CIRCLe

Children's Intestinal Rehabilitation Clinic *at Le Bonheur*

Care Notebook

Le Bonheur Children's Hospital
Methodist Healthcare Family

CIRCLe

Children's Intestinal Rehabilitation Clinic *at Le Bonheur*

NAME

DATE OF BIRTH

Care Notebook

Le Bonheur Children's Hospital

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What is CIRCLe?

CIRCLe stands for **Children's Intestinal Rehabilitation Clinic at Le Bonheur**. It is a specialized clinic for children with gastrointestinal issues leading to problems with nutrition. A child being seen at CIRCLe may have had some part of his or her gut surgically removed, may receive nutrition through a vein catheter, or may receive formula through a feeding tube.

What is a Care Notebook?

A **Care Notebook** will help you care for your child with special health care needs. It will help you keep track of information about health care, particularly as he or she if being followed by CIRCLe. This Care Notebook is very personal and you can customize it to show your child's medical history. It should be updated often to contain the correct information. Make sure that you updated the following regularly:

- Medications
- Any new information on treatment
- Contact numbers for providers
- Appointment visits

Store the Care Notebook where it is easy to find. Keep in a place that other members of the family have access to. Take the Care Notebook to all appointments and hospital visits. When your child is old enough, involve them in organizing their Care Notebook so that they can learn about their own medical history and play an active role in their care.

How do I begin to use the CIRCLe Care Notebook?

Step 1: Gather all the information that you already have. These include previous discharge summaries, immunization and medication records, laboratory results, etc.

Step 2: Review the pages of the Care Notebook. Choose which pages will be most helpful to you to keep track of information. You can use the notebook as it is, add or remove pages.

Step 3: Decide which information is most essential and assemble your Care Notebook. Your Care Notebook will come in a 3-ring binder to hold papers secure. You can use tabbed dividers, pocket dividers and plastic pages to keep things organized and clear.

All About Me

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Me and My Family

Child's Name: _____ Nickname: _____

Date of Birth: _____ Social Security Number: _____

Diagnosis: _____

Blood Type: _____

Legal Guardian: _____

Address: _____

City: _____ State: _____ Zip Code: _____

FAMILY MEMBERS

Mother's Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Daytime Phone: _____ Evening Phone: _____

Father's Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Daytime Phone: _____ Evening Phone: _____

Sibling's Name: _____ Age: _____

Sibling's Name: _____ Age: _____

Sibling's Name: _____ Age: _____

Sibling's Name: _____ Age: _____

Other Household members: _____

Important family information: _____

Languages Spoken at home: _____

Interpreter needed? (Yes/No) _____

FAMILY EMERGENCY CONTACTS

Name: _____

Address: _____

City: _____ **State:** _____ **Zip Code:** _____

Daytime Phone: _____ **Evening Phone:** _____

Name: _____

Address: _____

City: _____ **State:** _____ **Zip Code:** _____

Daytime Phone: _____ **Evening Phone:** _____

OTHER IMPORTANT INFORMATION

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

My Health Information

Child's Name: _____

Insurance Company: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Telephone: _____

Name of Contact Person: _____

Insurance contact person at place of employment: _____

Telephone: _____

Name of Employer: _____

Address of Employer: _____

Name of Insured: _____

Policy Number: _____ **Group Number:** _____

Policy Effective Date: _____

Is this policy the ❑ primary or ❑ secondary policy for payment for your child's medical bills?

How much is your deductible? _____

HOW MUCH IS COVERED FOR THE FOLLOWING SERVICES?

Doctor's office visits: _____

Doctor's Hospital visits: _____

Emergency room care: _____

Hospitalizations: _____

Surgeries: _____

Outpatient hospital care: _____

Durable medical equipment: _____

Orthotic/prosthetic devices: _____

Medical Supplies: _____

Prescribed medications: _____

Home care: _____

Skilled Nursing Care: _____

Therapy

Speech: _____

Physical: _____

Occupational: _____

Respiratory: _____

Other: _____

Diagnostic Tests

Laboratory: _____

X-ray: _____

Other: _____

Ambulance service: _____

Dental care: _____

Mental Health Services

Inpatient: _____

Outpatient: _____

What services are excluded from coverage? _____

_____

My Health Care Providers

Primary Medical Provider: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Preferred Hospital: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Specialty Hospital: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Specialist Name: _____

Clinic/Hospital: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Specialist Name: _____

Clinic/Hospital: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Specialist Name: _____

Clinic/Hospital: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Specialist Name: _____

Clinic/Hospital: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Specialist Name: _____

Clinic/Hospital: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Social Worker: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Home Health Agency: _____

Start Date: _____ **End Date:** _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Home Health Agency: _____

Start Date: _____ **End Date:** _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Home Health Agency: _____

Start Date: _____ **End Date:** _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Pharmacy: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Hours:** _____

Pharmacy: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Hours:** _____

Pharmacy: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Hours:** _____

Physical Therapist: _____

Start Date: _____ **End Date:** _____

Agency: _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Occupational Therapist: _____

Start Date: _____ **End Date:** _____

Agency: _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Speech Therapist: _____

Start Date: _____ **End Date:** _____

Agency: _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Other Therapist: _____

Start Date: _____ **End Date:** _____

Agency: _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Respite Care Provider: _____

Agency: _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Respite Care Provider: _____

Agency: _____

Contact Person: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Email:** _____

Equipment & Supplies

Type of Equipment/Supplies	Prescribed by	Reason Prescribed	Date Started	Date Ended	Response	Vendor	Equipment Problems

My Medications

Medication Name	Prescribed by	Reason Prescribed	Date Started	Date Ended	Pharmacy	Notes

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My One of a Kind Gut

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Intestinal Failure

The body has an entire system that is designed to digest food and absorb the nutrition our body needs. This is the digestive system sometimes called the gastrointestinal or GI tract. Sometimes this is even simplified more and called the "gut". To do its job the GI tract has many different organs and lots of separate jobs that are involved in turning food into nutrition. The simplest way to think about intestinal failure is that the GI tract is not able to do enough of its tasks that a person can get all of the nutrition they need from a normal diet.

The most common reason persons have intestinal failure is short bowel syndrome. For some reason, the bowel does not have the full length it normally does. There are many diseases that lead to short bowel syndrome. Also, the part and amount of GI tract missing effects how bad the person's intestinal failure is.

Some persons have a normal length of bowel but there is another problem with how the GI tract works. For the digestion to take place, the food has to be "pushed" through the bowel. This squeezing through the GI tract is medically called peristalsis. This is also referred to motility. If the nutrition just sits in the GI tract it cannot be digested or absorbed like normal.

Another problem that leads to intestinal failure is an absorption problem. The cells that line the GI tract are designed to take up the digested food and then put them into the blood stream. This involves a whole lot of pathways for different nutrients. When one of the pathways doesn't work right, then that type of nutrient will not be absorbed. Sometimes there is a problem with the lining cells themselves, they don't form right or get to the surface of gut.

Symptoms of Intestinal Failure:

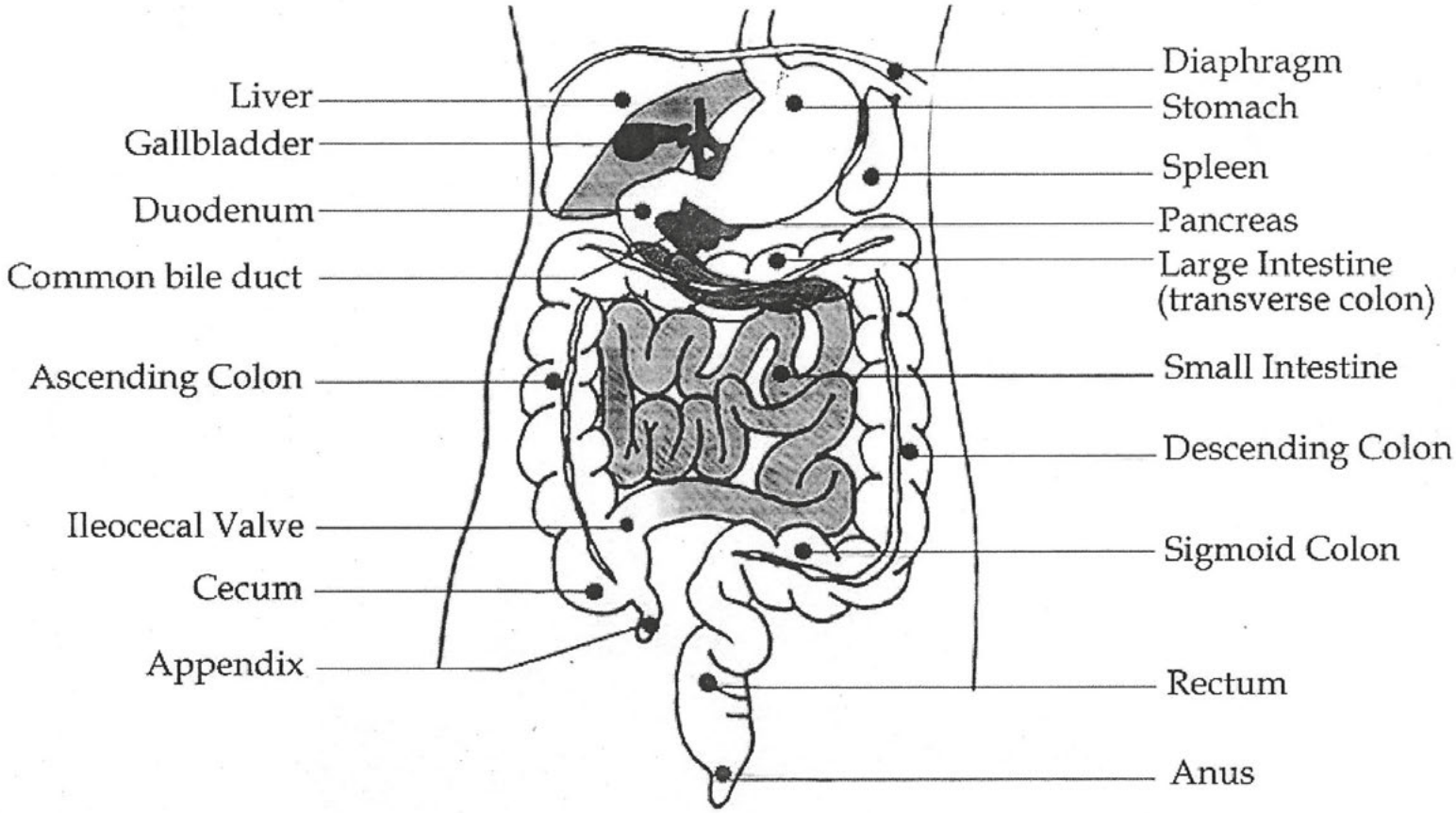
- Diarrhea
- Water and salt problems
- Malnutrition
- Poor growth
- Vitamin and mineral deficiencies

Gastrointestinal Tract Anatomy

My Diagnosis: _____

_____

A Healthcare Provider will use this drawing to explain your child's surgery.



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My CIRCLe Team

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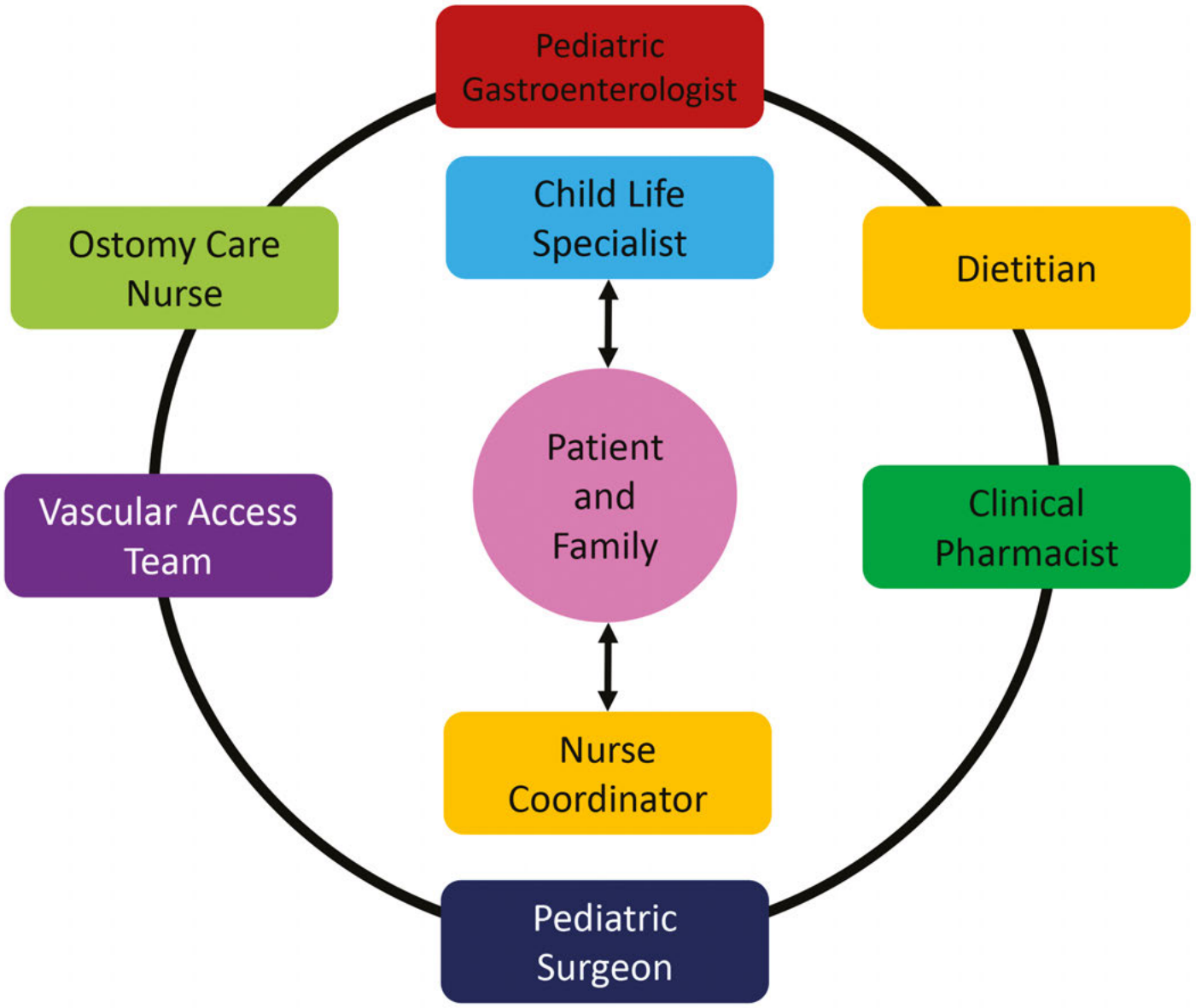
CIRCLe Clinic Structure



Get to know the CIRCLe Team!

Every parent hopes that their child grows well – and your child is no exception. Although your child has challenges, it is the goal of the CIRCLe team to make sure that we are closely monitoring his physical growth while making sure that he is receiving adequate nutrition. The CIRCLe team is composed of professionals from different but related fields. All these individuals work together to bring their expertise and experience in gastroenterology and nutrition, creating a personalized nutrition care plan that is as unique as your own child.

Pediatric Surgery

Pediatric surgeons are specially trained to perform surgery for a wide variety of conditions that may affect infants and children, including intestinal atresia, gastroschisis, necrotizing enterocolitis, and many other problems. For patients with missing or damaged intestine, which can happen before or after birth, pediatric surgeons may remove, reconnect, or modify the intestine to improve or allow feeding. We sometimes place tubes in the stomach or intestine to assist with feeding.

Pediatric Gastroenterology

A pediatric gastroenterologist is a pediatrician who completed further training for the treatment of conditions of the gastrointestinal tract of children. These include diseases of the stomach, small and large intestine, liver, gall bladder and pancreas. Closely related to this is the management of nutrition in children. As part of the team, the pediatric gastroenterologist assures that we are meeting the goals for growth. Pediatric gastroenterologists are able to use their knowledge of how the gastrointestinal tract works in order to maximize medical therapy.

Pediatric Dietitians

Pediatric dietitians are trained in assessing nutrient needs and growth of infants and children and making recommendations on advancement of formula feedings, table foods and adjustment of intravenous feedings. In intestinal rehabilitation, the dietitian works to help maximize intestinal adaptation by adjusting nutrient complexity as well as rate and volume of formula feedings. The intestinal rehabilitation dietitian also works with families to provide appropriate table foods and drinks to help the child grow and prevent excessive stooling.

Clinical Pharmacists

The clinical pharmacists on the CIRCLe Team are primarily responsible for managing your child's parenteral nutrition therapy, which is most commonly called PN or TPN (for total parenteral nutrition). In addition, the clinical pharmacists continually review your child's medication regimen to make sure the medicine is appropriate and effective with only minimal side effects.

Parenteral nutrition is lifesaving for many patients with intestinal failure but it is also a complex prescription that can result in complications in patients. The clinical pharmacists on the CIRCLe team have specialized knowledge and training in the area of parenteral nutrition therapy in infants and children. Together with the team, the pharmacists make sure that

your child's PN is correct and accurate. They coordinate with your home infusion company to make sure your orders and supply are complete and up to date. The clinical pharmacists also make sure that complications associated with parenteral nutrition are minimized whenever possible. They are often advocates for therapies that decrease risk for complications of parenteral nutrition, such as ethanol lock therapy to decrease central line infections.

Intestinal Failure Clinic Coordinator

As the title says, the coordinator's goal is to help coordinate the provision of care to your child once discharged from the hospital. The coordinator communicates with home care providers, receives information from those providers to share with the members of the CIRCLe Team, and trouble shoots problem that become barriers to your ability to care for your child at home. The coordinator is an advocate for you to obtain what is needed to care for your child at home. The coordinator meets with families well before their planned discharge and schedules follow up appointments when your child is ready to go home.

Child Life

Child Life Specialists are trained professionals who help to reduce stress and anxiety for children and families in the hospital setting. Armed with a strong background in child development and family systems, child life specialists address the psychosocial needs of children and families facing difficulties regarding hospitalization, illness, and painful, stressful, or traumatic events. Patients in the CIRCLe clinic have faced a variety of stressors due to lengthy hospital admissions, extensive treatments, and recurrent clinic visits. The child life specialist promotes positive coping and provides normalization to patients and families coming to CIRCLE clinic through play, procedural support, and emotional support. The goal is to meet patients and families where they are, providing comfort and support throughout their medical journey.

Wound, Ostomy and Continence Nurse

The role of a Wound, Ostomy and Continence (WOC) nurse is to provide consultation services and/or care for the patient population with wounds, ostomies or those with conditions contributing to continence issues, such as Spina Bifida. In addition, the WOC nurse also assists in the management, care and education of newly placed gastrostomy tubes. The wound care nurse works with families and physicians on an inpatient and outpatient basis, working in a collaborative fashion to provide education, treatments and referrals to and for families with the intent of the best patient outcomes.

Vascular Access Team

The role of the Vascular Access Team is to provide care and teaching for your child's central line. The team teaches dressing change technique and home care for your child's central line after it is placed in the hospital. The Vascular Access Team serves as a resource at the outpatient CIRCLe clinic as well so questions can be answered during clinic visits regarding the central line. We coordinate care with the rest of the CIRCLe team to ensure that your child's central access is maintained.

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My Gut Nutrition

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Enteral Nutrition

What is Enteral Nutrition?

- Enteral nutrition refers to the formula given to your child through his or her g-tube or the formula taken by bottle.
- The formula your child receives has the essential nutrients he or she needs to grow and helps the intestines to adapt.
- Pre-digested and hypoallergenic formulas are often used because they help to improve absorption of the nutrients.
- These formulas are often given slowly with a feeding pump. Dripping the formula in slowly gives the intestine more time to absorb nutrients.

Tell Me More About Formula

- In the beginning, the formula your child is prescribed will need to be prepared using formula powder and water. The dietitian will give you instructions and education on preparing the formula your child needs.
- The CIRCLe team may change the recipe of your child's formula based on your child's growth and how well he or she is tolerating their feedings. The dietitian will give you instructions each time the formula recipe is changed
- It is very important to follow the directions exactly, as any change will affect the nutrients your child receives.

What About Table Foods?

- The CIRCLe team will discuss with you when it is a good time to introduce solid foods. The dietitian will provide you with handouts on which foods to introduce first. As your child grows and starts eating more food, the dietitian will provide you with more information about which foods will help your child and which foods should be avoided.
- Avoiding certain foods will help your child achieve their optimal growth and help prevent diarrhea and dehydration.
- It is important to start building good habits from the very beginning. Once a food is introduced, it is more difficult to take it away. As your child gets older, and sees you eating foods he or she is not allowed, they may get upset and may find and eat these foods when you are not around. If the whole family can make these changes together, it will help your child to succeed

Feeding Tubes

A feeding tube is a medical device used to help children get the nutrition and hydration that they need to grow and develop. It may be short term or long term depending on the needs of your child. Whether the need is short term or long term will help determine the kind of tube your child will have.

In most cases, for short term use a nasogastric (NG) tube is placed. This feeding tube is inserted through the nose, runs down the esophagus and into the stomach. It is taped to the cheek to keep it in place. It is checked before each feeding to assure it is in the correct place (stomach). The NG tube can be placed by a trained nurse at the bedside and no sedation is necessary. An NG tube can stay in place for 6-12 weeks. Most NG tubes used for feeding are made of soft plastic.

For longer term needs, a gastrostomy tube (G-tube) is placed surgically through the abdominal wall into the stomach. When not being used for a feeding it is closed or clamped. Take note of the physician that placed your child's feeding tube. This will help with surgical care in the future.

For some patients who have persistent vomiting or poor stomach function another type of feeding tube may be helpful. It is a gastrojejunal tube (GJ-tube). A GJ tube is surgically placed through the abdominal wall into the stomach. A smaller tube is threaded into the jejunum, a portion of the small intestine. The GJ tube has an opening called the J port than is used for feeding into the jejunum and certain medications. Feeding straight into the small intestine through the J port can help relieve some of the difficulty that the stomach may be experiencing. A second opening in the GJ tube is the G port that can be used for venting of air from the stomach or giving medications into the stomach.

The site where the G-tube or GJ tube is inserted into the stomach is called a stoma. You will be taught how to care for the new stoma by the ostomy care nurses. There are regular weekly classes provided by the ostomy care nurses. Make sure you and other potential care givers for your child attend this session.

Feedings may be given over a short amount of time, usually less than 30 minutes, and are called bolus feedings. Or the feeding may be given continuously with a pump that provides a continuous rate over a given number of hours. The exact plan for feeding is different for each child. The dietitian following your child will plan his or her feeding regimen that will suit his needs and his feeding capacity.

Remember, your child's gastrointestinal tract may have issues at this time, but the ultimate goal is to allow your child to eat regularly. The journey to this goal is different for every child. Always communicate with the CIRCLe team your concerns. At each follow-up clinic visit with the CIRCLe team, your child's stoma site will be examined and the ostomy care nurses will be called in if there are issues.

Nutrition

Date	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Tube feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

Sugar & Short Bowel Syndrome

Sugar

- Sugar and sugar alcohols increase diarrhea in children with short bowel syndrome. When food goes through the body that quickly, the body is not able to use the nutrients for growth.

- Because of this, eating a lot of sugar can prevent children with short bowel syndrome from being able to decrease the amount of time on parenteral nutrition or tube feedings

- It can be hard for children not to eat the same foods that they see other people eating, so it is important that the whole family try to decrease their sugar intake too.

Sugar Free Foods

- Sugar alcohols are added to foods to make them “Sugar Free” however they can cause bloating and diarrhea.

- Common sugar alcohols include mannitol, sorbitol, xylitol, lactitol, isomalt, maltitol and hydrogenated starch hydrolysates (HSH)

- It is best for your child with short bowel syndrome to stay away from sugar alcohols. Eating foods with sugar alcohols can cause diarrhea which will prevent the child from absorbing all of the nutrients and growing.

Solid Foods During the First Year with Short Bowel Syndrome (without colon)

Age	Food	Portion Size	Times Per Day	Feeding Tips
4-6 Months	-Baby food meats (beef, chicken, turkey)	1-2 Tablespoons	2	Start baby food meats by spoon when baby shows these signs of readiness: -Sits with support -opens mouth when food is offered
6-8 Months	-First introduce baby food green beans (which have natural pectin to help slow down stools) -Followed by baby food carrots, squash -After trying all of the above foods, then introduce baby food bananas -After trying single ingredient baby foods, may offer: vegetable beef, chicken vegetable, turkey vegetable -After trying a food, may add butter for extra calories	2-3 Tablespoons	2	-Every food offered should be blended/mashed to prevent choking. -Add only one new food at a time and wait at least 3 days before starting another. Watch for any negative reactions like increased diarrhea or vomiting -It may take multiple introductions (10-15 times) of certain foods before your baby accepts them.
8-12 Months	-Mozzarella or cheddar cheese in bite-sized portions -Plain yogurt -Fresh, well cooked vegetables (with added butter) and fruits in baby bite-sized portions (avocado, carrots, mashed potatoes, bananas) -Unflavored teething biscuits -Puffs -Plain Cheerios -Rice Chex cereal	3-4 Tablespoons	2	-Let baby self feed with fingers or spoon. Be patient. Babies can be messy when feeding themselves. -Taste heated foods before feeding to make sure they are not too hot

- Signs baby is full: Closes mouth, pushes food away or shakes head no
- Baby may try small amounts of these foods with caution (these foods may cause increased diarrhea or gas):
  - Sweet potatoes, peas
  - Applesauce, pears, peaches, plums/prunes
- Foods to stay away from (these foods have too much sugar and can increase diarrhea):
  - Raisins and other dried fruits
  - Fruit snacks
  - Yogurt melts
  - Juice

Solid Foods During the First Year with Short Bowel Syndrome (with colon)

Age	Food	Portion Size	Times Per Day	Feeding Tips
4-6 Months	- First introduce baby food green beans (which have natural pectin to help slow down stools)	1-2 Tablespoons	2	Start baby foods by spoon when baby shows these signs of readiness: -Sits with support -opens mouth when food is offered
6-8 Months	-Baby food meats (beef, chicken, turkey) -Baby food carrots, squash -After trying all of the above foods, then introduce baby food bananas -After trying single ingredient baby foods, may offer combinations such as vegetable beef, chicken vegetable, turkey vegetable	2-3 Tablespoons	2	-Every food offered should be blended/mashed to prevent choking. -Add only one new food at a time and wait at least 3 days before starting another. Watch for any negative reactions like increased diarrhea or vomiting -It may take multiple introductions (10-15 times) of certain foods before your baby accepts them.
8-12 Months	-Plain yogurt -Fresh, well cooked vegetables and fruits in baby bite-sized portions (carrots, mashed potatoes, bananas) -Unflavored teething biscuits -Puffs -Plain cheerios -Rice Chex cereal	3-4 Tablespoons	2	-Let baby self feed with fingers or spoon. Be patient. Babies can be messy when feeding themselves. -Taste heated foods before feeding to make sure they are not too hot

- Signs baby is full: Closes mouth, pushes food away or shakes head no
- Baby may try small amounts of these foods with caution (these foods may cause increased diarrhea or gas):
  - Sweet potatoes, peas
  - Applesauce, pears, peaches, plums/prunes
- Foods to stay away from (these foods have too much sugar and can increase diarrhea):
  - Raisins and other dried fruits
  - Fruit snacks
  - Yogurt melts
  - Juice
- If baby is also missing his or her ileum, you may be at higher risk to form kidney stones and should avoid foods high in oxalates such as:
  - Chocolate, beets, collard greens, spinach, tomatoes, sweet potatoes

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My IV Nutrition

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Parenteral Nutrition Primer

Parenteral nutrition is a form of feeding through a person's veins when they cannot take adequate amount of food by mouth or through their intestine. The nutrition is in the form of a sterile fluid that contains sugars, proteins, fats and vitamins. The mixture is designed to give a child the correct amounts of each component so that they will grow and develop as they would with regular food. The parenteral nutrition is placed through a vein that is large enough to take the nutrition and fluids. Sometimes this is a temporary way to give nutrition, but some children need special intravenous catheters that are designed for long term use. In cases of intestinal failure, these catheters are needed because these patients are dependent on parenteral nutrition for all or most of their nutrition. The goal is to help these children to eventually be able to feed by mouth and stop the parenteral nutrition. In some cases, children may need this form of nutrition for long periods of time – it may be months or years. Some children may get part of their nutrition through their intestines and the rest as parenteral nutrition because they cannot grow and develop without the additional intravenous nutrition.

The formulation of parenteral nutrition is designed for each individual child. Your child will have his special formulation depending on his or her current nutrition and hydration needs. The formulation is planned with the pediatric gastroenterology, dietitian and clinical pharmacist with your child in mind. If your child needs long term parenteral nutrition, blood will be drawn from your child on regular basis to monitor specific electrolytes and nutrients. This is done to ensure that we are providing what is needed. The parenteral nutrition that will be given when your child goes home will be provided by a company known as an infusion company. Depending on your insurance coverage and home location, you will be assigned a company that will deliver the parenteral nutrition bags to your home. The special orders to have your child's parenteral nutrition made will be prescribed by the CIRCLe clinic. Please follow the specific instructions for storage and taken note of the expiration or "use by" dates.

If you have questions or concerns with regards to your child's parenteral nutrition, all questions can be received by the CIRCLe clinic coordinator.

Central Venous Catheters

If your child needs parenteral nutrition at home, it is likely that he or she will be discharged with a central venous catheter. A central venous catheter is a soft, flexible tube that is inserted into a large vein that is close to and leads to the heart. The central venous catheter is placed either by the Interventional Radiology physician or the pediatric surgeon. Take note of the name of the physician who placed your child's central venous catheter. This will help with future care of the catheter.

You will hear other names to refer to your child's central venous catheter: central line, Broviac and Hickman. The last two names are actually registered brands of central venous catheters. These catheters are made of specially processed silicone and can be seen on x-ray (also termed as "radiopaque"). In small infants and children, the Broviac catheter is often used because it is smaller.

The central venous catheter is used to give parenteral nutrition, medications and it can be used to take blood. It can stay in for as short as a few weeks or in some cases, years. The length of time depends on your child's needs. There are certain situations when a central venous catheter has to be removed and replaced. These include physical damage to the catheter, evidence of infection, or blockage of the catheter.

Before discharge from the hospital, the Vascular Access Team and the inpatient nursing staff will provide you and other care givers with the necessary teaching to take care of the central venous catheter at home. Make sure to ask all the questions you may have. We have experienced that meticulous care at home helps keep the central venous catheter clean and functioning well. This will help avoid problems in the future as urgent visits to the emergency room and catheter infections.

Central Line Action Plan

Name: _____

Emergency contact for central line issues:

Name: _____ **Phone Number:** _____

Home care company contact:

Name: _____ **Phone Number:** _____

Type of central line	Catheter Size	Location	Date Inserted

Group 1: Catheter Issues			
Alert Level	Possible problem	Action Items	Prevention
Green Zone			
□ Inability to flush central line □ No blood return prior to flushing □ Inability to infuse; pump alarm indicating blockage	Blockage or clot in catheter	□ **Call home care nurse if you cannot flush the line at home.** □ **May need to go to hospital to dissolve clot.**	□ Flush with clamp open □ Flush gently □ Follow strict procedures for flushing. □ Keep clamp closed when not infusing
Yellow Zone			
□ Catheter partially pulled out; cuff may be showing	Central line displacement	□ Cover line and tape in place. □ Call home health nurse for further instructions	□ Be careful when removing clothing. □ Keep child from pulling on his/her line
□ Changes in the appearance of the catheter: bulging, puffiness, swelling □ Moisture or wetness under the dressing □ Obvious hole or tear in the catheter	Central line damage	□ Place a clamp between area of damage and insertion site, if possible. □ **Call home care nurse. May need to go to hospital to repair line.**	□ Flush gently during regular use. □ Keep sharp objects away from central line. □ Do not clamp line anywhere but in the **"clamp here"** region. □ Always keep central line secure and protected.
Red Zone			
□ Catheter completely pulled out	Central line removal	□ Apply pressure to insertion site for 10 minutes. □ **Call home care nurse.**	□ Be careful when removing clothing.

Group 2: Patient Issues			
Alert Level	Possible problem	Action Items	Prevention
Green Zone			
□ Irritation or redness of skin under dressing	Mild infection at exit site	□ Take temperature □ **Call home care nurse/ physician if there is fever.**	□ Always wash hands before handling the central line. □ Always keep dressing clean. □ Scrub the hub prior to using the central line. □ Know details about changes in dressing supplies (specific brand used, type, etc.)
Yellow Zone			
□ Bleeding at the insertion site	Possible central line displacement or irritation during handling	□ Change dressing. Can apply gauze pressure dressing. □ **Call home care nurse for further instructions for care or if there is concern for displacement.**	□ Monitor dressing regularly. □ Secure central line tubing to avoid tugging or pulling.
□ Pus from insertion site	Infection at insertion site	□Take temperature □ **Call home care nurse/ physician for possible infection.**	□ Always wash hands before handling the central line. □ Always scrub the hub with alcohol prior to using the central line. □ Ensure that regular endcap changes are done. □ Always keep dressing clean.
Red Zone			
□ Fever, chills, sleepiness, dizziness, shakiness	Bloodstream infection	□ Take temperature □ **Call home care nurse/ physician for possible infection.**	□ Always wash hands before handling the central line. □ Always scrub the hub with alcohol prior to using the central line. □ Ensure that regular endcap changes are done. □ Always keep dressing clean.

□ Chest pain, coughing, difficulty of breathing	Air in blood stream or air embolus	□ **Clamp central line** □ **Have patient lay on left side** □ **Call 911 for breathing problems**	□ Protect central line from sharp objects. □ Secure and dress line properly. □ Keep end of central line capped. □ Make sure there are no air bubbles from syringes when flushing.
□ Rashes, hives, itching, wheezing or trouble breathing	Allergic reaction	□ **Stop infusion.** □ **Call 911 for breathing problems.**	□ Keep updated list of allergies and update all health care providers.

Using Ethanol Locks

***Always thoroughly WASH YOUR HANDS with soap and water to prevent infection. Sing the "Happy Birthday" or the "ABCs" while washing the hands – the amount of time it takes for the song to complete is the amount of time you need to lather your hands with soap. Dry your hands with a clean paper towel. Do not use a hand towel. Once your hands have been washed, you can then start the steps below. ***

1. ETHANOL LOCK THERAPY in CVL (CVAD)

- Gather supplies
- Wash hands – see instructions above
- When TPN Infusion completed, Clamp CVL
- Disconnect tubing
- SCRUB the Hub for at least 10-15 seconds, unclamp the line
- FLUSH with 5-10 ml normal saline (sodium chloride)
- Scrub the hub again with alcohol
- INSTILL ethanol (amount as prescribed) into line and clamp line.
- When ethanol lock time has finished **(no more than 12 hours), ALWAYS thoroughly** flush ETHANOL through line with 5-10 mls normal saline prior to reconnection for TPN or if heparinizing CVL

Remember: ETHANOL and HEPARIN are NOT compatible so cannot be in the line at same time.

2. HEPARINIZE CVL (CVAD)

- Gather supplies
- Wash hands – seen instructions above
- After TPN infusion completed, clamp line and disconnect tubing
- Scrub the Hub with alcohol wipe for at least 10-15 seconds.
- Unclamp line.
- FLUSH with 5-10 mls normal saline (sodium choride)
- Scrub the hub again with alcohol
- Flush with 3-5 mls HEPARIN.
- Clamp line at the end of the flush while still flushing (prevents blood from backing up in line).
- Scrub the hub
- Flush CVL with 5-10 mls normal saline (sodium chloride) before reconnection to TPN or **Flush Thoroughly** with Saline prior to Ethanol Lock.

CIRCLe

Children's Intestinal Rehabilitation Clinic *at Le Bonheur*

Care Notebook

Resources

Le Bonheur Children's Hospital

Methodist Healthcare Family

CIRCLe

Children's Intestinal Rehabilitation Clinic *at Le Bonheur*

Care Notebook

My Schedule

Le Bonheur Children's Hospital

Methodist Healthcare Family

CIRCLe Patient Resources

Oley Foundation
http://www.oley.org/

- Resources for both feeding tubes and parenteral nutrition
- Contents for adults and children
- Great source for patient advocates and support groups

Feeding Tube Awareness
http://www.feedingtubeawareness.com/

- Great group for parents of children with feeding tubes
- Formed by parents for parents
- Also with a strong Facebook page: **https://www.facebook.com/FeedingTubeAwareness**

The Feeding Pump Calculator
http://www.feedingpumpcalculator.bravesites.com/

- Android app that can aid in programming a feeding app

Airline Travel Tips

Airline Travel Tips traveling with TPN/Lipids or enteral formula

- No medical documentation is needed for medical fluids/pumps to go through security.
- Call **TSA Cares** at **866-289-9673**, or **855-787-2227**, at least **72 hours prior** to travel.
- Request help for airport screening.
- Provide information on travel arrangement such as:
  - Departing airport
  - Airline
  - Dates
  - Departure times
  - Destination
- At the airport, request a **Passenger Support Specialist** or **Security Supervisor (TSA)** for help with going through TSA Security.
- Once Airline is chosen it would be advisable to check with the airline regarding any requirements/limitations with the cooler needed for TPN/Lipids/formula.

Driving Directions
To Le Bonheur Children's Hospital Main Campus

From East:
- Take I-40 East into Memphis.
- Take the US-51/Danny Thomas Blvd., Exit 1B.
- Go STRAIGHT until the exit ramp dead ends.
- Turn RIGHT on Alabama Ave.
- Turn LEFT onto Danny Thomas Blvd.
- At the first stoplight, turn LEFT onto Poplar Ave.
- The Le Bonheur campus will be on your RIGHT.

From West:
- Take I-40 West toward Memphis.
- Merge onto Sam Cooper Blvd.
- At the end of Sam Cooper Blvd., turn LEFT onto East Pkwy.
- Take the first RIGHT on Poplar Ave.
- Continue on Poplar Ave.
- Turn LEFT at the 12th stoplight onto Dunlap St.
- The Le Bonheur campus will be on your LEFT.

From South:
- Take I-55 North into Memphis.
- Merge onto I-240 West, Exit 6B.
- Take Exit 30, Union Ave. West.
- Turn slight RIGHT onto Union Ave.
- Turn RIGHT onto Dunlap St.
- After the third stoplight, the Le Bonheur main hospital will be on the RIGHT, and the Outpatient Center will be on the LEFT.

From North:
- Take US-51 South into Memphis.
- US-51 will become Danny Thomas Blvd.
- Continue on Danny Thomas Blvd. until you reach Poplar Ave.
- Turn LEFT on Poplar Ave.
- The Le Bonheur campus will be on your RIGHT.

Hospital
848 Adams Avenue

Entrance open 24 hours a day. Short-term parking for hospital visitors in the lot at 848 Adams. Long-term parking in Outpatient Center garage at 130 N. Manassas St. Handicap parking available in lot and garage.

Outpatient Center
51 N. Dunlap Street

When visiting a clinic in the Outpatient Center, park in the garage at 130 N. Manassas St. Follow signs from the garage to the Outpatient Center. A patient drop-off area and entrance to the building are located on Dunlap St. Handicap parking is available on each floor of the garage.

Children's Foundation Research Institute
50 N. Dunlap Street

When visiting the Research Center, park in the garage at 130 N. Manassas St. Follow signs from the garage to the Outpatient Center. Go to the Ground Floor and follow the tunnel to the Research Center.

Emergency Department
Corner of Poplar Avenue and N. Pauline Street

Parking only for families using Emergency Service. Park in the lot at the southwest corner of Poplar Avenue and N. Pauline Street. Handicap parking is available.

You may request a security officer to escort you to or from your car by calling **Le Bonheur Security** at **901-287-6017**.

Appointment Log

Doctor	Appointment Date, Time & Location	Things to Discuss and Ask at Appointment

Questions for Parents

These are questions the Care Providers in CIRCLe Clinic will be asking at each visit to help assess how your child is progressing and understand any concerns you might have:

Any concern or problem you would like to talk about today to any of the care team? _____

_____

_____

Any recent Hospitalization or surgery? _____

Recent illness? _____

Vomiting? _____

Number of stools a day? _____

Feedings:

Formula (Name and Calories) _____

How much? _____ How often? _____

Other food? _____

Any change? _____

How is he/she tolerating formula or diet? _____

If your Child is On TPN:

TPN: Start time: _____ Stop time: _____

Do you do Blood sugar test? _____ If so, how often? _____

Are the numbers usually about the same? _____

Do you use Ethanol locks in the catheter? _____ How often? _____

Do you flush through or pull back the ethanol lock? _____

Any new medicine your child has been given by other doctors? _____

_____

_____

Make-A-Calendar

Month: _____ **Year:** _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Name: _____ **Date of Birth:** _____

CIRCLe

Children's Intestinal Rehabilitation Clinic *at Le Bonheur*

Care Notebook

Le Bonheur Children's Hospital

Methodist Healthcare Family

Additional Information

Nutrition Guidelines for Children with Short Bowel Syndrome

The type of food eaten and the way these foods are eaten is important because it will affect nutrient absorption and help prevent excessive diarrhea.

Eat 6-8 small meals each day. This will result in better digestion and absorption and help decrease symptoms of gas, cramps, diarrhea, fluid loss and weight loss.

Limit fluids to about 4 ounces during each meal. Drinking large amounts of fluids with meals pushes food through the bowel faster, which means nutrients may not be absorbed. Make sure to drink most fluids in between meals.

Foods to Focus on	**Foods to Limit**
• Baked, grilled or broiled meats such as fish, chicken, turkey, beef, pork • Eggs, tofu, peanut butter, almond butter, cashew butter • Start with small portions of dairy products, as dairy can sometimes cause bloating and gas	• Fried meats • High fat meats such as hot dogs, bologna, sausage and bacon
Complex carbohydrates such as: • Pasta, potatoes, whole wheat breads, unsweetened cereals, whole grains 	Simple Carbohydrates such as: • Candy, cookies, cakes, ice cream, sugary breakfast cereals, donuts, jelly, syrup
Soluble Fiber such as: • Oatmeal, barley, nut butters (for example: peanut butter, almond butter etc), fruit • The following may cause gas. Start with small portions to test tolerance: chickpeas, lima beans, kidney beans, lentils	Low carbohydrate foods that contain sugar alcohols such as sorbitol and manitol instead of sugar (for example, sugar free candy, gum and desserts)
Beverages such as: • Water, low fat milk, Pedialyte, Gatorade G2/Powerade Zero, flavored water, diet sodas, unsweetened tea	Sugary Beverages such as: • Regular soda, Koolaid, juices, sweet tea

Foods to Focus on	Foods to Limit
Well-cooked vegetables such as:  • Carrots, green beans, spinach, beets, potatoes (without skin), asparagus tips, lettuce, cucumbers (without skin or seeds), tomato sauce and tomatoes (without skin or seeds), squash (without skin or seeds)	• Raw vegetables • Onions, cauliflower, broccoli, cabbage, brussel sprouts, corn, kale, peas
Fruits  • Bananas, oranges, • The following fruits may cause diarrhea. Start with small portions to test tolerance: prunes, pears, nectarines, peaches, plums, apples	• Dried fruits, fruit skins, peels and seeds
Healthy Fats • olive oil, canola oil, nuts, avocado	• Limit fried foods, limit added butter, mayonnaise, salad dressings, chips • If you have a colon and you do not have an ostomy, limit your total fat intake

Low Sugar Cereal Choices

(grams of sugar per 1 cup serving)

1 gram

2 grams

2.4 grams

3 grams

3 grams

3 grams

3.2 grams

4.8 grams

5.6 grams

6 grams

6 grams

6.7 grams

Sugar Cereal in Moderation

(grams of sugar per 1 cup serving)

9 grams

10 grams

12 grams

12 grams

12 grams

12 grams

12 grams

12 grams

12 grams

12 grams

13.3 grams

13.3 grams

How to Feed Your Toddler with Intestinal Failure

- All foods should be cut into small pieces (around the size of a dime or smaller) to help prevent choking and to allow your toddler to feed himself.
- It is important to start good eating habits early on.
- If your toddler doesn't seem to like a certain food, keep offering it. It may take up to 10-15 times before your toddler wants to eat it.
- Model healthy eating. Your toddler wants to eat what you eat, so it is important for you to eat the foods he should be focusing on as well.
- Eat small frequent meals (~6-8 meals throughout the day)
- Drink fluids between meals

Power Punching Your Meals

Use these ideas to help you add more calories to your child's meals and snacks for weight gain.

Food	Calories	Suggested Uses
Peanut butter (for children 2+ years)	80 cal/Tbsp 4 g protein	Spread on bread, toast, crackers, fruit, tortillas, bagel, waffles, English muffins, or add to milkshakes, hot cereal, granola, grilled PB & jelly sandwich
Cheese	100 cal/ounce 6 g protein	Melted on bread, sandwich, pasta, eggs, hot dogs, meatloaf, meatballs, creamy soups, potatoes, boxed mac & cheese, rice dishes, cooked vegetables
Egg yolk (large)	55 cal/yolk 3 g protein	Mix in casseroles, meatloaf, baked goods, soups, baked rice and pasta dishes, rice pudding, bread pudding
Dry powdered milk	25 cal/Tbsp 3 g protein	Add to whole milk, milkshakes, ice cream, casseroles, spaghetti sauce, meatloaf, meatballs, gravies, sauces, baby meats, egg or tuna salad, potatoes, pot pies, mac & cheese, puddings, cereals, cream soup, baked goods
Evaporated whole milk	20 cal/Tbsp 1 g protein	Use in place of whole milk in desserts, baked goods, milkshakes, cream soups, and cooked cereals
Vegetable oil	120 cal/Tbsp	Add to soups, casseroles, cooked vegetables, gravies, cooked cereals, spaghetti sauce, canned pasta dishes (ravioli, Spaghetti-O's®)
Margarine/Butter	100 cal/Tbsp	Spread on pancakes, waffles, toast, crackers, potatoes, pasta, cooked vegetables, casseroles, hot cereals, rice
Sour cream	25 cal/Tbsp	On vegetables, potatoes, casseroles, guacamole, in salads
Cream cheese	50 cal/Tbsp 1 g protein	Spread on toast, sandwiches, bagels, or use flavored version (ie: Strawberry cream cheese) as dip for animal cookies and graham crackers
Mayonnaise	95 cal/Tbsp	Spread on sandwiches or use in pasta, salads, deviled eggs, vegetable dips
Heavy whipping cream	50 cal/Tbsp	Blend with whole milk, milkshakes, or use in hot cereals, creamy soups, sauces, hot chocolate, casseroles, pudding
Half & Half	25 cal/Tbsp	(Same as heavy whipping cream)
Chocolate syrup	55 cal/Tbsp	Top ice cream, pancakes, and add to milk and milkshakes
Sweetened condensed milk	60 cal/Tbsp 3 g protein	Drizzle over brownies and cakes, and add to coffee or hot chocolate, add to whole milk
Avocados	25 cal/Tbsp	Spread on sandwich or crackers, serve with chips, mix to make guacamole, serve as finger food for small children
Ranch or Creamy Honey Mustard Dressing	60-70 cal/Tbsp	Serve on salad, with raw vegetables, French fries, chicken nuggets, or any other items that child can dip
Carnation Breakfast Essentials packets	130 cal 5 g protein	Mix into 8oz whole milk to make a home-made version of "Ensure" or "Boost" ***select yellow box version***

High Sugar Cereals to Limit

(grams of sugar per 1 cup serving)

16 grams

18.7 grams

20 grams

20 grams

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