce) of water, or the amount prescribed.

6. Close the cap on your child’s feeding tube port or remove the extension set and close the feeding button.

**Gravity feeding**

With gravity feeding, the formula is placed in a feeding bag hung from an IV pole. A clamp can be adjusted to allow formula to flow faster or slower. Gravity feedings generally take 30 to 45 minutes. Be sure to follow your healthcare team’s instructions regarding checking tube placement, residuals, and the amount of water to use to flush the tube.

1. Wash your hands vigorously with soap and warm water for at least 20 seconds.
2. Clean the top of the formula can with a damp paper towel. Shake the can and then open it. For children prescribed with powder formula, only prepare enough for a 24-hour period and immediately refrigerate any unused formula.

3. Close the roller clamp on the feeding bag (roll down).

4. Fill the gravity feeding bag with the prescribed amount of formula. Next, close the top of the feeding bag.

5. Hang the feeding bag on the IV pole at least 18 inches above the level of your child's stomach.

6. Remove the cover from the end of the tubing attached to the feeding bag.

7. Hold the tubing tip over a container or a clean sink.

8. Open the clamp (roll up) to let formula flow to the end of the tubing. Then close the clamp.

9. Connect the gravity bag end to your feeding tube.

10. Open the clamp and adjust the flow of formula up or down.

11. After the feeding is complete, be sure to rinse out the feeding bag and tubing with warm water. To avoid bacterial contamination, use a new gravity feeding bag each day.

12. Flush your child's feeding tube with at least 5 mL of water (or the amount prescribed) before and after each feeding to prevent clogging.

**Positioning Your Child**

Never tube feed while your child is lying flat. Proper positioning of your child during tube feeding can help with the following:

- Reduces the risk of breathing formula into the lungs (aspiration)
- Promotes digestion
- Prevents reflux
- Aids in sucking and swallowing
Feeding position tips

- Make sure your child is comfortable and content.
- Infants should be held as if you are feeding them with a bottle. Maintain eye contact and offer the pacifier to help your child learn feeding skills and connect the sucking with the feeling of food in the stomach. If holding your baby is not possible, place your baby on his or her right side during the feeding.
- Older infants or toddlers who can sit up by themselves can be placed in a highchair for the feeding.
- For night feedings or feedings in bed, keep the head of your child’s bed raised 6 to 8 inches. You can place a pillow under the mattress or buy a wedge pillow. Place your child on his or her right side during the feeding.
- If you put your child to bed after a feeding, keep the head of your child’s bed raised 6 to 8 inches for 30 to 60 minutes after the feeding.

If your child has poor motor control, check with your healthcare team about safe positioning for your child during feeding.

How to Care for Your Child’s Nasogastric Tube

Nasogastric (NG) tubes all have a similar design. At the one end of the tube is an opening where a feeding bag or syringe can be attached, and the other end of the tube goes into the stomach. To help placement of the tube, some tubes are weighted. Other tubes are equipped with a thin hospital-grade metal wire, also known as a stylet.

Prior to leaving the hospital, a qualified member of the healthcare team will teach you correct technique for placing your child’s NG tube. They will also teach you how to confirm that the tube is in the stomach. You will be provided detailed instructions, and your healthcare team will go over everything as many times as you need until you feel comfortable. Your child will not be sent home with a feeding tube until he or she can be safely cared for at home with the feeding tube.

It is of great importance that you follow the instructions provided by your healthcare team. The information below is provided to supplement the instruction you have received from your healthcare team.
When to call your healthcare team

- If your child has difficulty breathing or speaking, has a distended stomach, or experiences pain.
- If you cannot unclog an NG tube.
- If you cannot tell if the NG tube is in the stomach or if you feel you cannot get it back into place safely.
- If, in the nostril where the tube is placed, there is swelling, redness, or bleeding.

NG tube care tips

Following these tips will help ensure your child will be safe and comfortable with the NG tube.

- Before touching the NG tube, always wash your hands. Wash your hands vigorously with soap and warm water for at least 20 seconds. Dry your hands well with a paper towel. Turn off the faucet using the same paper towel, so you don’t pick up germs from the faucet knob.
- Remove the tape that holds the tube in place when it becomes dirty. Try to alternate the location of the tape on the child’s face so it does not irritate the skin.
- When the tube is in place, clean around the edges of the nose with a soft, clean cloth.
- Changing the placement of the NG tube from one nostril to the other every week or two will help reduce irritation.
- After removing the tube, clean it with warm, soapy water and rinse with water between uses. Most NG tubes are reusable for up to a month.

Securing the NG tube

- Different tape or dressing products are available for use in securing an NG tube to help keep the tube securely in place. Please ask your Apria clinician for assistance in finding a device that will work for your child.
• If the tube is extremely long, using paper tape and a safety pin can help secure the NG tube to the back of your child’s clothing.

How to Care for Your Child’s G-Tube or J-Tube

If your child has a G-tube or J-tube, you’ll need to care for the skin area surrounding it. Care for a G-tube and J-tube are similar.

Proper care of your child’s feeding tube site is very important — especially during the first 72 hours after the tube was placed, because it is at higher risk of infection. It is normal to see some minor drainage around the tube site.

Always remember to wash your hands. Good care starts with thorough hand washing.

Daily cleaning

1. Prep: Wash your hands vigorously with soap and warm water for at least 20 seconds. Dry your hands well with a paper towel. Turn off the faucet using the same paper towel, so you don’t pick up germs from the faucet knob.

2. Remove dressings: Carefully remove the old gauze and tape from around the tube.

3. Sutures: Gently clean around any sutures, the skin around the tube daily.

4. Tube and bolster: Daily, gently clean around any sutures, the skin around the tube, and under the bolster with warm, soapy water. Dip a cotton swab in the soapy water, and gently clean under the bolster by gently lifting the bolster up just enough to place
a cotton swab underneath it. Be careful not to pull on the feeding tube. Gently push the bolster back into place against the skin, making sure there is enough space between the skin and bolster for airflow. Having the bolster too tight against the skin may cause skin irritation. If your child has a G-tube or PEG, turn the tube and external bolster ¼ turn each day when cleaning the site. However, please note you cannot do this if the tube is sutured in place.

5. Feeding port: Open the feeding port cover, dip a damp cotton swab in the opening, and swirl it around a few times to clean the inside of the port to remove any dried formula or medication.

6. Crusting: A small amount of clear or tan drainage is normal. If the tube or tube site develops any crusting around it, gently clean the area with a cotton swab and half-strength hydrogen peroxide diluted with water.

7. Watch for symptoms: Check the tube site daily and contact your child’s physician or nurse if you see any of these symptoms: swelling, redness, soreness, or unusual drainage.

8. Dry: Dry skin with a clean soft cloth.

9. No ointment: Do not apply ointment to the tube site unless you were told to by your child’s healthcare team.

10. Bathing and showering: It’s generally okay for children to bathe or shower 2 weeks after surgery.

Flushing Feeding Tubes and Extension Sets

You will need to flush the tube with water a few times a day. You can do this using a syringe and tap water. It is important to flush your child’s tube with water before and after each feeding, and also after you place medication down the tube. This will help ensure that your tube does not become clogged. It also decreases the chance of bacterial growth.
1. Fill a clean cup with lukewarm water. Do **not** use cold water, because this can cause cramping.

2. Put the tip of the syringe in the water and slowly pull the plunger to draw water in the syringe. Your healthcare team will inform you on how much water you should use to flush your child’s feeding tube.

3. Fold the feeding tube to prevent any stomach liquid from running out of the tube. Then open the cap of the feeding port.

4. Connect the syringe and the feeding tube. Unfold the tube. Then slowly push the plunger to push the water through the tube.

5. Remove the syringe and close the cap on the feeding port.

**About extension sets**

Extension sets are used if your child has a feeding button. One end of the tube has a connector that will fit into the opening of the feeding button, and usually will lock into place so they will not fall out during feedings.

**Types of extension sets:**

- **Right angle extension sets:** For use with gravity or pump feedings.
- **Straight or bolus feeding sets:** Designed to have a syringe attached to the end.

**It is very important that extension sets are cleaned out after each use.** Rinse the extension sets with warm water after every use and store in an area that is clean and dry. After 7 days, it is recommended to discard the extension set and start with a brand new one to decrease chance of bacterial build-up.
Venting the Tube

Children sometimes have difficulty with burping after tube placement. Decompression (also known as venting) provides relief by letting excess air and/or fluids out of the stomach. Venting can be done when your child shows signs of needing gas release:

- Discomfort
- A hard or swollen stomach
- Continuous crying
- Vomiting

To prevent gas from being pushed into your child’s stomach, before you start the feed, run the formula to the end of the feeding set before you attach it to the feeding tube.

How to vent

- **G-tube:** Attach a syringe with the plunger removed to the feeding tube and hold above the child’s stomach for a few minutes to let air escape.

- **Button:** If your child has a button, easily vent by attaching an extension set and unclamping the tube, if a clamp is present. Also, a special decompression tube set with a one-way valve is available that allows excess gas or stomach contents to flow out of the stomach.

- While venting, you should hear gas bubble up through the tube or see stomach contents come up into the syringe or tube. **Note:** Return any liquids back into the stomach, because it contains important body fluids.

- Remove the venting tube or adapter set as soon as the gas is released to avoid ruining the one-way valve.

- Clean the equipment and adapter sets.

Checking Residuals

“Residuals” are the amount of formula left in your child’s stomach from the last feeding before you start the new feeding.
You may be told to check residuals if your child:

- Has problems with an upset stomach
- Feels full
- Has problems with bloating, nausea, and/or vomiting

Sometimes the stomach is not emptying the formula properly. If more than half of the volume of the last feeding remains in the stomach, delay the next feeding for 30 to 60 minutes before starting the next feeding.

**How to check residuals**

1. Attach a 60 mL syringe to the feeding tube or adapter set.
2. Unclamp the tube, if clamped.
3. Gently pull up the plunger. Note the amount of formula and slowly replace back into the stomach.
4. Clamp the tube.
5. Remove the syringe.

**If the Feeding Tube Comes Out**

It sometimes happens that children pull out their feeding tubes. Or sometimes they get pulled out accidentally in other ways. If this happens, it’s okay and there is no need to panic, but you do need to act fast.

G-tubes will need to be replaced without delay, since the stoma (or stomach opening) closes within just a few hours. Do not try to replace in yourself, unless you have been taught by a healthcare professional. If you have received medical instruction, replace the feeding tube with the back-up tube you have and precisely follow the instructions provided to you by your child’s physician or healthcare team. Then cover the site with clean gauze or cloth, as the site may bleed or stomach contents may leak. Call your child’s physician or healthcare provider immediately, even if it is after business hours. If you live far from your child’s physician, you may need to go to your local emergency room. Be sure to take the feeding tube with you so the team knows the kind and tube size your child has.
Giving Medication Through Your Feeding Tube

Medication can be taken through your child’s feeding tube. If possible, it is best to get the medications in liquid form. But if the medication is only available as tablets or capsules, they will need to be crushed and mixed with water before you can give them through the feeding tube. Always check with your pharmacist, as there are certain medications that should not be crushed.

General information

1. Always use a clean syringe.
2. Do not mix medications together before putting them through your tube. Give each medication separately.
3. Do not add medication directly to your tube feeding formula, because it can lump up and block the tube.
4. Before giving a medication, stop the tube feeding and flush the tube with at least 5 mL of water. Confirm amount with your healthcare team.
5. After the medication has been given, flush the tube with at least 5 mL of water. Confirm amount with your healthcare team.
6. Repeat the above steps for each medication.
7. After about 30 minutes, restart the tube feeding after all medications have been administered.
8. Check with your child’s physician or pharmacist to find out if the tube feeding needs to be held for a longer period of time after taking medication, or if they should be given on a full or empty stomach.

Liquid medication

With feeding tubes, liquid medications are easier to deliver.

1. First administer thinner liquids and thicker liquids last.
2. If your child has an NG tube, check that the placement is correct before giving medication.
3. Flush the tube with 5 mL of lukewarm water (or the amount prescribed).
4. Pull the syringe plunger to draw up the exact amount of medication into the syringe.
5. Attach the syringe to the feeding tube or extension set. Slowly push the plunger to administer the medication.

6. Flush the tube with 5 mL of lukewarm water (or the amount prescribed) after giving the medication.

**Tablet medication**

To help make crushing medications easier, look for med-crushing syringes, mortar and pestle, or a pill crusher tool from your pharmacy.

1. After you have crushed the pills finely, let the pieces dissolve in 5 mL of lukewarm water (never hot water).

2. If your child has an NG tube, check that the placement is correct before giving medication.

3. Flush the tube with 5 mL of lukewarm water (or the amount prescribed).

4. Draw the medication into the syringe, attach the syringe to the end of the feeding tube, and administer the medication.

5. Flush the tube with 5 mL of lukewarm water (or the amount prescribed) after giving the medication.

**Capsule medication**

For medication that comes in capsules, consult with your child’s physician or pharmacist before administering it.

**Be sure to flush the tube with water after giving the medication.** This is very important — medication can easily clog a feeding tube if care is not taken to flush properly and consistently.

**Formulas, Feeding Plans, and Nutritional Needs**

Our Nutrition Support Dietitians screen all patients, develop nutrition plans, manage home tube feeding, provide education, and answer questions. Working with your child’s physician and healthcare team, our dietitians will be able to provide recommendations to your child’s physician on what is the best formula to use and how much your child will need to take on a daily basis.
All patients are re-screened as needed by Apria’s Nutrition Support Dietitians to monitor their response to therapy and identify any signs of problems, such as dehydration or weight loss.

**Formulas and feeding plans**

There are many brands and types of formulas available. The word “formula” is also used to refer to infant formula, breast milk, and special additives. Your child’s physician and/or Registered Dietitian will decide on the formula that will be best for your child.

Some children need to get all their nutrition through tube feedings while others get tube fed to supplement oral intake. Your healthcare team will inform you if your child can eat by mouth and/or any limitations.

You and your healthcare team will need to determine the type of tube feeding schedule that works best for your child’s nutrition needs. Finding the right schedule may take some time and include some trial and error. Be patient, as you will eventually arrive at a schedule that is best for your child and family.

**Types of formula and additives**

- Ready-to-feed formula: Does not need to be mixed with water.
- Infant formula concentrate: Prepare by adding equal parts of water to concentrated liquid.
- Powdered infant formula: Mix a specific amount of formula powder to a specific amount of water.
- Fortified Human Breast Milk: Mix breast milk with powdered formula.
- Modulares are specific nutrients or ingredients added to a formula to meet special nutrient goals. Examples are MCT oil or protein powder.
- Thickening agents: Can be added to formula to thicken the liquid.
Home Tube Feeding
Problem-Solving

Most children do very well on tube feedings, but sometimes there can be issues that arise. Below are some tips for avoiding some of the more common tube feeding problems and some simple solutions. Please note, however, that these are just general guidelines, and you should always contact your child’s physician or healthcare team for specific instructions.

Constipation
This is one of the most common tube feeding complications. Make sure to tell your Apria Nutrition Support Dietitian about your child’s constipation. Don’t be shy — it needs to be known to help resolve the issue.

Causes
• Lack of physical activity.
• Too little water is being given with the feedings.
• Medication, especially for pain.
• Lack of fiber in the tube feeding formula.
• Formula intolerance.

Prevention
• If permitted, increase your child’s activity.
• There is a need for water each day in addition to the formula. Make sure to give your child’s prescribed amount daily. If you are not sure how much water is needed, contact your Apria Nutrition Support Dietitian or physician for help.
• Talk to your child’s physician or your Apria Nutrition Support Dietitian about the amount of fiber in your child’s tube feeding formula.
• Talk to your child’s physician or your Apria Nutrition Support Dietitian about changing formulas.
• Adjust or change medications (check with physician or pharmacist).

Abdominal distention
Causes
• Constipation.
• Gas.
• Large feeding volume.
Prevention
• Run the formula to the end of the feeding set before you start the feed, then attach it to the feeding tube.
• Vent the tube to relieve gas.

Aspiration/reflux

Causes
• Incorrect positioning while feeding.
• Feeding too quickly.
• Medications.

Prevention
• Ensure proper posture/positioning.
• Ensure proper feeding tube placement.
• Check residuals.

Clogged feeding tubes
Feeding tubes can become clogged, which causes a delay in feeding and may result in a visit to your child’s physician.
• If your child’s tube becomes clogged, attempt to loosen the clog by gently flushing 10 to 20 mL of warm water into the tube with your syringe. Pull back and forth on the syringe plunger to help dislodge the clog.
• If the clog remains, call your child’s physician, or go to the nearest emergency room for assistance.

Causes
• The most common cause is inconsistent/inadequate flushing of the feeding tube.
• A bent or kinked feeding tube.
• Thick formulas.
• Medications.

Prevention
• Prevent clogged tubes by flushing your child’s tube before and after each feeding, and before and after administering medication.
• Be sure the tube is not kinked.
• Follow directions in this booklet for administering medications through feeding tubes.

Diarrhea
Diarrhea refers to frequent loose stools. After starting your child’s tube feedings, your child’s stools may become softer or looser. This may not necessarily be diarrhea.
Causes
• Medications.
• The feeding rate is too fast.
• The tube feeding formula is too cold, which can cause cramping.
• The formula is contaminated by bacteria.
• Malabsorption in your child’s intestines.
• Formula is too concentrated.

Prevention
• Infuse formula that is at room temperature.
• Do not exceed the recommended time formula is at room temperature.
• Adjust feeding schedule and formula. Talk to your child’s physician or your Apria Nutrition Support Dietitian about this first.
• Adjust or change medications (check with physician or pharmacist).
• If using a gravity bag, slow down the infusion rate by adjusting the roller clamp.
• If using a syringe feeding, reduce the amount of formula given at one time, or give the amount of formula more slowly.

Dehydration
Causes
• Too little water.
• Formula is too concentrated.
• Frequent diarrhea.
• Prolonged fever.
• A wound that is draining a large amount of fluid.

Prevention
• Give your child the prescribed amount of water each day. If you are not sure how much water needed, contact your Apria Nutrition Support Dietitian or your child’s physician for help.
• Consult your child’s physician and/or Apria Nutrition Support Dietitian and take additional water if your child has prolonged diarrhea, fever, or a draining wound.

Stomach upset/nausea/vomiting
It is possible to experience symptoms of nausea, vomiting, bloating, belching, and/or general stomach upset when tube feeding.
Causes
- The feeding rate is too high (feeding to fast).
- The formula is too concentrated.
- The tube feeding formula is too cold, which can cause cramping.
- Medications.
- Incorrect positioning.
- Tube dislodged.

Prevention
- If your child’s feeding rate is too high, try reducing the rate to the last comfortably tolerated rate.
- For syringe feeding, if you feel bloated at the time of feeding, wait an hour before giving your next feeding.
- If gravity feeding, use the roller clamp on the feeding bag to slow down the feeding rate.
- Try having your child rest an hour or so after the feedings, and avoid exercise after the feeding session.
- Try having your child sit upright in a chair or on the couch when feeding; do not lie flat. Always make sure your child’s head is raised 30 degrees, even if in bed.
- Adjust or change medications (check with physician or pharmacist).

Infection
Causes
- Not using a new gravity feeding bag each day.
- The feeding tube site has not been cleaned.
- Failure to wash hands before mixing the formula or touching the tubing.
- Formula was opened and sitting at room temperature or in feeding bag for greater than 8 hours for canned formula, or greater than 4 hours for powdered formula.
- Formula was opened and in the refrigerator for more than 24 hours.

Prevention
- Use a new gravity feeding bag each day.
- Wash your hands with soap and water before preparing formula or coming into contact with the tubing.
- Clean your child’s tube site daily as directed by your child’s physician.
- Make sure any unused open formula is discarded after 24 hours in the refrigerator.
• Do not allow the tube feeding formula to be at room temperature for more than the recommended time.
• If using a gravity feeding bag, infuse all of the formula in the feeding bag before adding more formula; rinse the bag with lukewarm water once all formula is infused; then add the fresh formula.

Skin irritation or bleeding around the tube

Causes
• Infrequent/inadequate cleaning.
• Irritation from tape or type of soap used for cleaning.
• Leakage of stomach liquids.
• Unhealed tissue where the tube enters the body.
• Infection.
• Pressure.

Prevention
• Clean around the tube and dry every day.
• Change type of soap used.
• Examine to see if bumper or external disc is too tight.
• Apply skin barrier cream or ointment, but only if directed by your child’s physician.

When to Call Your Child’s Physician

Call your healthcare team when your child has:
• Nausea, vomiting, or heartburn.
• Pain or unusual abdominal distention.
• Diarrhea.
• Constipation.
• Coughing or choking during tube feeding.
• Trouble breathing.
• Unintended weight loss.
• Decreased urine, mouth dryness, fever (100.4° F or higher), which could be signs of dehydration.
• Swelling, unusual drainage, soreness, or redness from the feeding tube site.
• Signs that the feeding tube is not in the right place.
• Frequent tube blockage. Also, call the physician if you cannot clear a clogged feeding tube.

In a medical emergency, call 911.
The information provided in this booklet should not replace any medical advice from your healthcare professional or the manufacturer’s product information, directions for use, and instructions.

**Mouth Care**

Even though your child is eating less or in some cases not consuming any foods by mouth, it is critical to maintain good mouth and dental care. Mouth bacteria are still present and will cause dental carries and tooth loss. Also, even if your child is very young and has his or her baby teeth, losing teeth prematurely can cause the permanent teeth to come in crooked. Proper care will help prevent damage to the teeth and gums and also establishes healthy brushing and oral hygiene habits for the future.

**Follow these steps for a healthy mouth and teeth:**

- Brush teeth 2 times a day with a soft toothbrush.
- Generally, the best position for brushing your child’s teeth is from behind while facing a mirror.
- Wipe the inside of the mouth with a damp washcloth, if your child does not have teeth yet.
- If your child’s lips get dry, try using lip balm.

Ask your dentist or dental hygienist what toothpaste or product he or she recommends.

**Information for School**

If your child requires feeding during the day while at school, the school nurse will need some basic information about your child’s feeding tube and feeding schedule. The school will need instruction forms that will need to be signed by either your primary care physician or your surgeon. A “School Tube Feeding Plan” form is shown on the next page. You may also want to discuss this with the school nurse to see if your school district requires any special/specific forms from them.
School Tube Feeding Plan

The caregiver should contact the school for the school’s specific guidance regarding school tube feeding plans.

Student’s Name: __________________________________________ Date: _____________

Formula Name: __________________________________________ Time: _____________

Formula Amount: ___________ Water Amount: ___________ Rate: ______________

Feeding Method: ___________________________ Rate: __________________________

Bolus/Syringe

Gravity

Feeding Position: ___________________________________________________________________________

Tube Type: □ NG □ NJ □ Gastrostomy / PEG / Low Profile □ Jejunostomy / PEJ / Low Profile

Tube Information: French Size: __________ cm / Length: __________ Balloon Volume: ______________

□ Confirm tube feeding placement. □ Clean tube site.

□ Check for residual contents. □ Unclog tube.

□ Replace tube if falls out.

(Note that if the tube is to be replaced by a school nurse, provide a replacement tube.)

Other Special Considerations: _______________________________________________________________

Physician Name

Address

Physician Signature

Phone
**Tube Feeding Traveling and Emergency Kits**

Preparing kits in the event of an emergency or for traveling is highly recommended. Use the information below as a guide.

- Plan on enough for 2 to 3 days’ worth of supplies for emergencies.
- If traveling, ensure enough supplies to last the length of your trip, including the time to get to and from your destination.

When traveling to another country, please contact TSA and if necessary, a U.S. embassy in regards to customs and any special procedures and/or forms required for your child’s tube feeding and medical health supplies (especially if your child requires a product that is not available in the country you are traveling to). Learn more online at TSA.gov.

The list that follows includes general guidelines and recommendations to help you get started. However, it is not all-inclusive, so talk to your healthcare team about anything else you may need.

**Supplies for your emergency and/or traveling kit**

- Formula.
- Water for tube flushing and overall hydration, medication, stoma care.
- Syringes for flushing/medication.
- Feeding supplies (tubing set, etc.).
- Container with cap for mixing and storing extra formula.
- Stoma care supplies you normally use.
- Hand sanitizer. (NOTE: do not use on stoma site or near nose of your child.)
- Backup tubes and accessory devices.
- Any other supplies you normally use.
- Remember to bring a letter from your child’s physician if you are carrying greater than 3 ounces of formula or have medical equipment, such as a feeding pump.
Patient Information

Patient’s Name________________________________________________________ Date of Birth ____________

To the parent or caregiver: The following pages can be used to record information that may be helpful for future reference by you and your healthcare team.

Important Contacts and Phone Numbers

Physician _____________________________________________________________ Phone ___________________________
Emergency Contact _________________________________________________ Phone ___________________________
Home Health Agency ________________________________________________ Phone ___________________________
Supplies/Equipment Company _________________________________ Phone (844) 260-1788
Apria Dietitian phone number __________________________________________

Home Tube Feeding Orders

The prescription provided by your child’s physician may be recorded in the section below.

Formula name ________________________________________________________________________________
Calories _________ Protein _________ Fiber _________ Fluid _________
Method:  □ Bolus (Syringe) Feeding  □ Gravity Feeding

Total volume per day (number of cans or mL volume per day): __________

Bolus/gravity/intermittent feeding: __________ mL/hour (number of cans or mL volume per feeding) at the following times:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Feeding tube flushed every ____ hours with water at the following times:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Special Instructions: ____________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Supply Information

Formula name ____________________________________________

FEEDING TUBE:
Type ______________________  Manufacturer _______________________  Size (French) _____

FEEDING CONTAINER:
Type ______________________  Manufacturer _______________________  Changed every _____ (hours/day)

TUBING NEEDED TO ATTACH TO FEEDING CONTAINER:
Type ______________________  Manufacturer _______________________  Changed every _____ (hours/day)

Daily Diary

The following pages include a Daily Diary for monitoring your child’s weight, formula and water intake, tube site condition and other information regarding your child’s tolerance to home tube feeding therapy.
Daily Diary

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Metric Conversion Table (Liquids)

| STANDARD: | 1 tablespoon | 1 fluid ounce | 1 cup | 1 quart |
| METRIC: | 15 mL | 30 mL | 240 mL | 960 mL |

(1 cc = 1 mL)
## Daily Diary

Month ________________________________

Formula Name _________________________

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Resources and Adjusting to Home Tube Feeding

The transition to home tube feeding does require some adjustment — for both you and your child. But you can do this and it gets easier as you both get familiar with the process.

Whether the feeding tube is needed only for a short time during medical treatment, or for a longer period based on a specific medical condition, Apria is dedicated to providing you and your family the highest quality clinical care and compassionate support. We are a good place to start to help answer questions, and you can find more resources listed below.

Some additional resources

Refresh Home Enteral Nutrition Support Program
Apria’s enteral nutrition support website provides a growing collections of patient and caregiver tube feeding resources. Go to Apria.com/Refresh to access these resources.

The Oley Foundation
www.oley.org • 800-776-6539
A national non-profit support group that has a variety of resources to help patients and families adjust to home tube feeding.

Enteral Feeding for Children
www.feedingtubeawareness.com
For parents and caregivers of children who are tube fed.

American Cancer Society
www.cancer.org

Complex Child
www.complexchild.com
Complex Child is a free monthly online newsletter written by parents of children with special healthcare needs and disabilities.

Stay Connected (GEDSA)
www.stayconnected.org
Patient safety with medical device tubing connectors.
Home Enteral Nutrition Support Program

See program details at apria.com/Refresh

Or call (844) 260-1788
to reach our Nutrition Support Specialists

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