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Gain Understanding of Transitions:

A Guide to Key Milestones in Short Bowel Syndrome (SBS)

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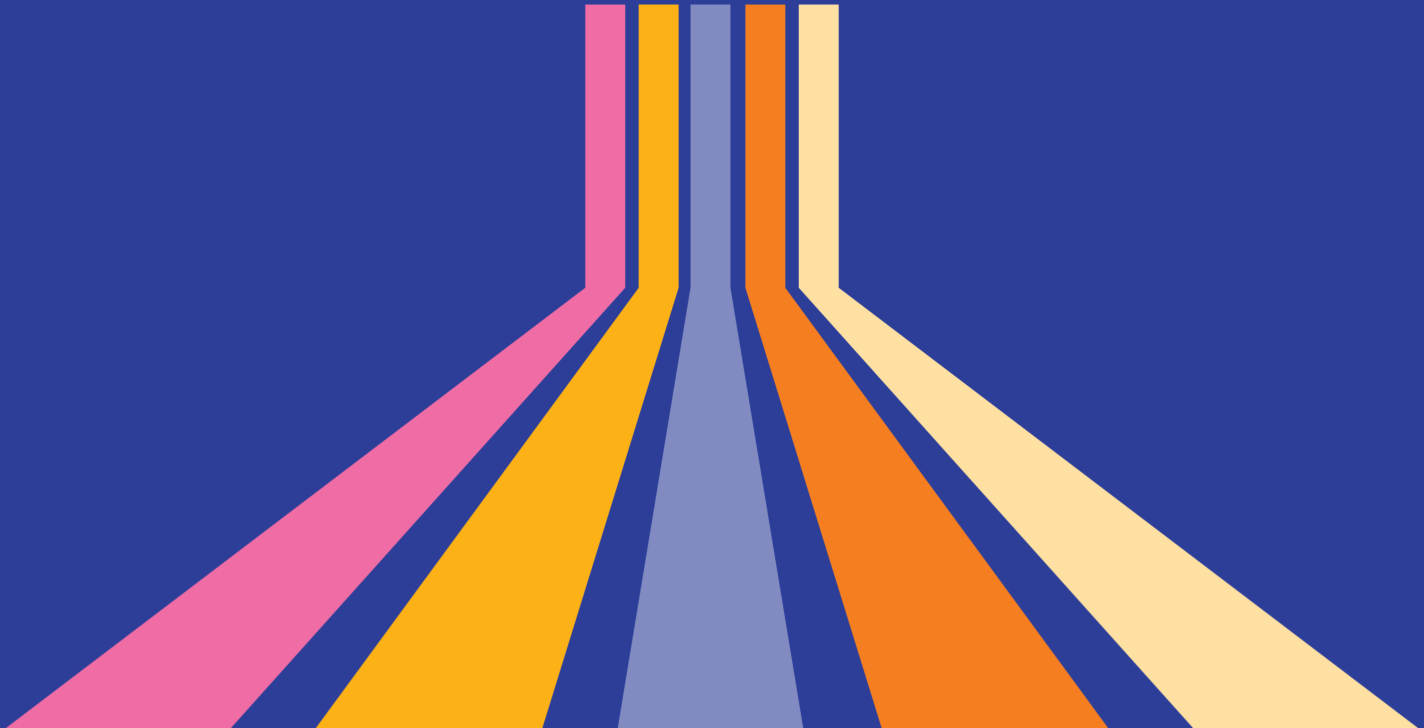
SBS
SHORT BOWEL SYNDROME
STRENGTH INSIDE



Transitions of Care

are the key milestones a patient with short bowel syndrome may experience. The medical care for a pediatric patient with SBS changes as the patient grows, and the resources, needs, and support will also develop and change. This guide aims to help improve understanding and increase awareness of the important considerations during these transitions.

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This collection of resources and information was created to inform and help patients throughout the SBS journey. For additional considerations, information, and resources look for the below icons throughout this guide.

› This symbol indicates additional resources or where to go to learn more.

✸ This symbol indicates actions for consideration and discussion topics you may want to have with your child's healthcare team.

The contents are for informational and educational purposes only and not intended as medical advice. Consult your child's healthcare provider regarding his/her medical condition and before making any changes to your child's care.

THE BASICS OF SHORT BOWEL SYNDROME (SBS)

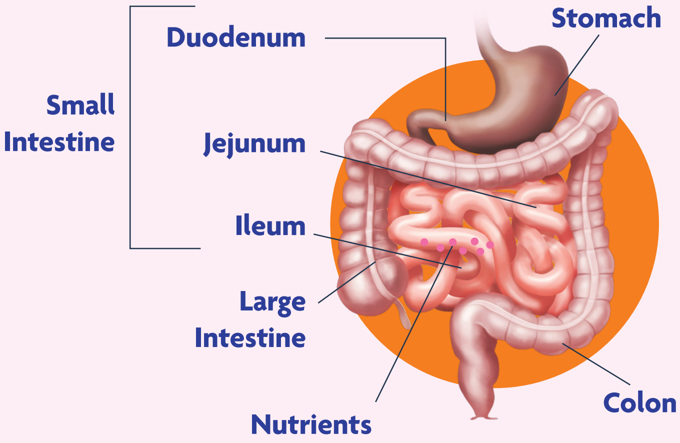
Meet the Intestines

Before we dive into the details of short bowel syndrome (SBS, for short), let's explore how the intestines (or bowels) work under normal conditions.

What Are the Intestines and What Do They Do?

The **intestines** are tube-shaped organs that connect your stomach to your anus. They are responsible for:

- Digesting food
- Absorbing nutrients
- Taking in water and minerals



You digest and absorb nutrients in the **small intestine**, which is divided into three main parts:

- **Duodenum:** This is the first and smallest section of the small intestine. This is where important digestive juices used to break down food mix together: bile and digestive enzymes. It is the main location where iron and other important nutrients are absorbed
- **Jejunum:** The middle section, which processes nutrients and the medicines you take
- **Ileum:** The last and largest section of the small intestine is responsible for absorbing important vitamins such as B12. It is also where fluids that aid in digestion are taken back to be reused by your body

The **ileocecal** valve (ICV, for short) connects the last part of the small intestine to the large intestine. It acts as a gatekeeper between the two. It:

1. Helps keep nutrients in the small intestine longer allowing more nutrients to be absorbed
2. Keeps the contents of the large intestine (digested food and bacteria) from making their way back into the small intestine

The **large intestine**, often referred to as the **colon**, is responsible for taking in water and remaining nutrients, including **electrolytes** such as salt and potassium. It is also responsible for **transforming** or changing broken down food from a liquid state to a more solid state known as **stool**.

What is Short Bowel Syndrome (SBS)?

SBS is a rare, serious, and life-long disorder. It prevents your body from absorbing nutrients, water, and electrolytes effectively. When you lose or damage part of your intestines, they may not work properly. This can create problems with your nutrition and hydration. It can also change the way your body absorbs electrolytes and nutrients.

What Conditions Might Lead to Short Bowel Syndrome (SBS) in Children?

While some children are born with intestines that are missing or too small, most children develop SBS when they have surgery to treat a disease, injury, or defect.

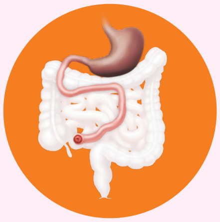
There are many reasons that your child might have had to have surgery. The most common causes in children with SBS are:

- **Crohn's disease**, a disease that causes swelling in the intestines that can lead to blockages
- **Gastroschisis**, when the intestines stick out of the body through the belly button
- **Hirschsprung's disease/intestinal aganglionosis**, a condition where some nerve cells are missing in the large intestine preventing it from working properly. This can lead to blockages in the intestines
- **Intestinal atresia**, when the intestines haven't formed correctly
- **Necrotizing enterocolitis**, when the lining of the intestines becomes swollen causing some of the tissue to die
- **Malrotation**, when the intestine doesn't fully rotate into its normal position at birth
- **Midgut volvulus**, when blood supply to the middle section of the small intestine is completely cut off
- **Trauma**, or injury

The need for surgery differs from person to person. So does the type of surgery. For the intestines, the three most common surgeries are:

JEJUNOCOLIC ANASTOMOSIS:

- In this type of surgery, doctors remove the ileum and connect the jejunum and the colon.



END-JEJUNOSTOMY:

- Surgery where the colon, ileum, and some of the jejunum is removed. The doctor then connects the rest of the jejunum to the belly. They leave a surgical opening (called an **ostomy**) so that waste can leave your body

JEJUNOILEAL ANASTOMOSIS:

- Surgery where the doctor removes parts of the jejunum and ileum. The colon stays unaffected

It's important to understand these different types because each surgery aims to address a different part of the intestine. Knowing this can help caregivers work with doctors and surgeons to develop the best care plan possible.

Ask your child's doctor to fill in the diagram found in the **List of Possible Medications/Supplements resource card**, marking which of your child's anatomy was removed and documenting how much of the intestines remain. Ask your child's doctor to keep a copy for their records and reserve a copy for yourself.

What Happens to Your Child's Body After Surgery?

When you damage or lose a part of your intestines, **malabsorption** may occur. This means your body has trouble absorbing nutrients from the food you eat. As a result, your body changes, or **adapts**, to make up for what's not working right. This ability to adapt after surgery affects how well your intestines will heal.

What to Expect When Your Child Has SBS

Your child is one of a kind. With SBS, severity, symptoms, and nutritional needs are unique to each person. Managing this condition will depend on how much of the intestines are healthy and working properly.

SBS Symptoms

SBS symptoms can range from mild to more severe, and your child may experience a number of them. The most common SBS symptom is diarrhea, which can lead to **dehydration** (when your body doesn't have enough fluid), **malnutrition** (when your body doesn't have enough nutrients), weight loss, and **vitamin deficiency** (when your body has fewer vitamins than it needs). Other symptoms may include:

- Bacterial infections
- Bloating
- Cramping/stomach pain
- Difficulty maintaining weight
- Fatigue
- Gas
- Heartburn
- Irregular stools or changes in bowel habits
- Malnutrition
- New food allergies or sensitivities
- Signs of dehydration
- Vomiting

Over time, your child may also have symptoms such as:

- Problems with their electrolytes
- Kidney stones
- Too much bacteria in the gut, which can affect how you digest food and liquids. This can lead to diarrhea, bloating, vomiting, and feeling nauseous, or sick to your stomach

It's important to identify and track symptoms. You may want to write them down in a notebook and take it with you when you go to the doctor. This can help you when you and your child's doctor are discussing treatment and management plans.

The Hospital Experience

The hospital experience may be different for everyone. Following surgery and diagnosis, your child will encounter a number of different specialists working together to develop your child's individualized care plan. In-hospital care may include the following: running tests to assess nutrition and hydration, administering medicines and feeding therapy, managing your child's health and nutrition needs, and educating your child on how to manage care at home.

TO LEARN MORE about the roles of the different specialists that may be involved in your child's care, see the **Multidisciplinary Team (MDT) List resource card**.

You Are Not Alone

Receiving a diagnosis of SBS and all that goes with it can feel like being hit by a tidal wave—a tidal wave of emotions, information, and change. You are not alone in this. There are resources and support organizations to help you along the way.

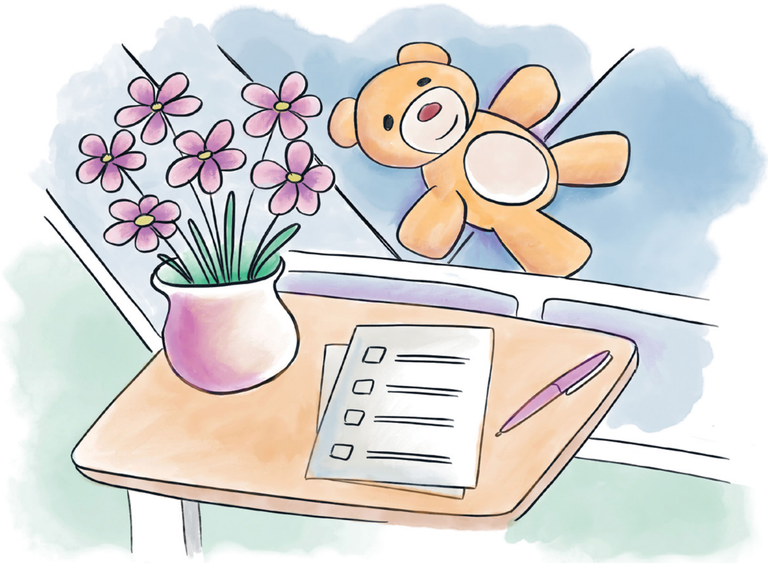
- For additional resources to help you learn about and manage SBS, and to read about nutrition and how it affects your health, see the **resource cards** found in this guide

FOR INFORMATION on milestones you and/or your child may encounter along the way, see sections 2 through 5 of this guide.

TRANSITIONING INTO LIFE AT HOME

When children are diagnosed with short bowel syndrome (SBS, for short), it's common for them to spend a long time in the hospital at the beginning of their illness. When it's time to go home, it can feel both exciting and overwhelming. All emotions are valid. Starting early to create a plan with your child's medical team can help make the transition home go as smoothly as possible.

In this section, we discuss some of the strategies to help you and your family prepare for, and transition to, life at home.



Preparing to Leave the Hospital

There's no doubt, making the move from hospital to home is a complex process. It doesn't begin or end at discharge. It takes a lot of communication between you, your family, hospital staff, and community providers both during your child's stay and afterward. You will be given a lot of information and things to do before you take your child home, so it is normal to feel overwhelmed. A discharge checklist can help keep this information organized, identify questions you might ask your child's care team, and keep track of the supplies and arrangements needed. Ask your child's medical team to have family meetings with you to discuss discharge planning, questions, and timelines. Speak with your social worker or care coordinator to find out if you can receive additional support at home, such as home nursing, visiting nurse services, or family caregiver support.

To learn more about the medical team members involved in your child's care, see the **Multidisciplinary Team (MDT) List resource card**.

My Child's Hospital Discharge Checklist

You and your child's care team can use this checklist to help with the transition home.

☐ **Review Care Plan**

Ask your child's medical team to review the care plan with you throughout your child's hospital stay. This should be monitored and you should talk to your doctor about your long-term treatment plan. Take these opportunities to ask questions and increase your comfort and confidence with the plan, and feel encouraged to share with the care team what you've observed about your child, what has worked well in the hospital that you'd like to continue, and your goals for homelife.

☐ **Receive Medicine List and Counseling**

Have your child's doctor print you a list of all the medications your child receives, including dosage, frequency, administration instructions, and potential drug-drug interactions and drug-food interactions. Ask the doctor to explain the purpose of each medicine, what to expect, and any potential side effects.

TO VIEW A LIST of some medications/supplements your child's medical team may prescribe, see the **List of Possible Medications/Supplements resource card**.

☐ **Understand Potential Warning Signs and Problems**

Ask your child's medical team to go over any potential problems that may occur related to your child's care. Have them explain warning signs and how to recognize them, as well as what to do and who to contact if there is a problem (such as what symptoms warrant a trip to the ER versus a call to their office). Write down the name and contact information for who to call and put them in your cell phone. Ask your child's medical team to help you create and fill out an "Emergency Department Letter" to help you communicate with emergency department staff and to help them care for your child.

☐ **Ensure You Have All Necessary Equipment and Supplies**

If your child requires **parenteral nutrition** (intravenous [IV] feeding) or **enteral nutrition** (tube feeding) support, you will be connected with a home care supplier who can help with things ordered by your child's medical team that you need to care for your child's nutritional needs at home.

These supplies may include: Alcohol/antiseptic preparations, dressings/gauze, catheter repair kit, feeding tubes, infusion/feeding pumps, parenteral nutrition solutions, syringes, special sharps containers, gloves, etc.

Your child's medical team and home care provider will provide guidance and educate you on how to obtain and properly use the supplies, how to administer the nutrition, and how to monitor your child's response. Set up a clean, separate, dedicated space at home to store all the supplies. Store medications according to their storage instructions.

☐ **Ensure Follow-up Appointments Are Scheduled**

It's possible to schedule all follow-up appointments with your child's medical team before leaving the hospital. This may include appointments with a gastroenterologist, dietitian, pharmacist, social worker, psychologist, and other specialists. Ask your child's medical team if any of the appointments can be coordinated to occur on the same day. Request a meeting with your child's home care provider before discharge to understand their role and responsibilities in caring for your child and what to expect during their visits. Also, schedule an appointment with your child's pediatrician as instructed and for routine medical care. Work with your medical team to create a communication plan regarding your child's condition and unique needs.

☐ **Contact Your Insurance Provider**

Have a conversation with your insurance provider to discuss how your child's coverage will stay the same or change once you are home.

☐ **Have Emergency Contact Information on Hand**

Keep a list of the medical team's contact information, including the hospital's emergency department phone number, in case you have any questions or concerns after leaving the hospital. You may also want to save emergency contact numbers, and a photo of the resource card and medication list on your cell phone so you always have them on hand.

☐ **Make Sure All Caregivers Are Trained**

If someone in addition to you will be responsible for caring for your child, make sure they receive proper training and instruction on your child's medical needs. Familiarize them with your child's care plan and how to properly prepare, use, and clean medical equipment and give medications. Alert them to any safety precautions that should be taken. Be sure they understand your child's unique nutritional needs, how to recognize potential complications, and what to do in case of an emergency.

☐ **Ask for Education and Resources**

Ask your child's medical team to provide you with education in plain language (language that is easy to read, understand, and use) about your child's condition, their care plan, next steps throughout the hospital stay, through discharge, and related to care at home. This includes education about mental/behavioral health resources that might be available to them. Seek resources such as support groups or educational materials to help you learn more and discuss your learnings with your child's medical team before making any changes to your child's care.

FOR MORE RESOURCES to help you learn about and manage SBS, see the **resource cards** found in this guide

The provided checklist can be used or create your own. You can keep it with you at the hospital, use it in conversations with your child's medical team, jot down questions to ask the team later, and use it to track your action items in preparation to transition home.

Learning to Care for Your Child at Home

The excitement of going home will most likely be mixed with concern over the additional care that's needed, and the responsibility of managing your child's needs at home. There will be many emotions and that is completely normal! To help you feel more comfortable about caring for your child at home, start practicing while you're still in the hospital, and don't hesitate to ask questions. Ask to do specific care routines yourself while a nurse watches, and ask your medical team to do a 24-hour **"room in"** before going home. This means you can practice everything that you will be doing at home. Make sure you are comfortable with every step before going home and always ask your medical team to clarify anything that you do not understand.

Management Practices for Ostomies, Feeding Tubes, and Central Lines

Taking care of **ostomies**, **feeding tubes**, and **central lines** requires specific practices to keep them working correctly and to prevent infection and other problems. Here are some tips to take care of each one and be sure to discuss proper care with your medical team:

Ostomies: Surgical openings created so that waste can leave your body

- Keep the area around the ostomy clean to prevent infection and skin irritation
- Use a solid skin/ostomy barrier or protective paste around the **stoma** (or surgical opening) to protect the skin
- Empty and/or change the pouch regularly to prevent leakage and odors

Feeding Tubes: Tubes that allow liquids/liquid food to enter your stomach or intestine

- Make sure the tube is securely in place to prevent it from moving around
- Clean the tube and the area around it regularly to prevent infection
- Keep the skin around the tube dry to prevent skin irritation
- Monitor the place where the tube goes in for signs of redness, swelling, or discharge
- Check the tube for kinks or other blockages
- Follow the feeding schedule provided by your child's team
- Vent the feeding tube as instructed by your medical team
- Ask your child's doctor what to do if the feeding tube accidentally comes out
- Ensure adequate hydration (see **"Staying Hydrated"** below) to prevent **dehydration** (when your body doesn't have enough fluids)
- Monitor any output from the tube to ensure it is working correctly

Central Lines: Catheters inserted into a vein used to deliver parenteral nutrition, IV fluids and/or medicines into the bloodstream

- Ensure the central line is securely in place
- Monitor the place where the line goes in for signs of redness, swelling, or discharge
- Ensure the sterile dressing is appropriately covering the line
- Keep the line, dressing, and surrounding area clean and dry to prevent infection
- Keep the line and dressing protected (ie, with a vest or onesie) to prevent accidental pulls and breaks
- Use a sterile technique when handling the line to prevent contamination
- Keep the line tip away from diapers, feeding tubes, and ostomies to prevent contamination
- Use lock therapy to help prevent a line infection and treat **bacterial biofilms** (a group of bacteria stuck to each other and a surface)
- Give medicine, IV nutrition, and/or fluids according to the prescribed schedule
    - Monitor any output from the catheter to ensure that it is working correctly

Always talk to your child's doctor about management practices and before trying anything new.

Staying Hydrated

Staying **hydrated** (getting/absorbing enough fluids) can be difficult for children with SBS, because of their gut's decreased ability to absorb, putting them at a higher risk for dehydration. In general, being dehydrated is a serious concern, but when someone with SBS is dehydrated, drinking more water could make the problem worse by increasing diarrhea or ostomy output. If you notice signs of dehydration, it's incredibly important to talk to your child's care team.

Some signs of dehydration in children are:

- Breathing faster than usual
- Cold hands and feet
- Diarrhea or ostomy output is higher than total fluid intake
- Dry and wrinkled skin
- Dry mouth with sticky saliva
- Feeling lightheaded when you stand up
- Feeling very thirsty
- Feeling very tired or sluggish, being less active than usual
- Lower abdominal skin staying "tented" after lightly pinching
- No tears when crying
- Not peeing as much or pee is darker in color (older children/adolescents), fewer than six wet diapers per day (for infants), and no wet diapers or peeing for eight hours (in toddlers)
- Sunken eyes
- Sunken soft spot on an infant's head

To help with dehydration, you can have your child try **oral rehydration solutions**. This balanced mixture of salt, sugar, and water can help the small bowel wall absorb more fluids. You can purchase oral rehydration solutions or check out the **oral rehydration solution** recipes below. **Always talk to your child's doctor about his/her hydration practices and before trying anything new.**

Basic Oral Rehydration Solution Recipes

Recipe 1:
2 tablespoons sugar
½ teaspoon to ¾ teaspoon salt
1 liter (4 and ¼ cups) water

Recipe 2:
½ cup precooked baby rice cereal
½ teaspoon salt
2 cups water

"A Kid's Guide to Short Bowel Syndrome" by Tegan Medico MS, MPH, RDN, CNSC and Carol Rees Parrish, MS, RDN

FOR MORE RECIPES, find the **"Staying Hydrated with Oral Rehydration Solution" book** on the list of **additional resources**. To read more about nutrition, staying hydrated, the important role of replenishing electrolytes and how it affects your child's health, see the **Nutrition resource card**.

Considerations for Adjusting to Life at Home

At times, especially in the beginning, life with SBS can feel chaotic, both for you and your child. To help navigate the transition to life at home partner with your doctor, specialist, or healthcare team. Here are some things to consider at a time and a pace that works for you:

- **Keep things as normal as possible:** Work together as a family to define what is right for you and the different roles every family member can play. Setting realistic expectations for your child is important, remember, kids still need to be kids!
- **Maintain a schedule/stick to a consistent family routine:** Children, as do many adults, thrive in a structured environment. It is okay if the routine gets changed, there are many things outside of your control. Try to get back into your routine once you are able to maintain consistency and stability as much as possible
- **Get siblings involved:** When a child has SBS it impacts the whole family, including siblings. Involve siblings in your child's care to the extent that is possible, invite them to sit with your child during their treatment if appropriate to watch a special show or help keep them distracted. Do special things with siblings alone on occasion so that they know they are special too!
- **Manage personal/caregiver stress:** Your well-being matters, too. Remember to take time for yourself. Here are some considerations for dealing with caregiver stress:
  - Try to remember that you will be best equipped to care for your child when you also care for yourself. When possible, try to find some time for self-care like exercise or meditation, eat a nice meal, and catch up on your sleep
  - Schedule time each day to rest and do the things you enjoy (eg, read a book, work in your garden, take a relaxing bath), even if it's just for a short period of time
  - Set realistic goals and don't overload your daily to-do list or schedule. Prioritize, make lists, and break large tasks up into small steps that can be done one at a time
  - Have grace for yourself. Things may not go as planned. This is normal. Remember, you are doing your best with what you have. You will learn and be inspired by your child and your child from you
  - Accept help from others. If appropriate, consider allowing your partner, other family members, and friends to help with childcare, household chores, meal prep, and errands. At the same time, don't be afraid to say no to invitations, events, and questions that may be taxing
  - Seek social support. Stay connected with family and friends who can offer non-judgmental emotional support. Join a support group and get connected with caregiving associations/community groups
- **Create a calm/comfortable space** where your child can receive treatment. Here are a few ideas you can start using now:

Infants/Toddlers (0–3 years)

- Try to maintain the child's normal routine as much as possible
- It is normal to need to use toys, activities, videos, and another person's help to aid in distraction and minimize movement during care
- Have only one toy or activity available at a time to prevent overstimulation
- Designate a clean space for setting up treatments and medicines whether it be at home or when you're on the go

Preschoolers (3–5 years)

- Provide constant verbal support and encouragement
- Consider using a sticker chart or reward system to encourage staying on track with treatment
- Encourage supervised interaction with medical kits to help your child better understand the equipment they'll see at home
- Provide age-appropriate books on central lines and feeding tubes, and a doll or teddy bear that is like them with a feeding tube or central line on it
- Use distraction techniques such as music, tablets, books, toys, or their favorite TV shows
- Create positive associations with unpleasant tasks such as the opportunity to watch a special show or getting to have a special treat

Words of Support and Encouragement:

"You're doing a great job"

"You are capable"

"You are strong"

"You are loved"

"You are perfect the way you are"

School-Age (6–11 years)

- Prepare and educate your child about diagnosis of SBS and different treatment plans
- Provide choices and allow for independence when possible
- Use distraction techniques such as a stress ball, deep breathing, books or tablets

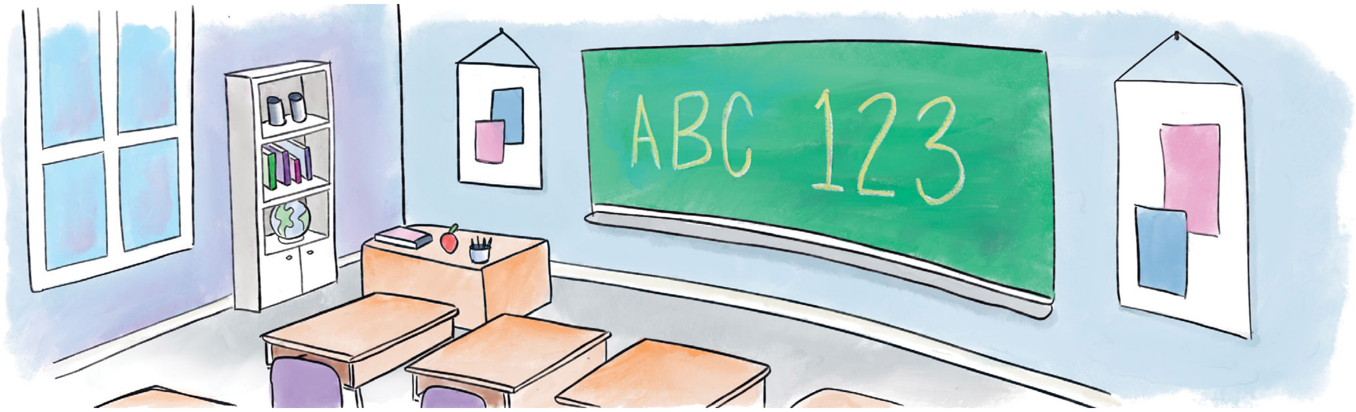
Adolescents (12 years and up)

- Encourage curiosity, questions, and involvement in their own care
- Educate them about being consistent with treatment and what could happen if their regimens aren't followed
- Use distraction techniques such as music, smart phones, deep breathing or their favorite movie
- Encourage fitting in treatments and medications into their desired life and activities

FOR MORE STRATEGIES, visit **oley.org.**

BE PREPARED: PLANNING FOR THE UPCOMING SCHOOL YEAR

Going to school is an exciting milestone for any kid, including those with short bowel syndrome (SBS). It is normal for both you and your child to experience many different emotions during this time. Be kind to yourself and let your child know that their emotions are completely normal for any kid who is about to start school. Planning ahead can help you feel more comfortable with the transition to school life and allow your child to focus on learning. Talk with your doctor and/or school to see if your teacher could benefit from any of the following.



Considerations for the start of the school year:

Determine if your child could benefit from a **504 accommodation plan** and/or an **individualized education plan (IEP)**

- Under the law (Section 504), schools are required to make reasonable accommodations for students with chronic conditions such as SBS. This law ensures they are able to learn alongside their peers in a regular classroom
  - Examples of accommodations that may benefit your child include unlimited bathroom access, access to a private restroom, access to snacks throughout the day, excused visits to the nurse, rest periods, extra time to complete work and tests, an extra set of books to keep at home, a system for providing assignments during absences, and modifying normal attendance rules
  - 504 plans are usually created with the parents/caregivers, teachers, and school principal and are of no cost to the family
- An IEP allows children to receive individual specialized education and related accommodations and services to help students overcome potential barriers created by their condition. These may include adjusting the learning/testing setting (for example, specific seating and study/testing rooms) and the student's schedule or schoolwork deadlines (such as frequent breaks, extended time for assignments or tests, and taking tests at specific times of day), as well as other reasonable accommodations
  - To get an IEP, the child must have one or more of the disabilities listed under law that affect the child's educational performance or ability to learn and benefit from the general education provided in the classroom. You and your child's medical team can work together with the school to assess and determine what is right for your child
- You can ask your child's school in advance about the specific requirements for educational assistance and to arrange a planning meeting
- Talk with your child's medical team to find out if they have school liaisons or social workers who can support this process

Assemble all relevant medical information and forms, including instructions from your child's medical team for any medications or feeds that need to be given at school. The school will require new forms to be completed by your child's doctor each school year

Get to know school staff including teachers, nurses, counselors, and student aides. Request a meet and greet to introduce yourself and your child, discuss special arrangements, and address any additional questions or concerns with school staff

Create a communication strategy to inform and educate school staff on your child's medical condition and needs, as well as other pertinent considerations. Understand that communication may need to be frequent, and can evolve over time, especially when the teachers and staff who care for your child change

- Gather and distribute resources to help educate on SBS and on your child's specific needs to school staff. These resources could include a biography sheet with information specific to your child or books that help educate on SBS

Talk with your child's doctor and/or school to see if your child's teacher could benefit from any of the previous.

SEE THE **ADDITIONAL RESOURCES resource card** for books and additional resources.

Considerations (continued)

Create a written emergency plan with the help of your child's medical team. Prepare emergency kits with emergency procedure and contact cards that you can send to school with your child

- See the **"Preparing for an Emergency" section** and in the **resource cards** found in this guide for suggestions as to what to include

Stock up on medical supplies and equipment to keep at school such as:

- Alcohol/antiseptic preparations, clave supplies, dressings/gauze, feeding tubes, formulas, infusion/feeding pumps if possible, ostomy supplies, syringes, special sharps containers, gloves, wipes, change of clothes and skin creams

It's a good idea to assemble a school readiness packet to organize and keep track of all the important forms, plans, educational and emergency materials needed. Make copies, ensuring to keep one for yourself, and provide them to the appropriate staff members in preparation for the school year. Update the packet as needed throughout the year and later years.

Communicating with School Staff

Whether it's your first year sending your child to school or you're a seasoned vet, it's important to talk proactively with teachers, nurses, and counselors about your child's SBS. It may feel overwhelming, but remember that the more informed they are, the better the care and support they can give to your child. Furthermore, it can help prevent the school from making incorrect assumptions about your child's performance or conduct.

Here are some **"subjects"** to discuss with school staff.

Spelling out what SBS is, its symptoms, and its impact on the body. Inform them of your child's symptoms, treatments, and medicines. Basic knowledge about SBS will help the staff understand your child's needs, expectations, energy levels, and physical limitations.

History. Providing up-to-date information on your child's condition can help ensure their needs are being met. Some topics to mention include:

- Instructions or restrictions related to medicines, diet, fluids, and allergies, and how to best encourage communication between your child and staff about your child's needs
    - If there is a clinical goal you would like to improve on with the help of school staff, let them know (eg, drinking more oral rehydration solution, eating with peers, teaching your child to ask for help)
- The type of nutrition therapy your child receives; a specialized oral diet, supplements, enteral nutrition and/or parenteral nutrition. Alert them to any side effect that could impact your child during the school day (eg, fatigue, daytime wetting, increased energy or hunger/fullness at certain times of the day, observable differences to the face or body after unhooking from parenteral nutrition). If applicable, give them specific written instructions and show them how to assist or administer enteral nutrition and fluids. A formal training with monitored guidance may be needed
- How often your child may need to use the bathroom, the time it takes, the possible odors and why, and if they'll need reminders or help

Reading materials to prepare them for any emergency, mishap, or complication. Share a written emergency protocol created with the help of your child's medical team, or repurpose materials provided from your child's home care team.

Geography. Give them your home and, if applicable, your work address. Provide them with addresses of your child's local medical and subspecialist team, and the nearest hospital approved for your child to go to. Provide them with the best phone number to reach you and your child's medical team. Discuss the best methods (ie, phone, email, text) to communicate with you, your child's medical team, and first responder services in the event of any health emergencies. List these out in order of priority of who to call first, as well as when to call.

Language Arts. Discuss with school staff how to describe your child's condition to others. Share any special names or terms your child uses to describe their medical devices and any code words they may use when they need something but don't want to say it out loud.

Social Studies. Encourage school staff to promote friendships and interactions between your child and their peers, and to address bullying or isolation concerns. Discuss any changes with regard to interactions and how to continue to promote peer-to-peer communication, when your child is hospitalized or has to stay away from school for a period of time.

Physical Education. Taking part in activities with peers is important despite their potential limitations. Review with your child's medical team which activities are safe for your child to participate in. Discuss any necessary modifications to activities so they can still participate and socialize with their peers in a safe way. Communicate and check in regularly with physical education teachers and school staff to see if your child is satisfied with their involvement and if modifications need to be considered.

Public Speaking. Discuss with your child how to talk about SBS and their needs with others at school. Encourage them to advocate for themselves and discuss with them some approaches they could use. You can also talk with them about strategies and approaches for responding to questions about their condition and ask your child if they want you to go to school and do a presentation to the class about their SBS.

EXTRA CREDIT: Remember, managing SBS is an **art** and **science**. It is normal for there to be hiccups and misunderstandings along the way. Education, preparation, and communication go a long way in helping your child succeed in the classroom. They also help you navigate the emotions that come with placing the care of your child into the hands of others. Keep lines of communication open throughout the school year. Reach out to school staff often to see how things are going and show appreciation to the staff for the special care they provide to your child.

Preparing for an Emergency

Sending your child to school and trusting their care to someone else can be stressful and worrisome. This feeling is completely normal. To help prepare for potential emergencies, create an emergency kit to give to the school to have on hand if a situation occurs. Discuss potential emergency situations with school staff as well as which actions should be taken. You can include this information on emergency procedure cards for quick reference. Potential emergencies that may arise include:

Fever	Explain to others that fever in a child with a central line could be life-threatening and the child should be sent to the emergency department immediately. Alert them to notify you as soon as possible if your child develops a fever.
Vomiting blood, or vomit that is green or brown in color	Alert school staff to notify you as soon as possible if your child is vomiting blood, or if their vomit is green or brown in color.
Blood in stool or black stool	Alert school staff to notify you as soon as possible if they notice bloody or black stool in your child.
Dehydration	Inform school staff about the signs of dehydration (see Section 2 of this guide) and what to do if your child gets dehydrated. (These signs and steps could differ from child to child, so consult with their medical team to develop a plan.)
Central line complications	Inform school staff about the possible central line complications that may occur such as if a line comes out, breaks, there is bleeding or leaking, or if the dressing or cap falls off. Alert them to notify you as soon as possible if any of these complications occur and give them details on what the nurse or teacher can do while they wait for help.
Feeding tube comes out	Instruct school staff on what to do if your child's feeding tube comes out. They should place the tube back in and notify you as soon as possible. You may need to show them how to put the tube back in.

Remind them that, in an emergency, do their best to remain calm and move quickly. The school should follow their emergency procedures and should call 911 in case of a medical emergency requiring immediate medical attention.

In addition to discussions with school staff regarding potential emergencies, encourage your child to keep their emergency cards in their wallet or backpack. These cards and kits can also be shared with babysitters, grandparents, and others who might help care for your child. Here are some suggestions as to what to include in each of these resources.

SBS Emergency Kit

Based on your child's unique needs, their medical kit could include a variety of items. Ask your child's medical team for recommendations on what to include in your child's emergency kit. Check these often and make sure the contents are not expired.

Emergency Contact Card

Your child's emergency card should contain pertinent information such as their name, date of birth, home address, caregiver's emergency contact information, important clinicians' information, home infusion team information, if applicable, as well as their allergies, condition, medicines, and any accommodations needed. Work with your child's medical team to ensure that all relevant medical information is included.

Emergency Department Letter

Ask your child's medical team for assistance filling out an "Emergency Department Letter" to help you communicate with emergency department staff and to help them care for your child.

Continued Action During the School Year

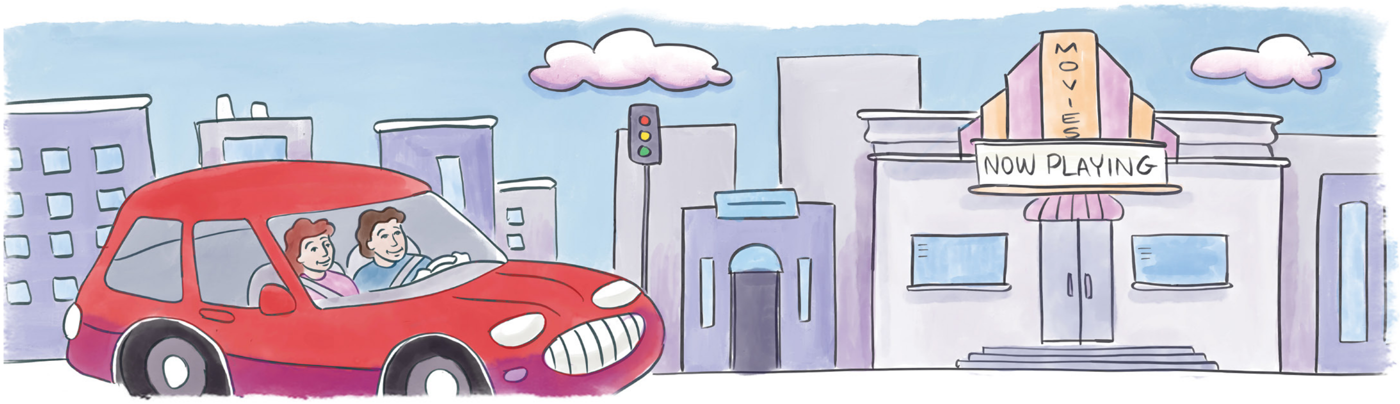
In addition to the preparation leading up to the start of school, periodically follow up with school staff throughout the year to ensure that your child's emergency kit is stocked with necessary supplies and equipment, and that they are getting the support and resources they need. If there are any changes related to your child's needs, ensure that you communicate them to the staff.

FOR MORE INFORMATION, see the **resource cards** found in this guide.

THE JOURNEY TO BECOMING A COURAGEOUS AND CAPABLE ADULT

Adolescence (ages 12-18) can be a time period where frequent changes occur with self-esteem, confidence, relationships and dating, school, identity, and independence. Living with short bowel syndrome (SBS) can amplify these challenges. To help teens navigate a serious, life-long illness and become empowered to take charge of their own healthcare, it's important to develop a sense of confidence and capability.

In this section, we will discuss some tools to help navigate through these transformative adolescent years, to help empower teens to take charge of their own healthcare, and to help ease the transition into adulthood.



Navigating Adolescence with Short Bowel Syndrome (SBS)

While we're all unique, teens face a unique set of challenges living with SBS:

- They may become increasingly self-conscious of physical differences (such as with their ostomy and catheter, or with their height and weight), or of accommodations related to SBS that may be needed (eg, frequent bathroom visits, dietary restrictions, limiting certain activities)
- Hospital stays or bouts of illness that keep them out of school or prevent them from participating in extracurriculars or social events may interfere with relationships and time spent with peers
- The need to increase independence while balancing healthcare concerns

Here are some ideas to help teens deal with having an array of feelings and to help increase confidence, comfort, and independence during this time:

- **Talk it out:** Check in with your teen about their symptoms, treatments, and feelings. Know when to just listen versus when to give advice. Encourage them to ask what role they want their caregiver to have in that conversation. If you're a teen, seek support from others, whether it be close family members, friends, your healthcare providers, or others living with SBS. Ask your care team to help you connect with others living with SBS or reach out through social media or patient support organizations. Share your concerns with your medical team or other trusted adults like a teacher or counselor. If you don't feel comfortable talking about it, consider writing in a journal to give yourself an outlet while creating a personal history available for future reference
- **Plan ahead:** When out of the house engaging in more activities alone, plan ahead with your teen and discuss how to handle practical issues that might arise (eg, emptying an ostomy bag, taking medicine), how to monitor symptoms, and how to assess the risk in each activity. Remind your teen that you're a safe resource to come to when urgent medical needs occur, and that, as a team, you and your teen will decide together on what plan of action to take. If the needs require going to the emergency room or a doctor visit, reassure your teen that you will be with them as support at every step. When appropriate, discuss what might happen if they combine their medicine with alcohol or other drugs, and how alcohol can affect their hydration status, sleep, **urine output** (how much you pee), and **gut motility** (how well food moves through your intestines). Ensure your teen knows what to do in an emergency. Set up a medical ID on their phone and make sure close friends know who to reach out to if something happens
- **Use technology:** Our smart devices help us keep in touch with others when we are unable to be together in person. They can also help us keep track of important information and remind us when to take our medicines and go to our appointments.
- **Embrace independence:** Start small. Have your teen begin with what they are comfortable with. Involve them in healthcare discussions. Ask them which responsibilities they feel they can handle and start there (*see* ***page 17*** *for more detailed approaches on involving your teen in their own healthcare*). Within reason, allow teens to make their own decisions. Empower them to step up and take responsibility. Teens need to learn to trust their judgment and now may be a good time for them to test the waters, while you're still there to take care of them if a setback were to happen
- **Learn from setbacks:** Life is not perfect, we are not perfect, and that is okay! We can't control everything. When things don't go as planned or a setback happens, take it as an opportunity to learn and, when applicable, plan for what to do next time

Recognizing and Supporting Teen Emotional Struggles

Teens with SBS may have stressors, anxieties, and worries that are unique to their condition. In general, when children reach the adolescent stage, doctors recommend screening them for anxiety, depression, and thoughts of suicide. If emotional well-being is a concern, contact their healthcare provider or care team and discuss support options available. Signs of depression in adolescence may include:

- Fatigue, changes in appetite and eating behavior, sleeping issues
- Feelings of hopelessness and helplessness
- Highly impulsive/risk taking behavior (such as alcohol use, crime)
- Moodiness and emotional outbursts
- Poor school performance
- Suicidal ideation
- Withdrawal and isolation, lack of interest in activities once enjoyed

If you or someone you know is experiencing suicidal thoughts or a crisis, please reach out immediately to the Suicide Prevention Lifeline at **800-273-8255** or text **HOME** to the Crisis Text Line at **741741**. These services are free and confidential.

Addressing Teen Concerns and Struggles

Dealing With Bullying and Cyberbullying

Bullying is an unfortunate problem that affects millions of youth nationwide. It can be traumatizing and contribute to poor physical and mental health, socialization, and academic performance. As a teen, if you're being affected by bullying or cyberbullying, keep a record of what's happening and where (take screenshots of messages or social media posts) and alert a parent, teacher, or other trusted adult immediately to work on a solution. As a caregiver, if your teen is being bullied, here are some suggestions on what to do:

- Be supportive. Encourage your teen to describe what's happened and reinforce that it is not their fault
- Ask specific questions to learn about what is going on, when it started, and who's involved
- Consider getting the school involved. Communicate concerns to school staff and work with them to ensure that steps are being taken to stop the bullying
- Keep records including screenshots of messages or social media posts related to the situation and put concerns in writing. These can be used to communicate with school officials or authorities, if needed
- Speak with the school and or medical team to identify available support services and counseling
- Follow up. Talk with your teen and school staff regularly to see if the situation has improved

Important Note: Oftentimes, teens who are being bullied won't ask for help. If you suspect your teen is being bullied, don't wait for them to come to you. Be aware of the signs and look out for them while talking about their friendships and interactions with peers.

FOR A LIST OF WARNING SIGNS and additional information related to identifying and addressing bullying/cyberbullying, visit **stopbullying.gov**.

Managing Isolation

Living with a serious illness such as SBS can feel isolating. As a teen, if you're feeling this way know that you're not alone. Many people with a serious illness feel this way at one time or another. When these feelings creep in, seek support and reach out to others. Talk with your caregivers, medical team, teachers, counselors, and peers about how you are feeling. Your care team may be able to help connect you with others who live with SBS so you can share what you're going through. Also, there are support groups, organizations, and social media groups that can help. As a caregiver, encourage your teen to connect with others, especially when they are unable to be with others in person. Be there to support your teen when needed. Listen to their concerns, offer advice when appropriate, and keep an eye out for signs of isolation. Also, reach out to professionals for suggestions on what you can do to help.

Managing Strong Emotions

Emotions run high during adolescence and managing SBS may elevate these emotions. This is a time when your teen's knowledge and acceptance of their SBS as a lifelong disease may develop, in addition to an evolved identity of being a person with SBS. They may be dealing with insecurities and self-doubt. As a caregiver, remind your teen that they're not alone in feeling this way. Give support as appropriate and encourage them to talk it out, write it down, and seek support from others. Listen to your teen without judgment and share personal experiences where you had to deal with difficult emotions. Give them the tools to work through their feelings and cope. Know that those same strong feelings can ultimately make them stronger, positioning them to have a full, rich life. Consider connecting your teen with other kids with SBS or similar conditions. That way, your teen has peers who "get it".

Getting Comfortable Talking About SBS With Doctors

As your teen grows, encourage them to spend one-on-one time with their doctor. Talk with your teen about their concerns and remind them that the conversations they have with their doctors are confidential and protected by federal law. Encourage them to prepare questions ahead of time and help them remember the role of each healthcare provider on their care team.

Gaining Independence and Staying on Track With Nutrition and Medicine

It can be challenging for anyone to follow a treatment or nutrition plan. This is especially true for teens. But not taking medicine as prescribed can have serious consequences. Preparing and supporting your child with a medication management and nutrition "game plan" can help them as they take on more responsibility for their health and wellness. Explain to them why they need to follow their medication and nutrition regimens, and what could happen if they don't. Stress the importance of honesty and of letting you and the doctors know if they're not taking something as directed. Where possible, discuss making the regimens more practical for them (for example, scheduling infusions around their activities, within reason). The key is having open communication and strategizing, such as by talking about tools and techniques they can use to stay on track (like setting alarms or using a medication tracker).

Talk to your doctor about your mental and physical health.

Fostering Independence During Healthcare Transitions

The transfer of healthcare responsibilities from caregiver to teen should be gradual. As a caregiver, focus on increasing their knowledge of SBS, including self-management techniques and symptom control. Talk about keeping healthy both mentally and physically and how to recognize health changes. Discuss with them available treatments, their control over the disease, and how they identify with the disease, as well as their medical and personal goals. Timing can make a huge difference, so start this process early and be sure to work with your child's medical team on a transition plan.

Many adolescents go through three phases in their transition from pediatric to adult healthcare:

Early Transition (10-12 years)	**Middle Transition (13-15 years)**	**Late Transition (16 years and up)**
CAREGIVER Manage healthcare tasks **PRE-ADOLESCENT CHILD** Participate in healthcare conversations and tasks	**CAREGIVER** Supervise healthcare tasks **ADOLESCENT CHILD** Manage healthcare tasks with supervision	**CAREGIVER** Consult on healthcare tasks **ADOLESCENT CHILD** Manage healthcare tasks with minimal supervision

Table adapted from Kinberg et al. *J Parenter Enteral Nutr.* 2023.

During each of these three transition phases, it's important to support your teen's growing independence and prepare them for the transition to adulthood. Here are some suggestions:

Pre-Adolescence	**Adolescence**	**Older Adolescence**
• Talk with your teen about their SBS and encourage them to learn more about it • Encourage them to start asking their doctors questions • Inform your teen's doctors that you're beginning to encourage them to take part in healthcare discussions • Encourage the medical team to speak directly with your teen about their care	• Encourage your teen to get involved in managing their SBS, like remembering to take their medicine on their own • Encourage them to see their doctor alone for part of their visits • Guide them through the process of making appointments and refilling prescriptions • Give your teen a copy of their health insurance card. Walk them through what each section on the card means • Review how to access and navigate their patient portal, as certain portals will default access to them at 13. Encourage them to share access with you until they are 18 • Tell them about their privacy rights and the changes they can expect when they turn 18	• Increase the number of tasks your child is solely responsible for, and encourage them to complete more and more tasks on their own • Encourage them to make their own doctors' appointments, have one-on-one conversations with their doctors, and refill their medications • Support them in their search for medical professionals who treat adults with SBS. This will help them prepare for the transfer of care at age 18 (or 21 in some cases)

As noted earlier, your teen's medical team can help create a plan for transition to an adult team and identify when that time is right. **Always talk to your teen's doctor about their journey.**

Here are questions to ask your teen's doctors to help with the transition to adult healthcare:

- When should my child start spending one-on-one time alone with you to learn how to become more independent in managing their own healthcare?
- When can we begin creating summaries of my child's medical histories together with my child?
- What do my child and I need to know about privacy, consent, and insurance changes when a teenager turns 18?
- Where can we find information to help caregivers and teens make healthcare decisions?
- At what age will my child need to start seeing a new doctor who specializes in SBS care for adults?
- Do you recommend any specific medical professionals who specialize in adult SBS care that we can look into?
- Where can we go to be connected with SBS or other chronic disease peer support groups to help with this transition?

Wondering if your teen is ready to graduate to adult healthcare?

Check out this Transition Readiness Assessment (gottransition.org/6ce/?leaving-readiness-assessment-youth) and remember to talk with your child's healthcare providers.

This information is provided as a resource and is not an endorsement, and Takeda is not responsible for their content.

FOR ADDITIONAL RESOURCES, see the **resource cards** found in this guide.

FOR MORE INFORMATION on making the pediatric to adult transition, see **section 5 of this guide**.

HEALTHCARE TRANSITIONS

Moving from one care team to another represents what is referred to as a **healthcare transition** (HCT). Healthcare for short bowel syndrome (SBS) can involve a number of these HCTs across a patient's lifetime. Three of the most common HCTs that your child may encounter include the:

1. Transition from hospital to home (discussed in section 2 of this guide)
2. Transition from one medical practice to another
3. Transition from pediatric care to adult care

Here we will focus on the pediatric to adult transition, as well as discuss some considerations you can use for other HCTs.

Pediatric to Adult Healthcare Transition

For a child with SBS, perhaps one of the most important care transitions is the purposeful and planned movement from pediatric-centered care to adult-centered care. The transition is a multistep process that starts in early adolescence and continues through young adulthood. The transition addresses the medical, psychosocial, and educational needs of **adolescents and young adults** (AYA). It includes initial planning and gradual shifting of responsibility from caregiver to AYA and from healthcare provider to AYA.

SEE SECTION 4 of this guide for an overview of the healthcare transition process.

The pediatric provider typically initiates the transition, but both pediatric and adult healthcare providers are responsible for ensuring a safe and complete transfer. The goal is to transfer care to adult providers by age 18 to 21, but this timing may vary. The term **"transfer of care"** is the moment when the care responsibility moves from the pediatric provider to the adult provider. Be sure that your AYA is as involved as possible in this process and that you and the healthcare team are discussing with them their transition goals along the way.

Transition planning is an important part of clinical care for all adolescents and young adults. Start talking with your child's healthcare team around age 12 to learn more about the steps you and your child can take to prepare for the pediatric to adult transition.

In **section 4 of this guide**, we discussed some steps you can take while preparing for this transition. Here we will discuss some practical strategies you can use during this time:

Multidisciplinary Collaboration

Multidisciplinary collaboration involves a team of healthcare professionals including doctors, **advanced practice providers** (APP) (for example, **physician assistants** [PAs] or **nurse practitioners** [NPs]), nurses, dietitians, social workers, and pharmacists. This team works together and in collaboration with patients and families to develop a plan centered around the needs of your child. The team may coordinate treatment goals, like nutritional support, medication management, and monitoring your child's progress. By sharing expertise, exchanging information, and coordinating care, healthcare professionals can help ensure a smooth transition, prevent gaps in care, and quickly address any difficulties that may arise. Work with the medical team to create a transition plan that is tailored to your child's needs. Effective communication and collaboration are key to getting the best outcomes and promoting **continuity of care** (continuous care, without disruption).

Multidisciplinary Care Roles

There are several roles in a multidisciplinary SBS care team, with nutrition and fluid management being a critical goal of the team. Depending on the institution and its resources, the roles of team members may overlap. The team is usually led by a gastroenterologist or surgeon with experience in **intestinal failure** (IF)/SBS. The ideal scenario would be to have both doctors involved and working together, along with a dietitian.

TO LEARN MORE about the different multidisciplinary team members that may be involved in your child's care, see the **Multidisciplinary Team (MDT) List resource card**.

Patient Education

A key component of a successful transition of care is the education that you and your child receive.

- You and your child will learn how to manage SBS, including adjusting diets, administering medicines, and recognizing potential complications
- Ask your child's medical team to review educational materials with you and your child. It is encouraged to ask for visual aids, request written materials to review later, and ask for the medical team to repeat any instructions
    - You and your child separately can repeat in your own words to clarify what you learned
    - Speak up if you have questions about the material or would like to learn in a different format
- Prepare your child for how adult-centered care may look different from pediatric-centered care. Pediatric care teams often handle more tasks for families, such as communicating directly with insurance companies and pharmacies, scheduling appointments, and calling home if appointments are missed. With adult-centered care, there are more consequences for not being an active participant in your own care. This shift can cause a bit of culture shock for patients and their families
- Just like when you, the caregiver, first learned how to take care of your child, your child must now learn and practice how to do the same. Ask medical team members to demonstrate these care techniques in front of you and your child. Help supervise your child as they practice these techniques. Remind the child that this is a safe place to learn and make mistakes. Mistakes are expected to happen. As a caregiver, share any memories from your experiences. Discuss what part of the process is most important and cannot be skipped and explain the why behind every action. Knowing the why can help comprehension and adherence by helping to make sense of the medical steps, instead of them just being a series of chores
    - Your child should also practice taking medicines and supplements on the right schedule, giving themselves their own tube feedings, if applicable, and making/keeping track of their medical appointments

By being empowered with the necessary knowledge and skills, adolescents, and young adults with SBS can actively participate in their own care and make informed decisions, promoting better health outcomes. However, feeling empowered and confident in their routine may take time. Some days and weeks will be better than others. Allow for grace and reinforce the message that it is okay to ask for help from caregivers or clinicians at any time. They are always ready to help and want you to succeed on your own!

TO LEARN MORE about managing SBS and transitions of care, see sections 1 through 4 as well as the resource cards found in this guide.

Support Programs and Home Care

Entering into adulthood is about becoming independent and being responsible for your own care. Your child may even be living on their own for the first time. Support programs can be a very important source of help while your child is going through all of these changes. For example:

- **Patient assistance programs** can help with the costs associated with SBS care, such as by covering the cost of medicine or providing a discount
- **Social work services** can assist with accessing community resources and navigating insurance coverage
- **Support groups** can provide emotional support and give practical advice from people in similar situations

Another form of support is from home healthcare services. Home healthcare professionals, such as nurses, can be instrumental during your child's transition to adulthood, and they're also useful when going back home after a hospital stay. These professionals come to your home and provide services such as:

- Administering enteral and parenteral nutrition
- Administering medicines
- Caring for wounds
- Doing lab draws, if applicable
- Monitoring vital signs
- Doing weekly check-ins

These home healthcare professionals can work closely with your child and your family, providing ongoing support, education, and regular assessments to ensure optimal management of SBS. It is important to note that not all home healthcare companies or professionals are the same and it may take time to find the company and professionals that are best for your child. If you do use home healthcare services, be sure to point out your preferences for your child's care, such as specific techniques you use to minimize the risk for infection.

Considerations for Other Potential Transitions

Other types of healthcare transitions can occur many times over the course of your child's life. It's important to consider and plan for these potential challenges, rather than waiting for them to happen.

Let's discuss a few examples of these HCTs along with some considerations to help navigate them.

Employment and Health Insurance Changes

Be aware of when your child's health insurance coverage will end. Under the Affordable Care Act, plans that offer dependent coverage allow a child to remain on their parent's health plan until they are 26 years old, but it is best to confirm this with the insurance provider as some states and plans may have different rules. It's important to plan for this change ahead of time because this process can take a while, and you want to make sure there are no lapses or gaps in coverage.

If you're employed, speak with your company's Human Resources department or, if applicable, Medicaid and/or Medicare to understand your insurance policy, what it does and doesn't cover, the ability to use out-of-network providers, how to submit claims, and how a change in coverage might impact services such as home healthcare.

Contact the insurance provider to check if your child's current healthcare providers take their new insurance. Do this early so that if any changes to their care team are required, you can identify new healthcare providers before the change in insurance coverage takes effect.

SEE THE ADDITIONAL RESOURCES resource card found in this guide for resources to use with your child to better understand their health insurance.

Geographic Changes

If you're moving but want to keep your current care team, be sure to inform them of your new address. Discuss how often in-person visits are needed and if telemedicine can be used. If you need to switch providers, begin your search several months before your move and alert your current care team to prepare for the transition of medical records. Find a new pharmacy (if applicable), identify the nearest emergency room, and update your emergency contact cards/information.

If moving into a dormitory or other college/university housing, discuss your needs with the housing department to develop a plan for safe deliveries of medicine and supplies. Ensure there is an adequately sized refrigerator in your child's dorm room or the residence halls. Also, do your research to determine where they can get food for their special dietary needs, both on and off campus.

Planning for, Starting, or Changing Home Healthcare

If you are thinking about or just starting home healthcare, work with your child's care team to develop a detailed home care plan that you can all review together. Many times, your care team can recommend a home healthcare company. Be sure to interview your options. Contact the home healthcare company to discuss what they will be responsible for. Every company is different, so it is important to understand the services they offer and how they can help your child.

SEE THE OLEY FOUNDATION'S SPRING 2023 NEWSLETTER for a list of questions to ask potential home healthcare provider: **issuu.com/oleyfoundation/docs/spring_2023_lifeline_final**.

This information is provided as a resource and is not an endorsement, and Takeda is not responsible for their content.

Transitioning Home Following a Hospital Stay

If your child winds up in the hospital, comprehensive discharge planning can help facilitate a safe transition home while helping to ensure continuity of care. Discharge planning should start at admission. It should involve setting realistic goals, addressing potential obstacles, stating your wishes for a home routine, and organizing necessary resources and follow-up appointments.

This planning should address your child's specific needs. It involves evaluating their current medical condition, nutritional requirements, the need for psychological support, learning how to operate new devices and manage new routines, and identifying any potential risks and complications that may arise during the transition and who to contact.

With the involvement of your child's multidisciplinary healthcare team, you can create an individual care plan for a smooth transition home. Be sure to ask your child's medical team to speak with their home healthcare company, if applicable, to inform them of the plan and alert them to any changes or needs specific to your child's transition home. If any new medicines, treatment, or supplies were started during the hospital stay, make sure they are ordered and covered by your insurance so that there isn't a delay in getting them when your child comes home.

You Can Do It

The transition of care is likely to be complex and will require careful planning, education, home healthcare services, and multidisciplinary collaboration. While the *transfer* of care from pediatric to adult may occur as a moment, the *transition*, with all its key components, is a gradual process, taking place over time. Ongoing partnerships with your child's medical team are important not only for the success of future transitions in your child's life, but ultimately, to their continued health and well-being. **Always talk to your child's doctor about their treatment considerations.**

MULTIDISCIPLINARY TEAM (MDT) LIST

Who may be part of your care team?

Your child will be closely followed throughout their short bowel syndrome (SBS) journey by an extensive team of healthcare professionals for more individualized and coordinated care. The specific team members may vary depending on your child's needs and the resources available in the healthcare setting.

Here are some of the team members that your child may receive care from:

Gastroenterologist	A healthcare provider who specializes in disorders and diseases of the digestive system. They oversee the treatment and care strategy for a person with SBS
Surgeon	A healthcare provider who specializes in surgery. They determine if surgery is needed at any point during the patient's journey and carry out the procedure
Dietitian	A healthcare provider who has special training in diet and nutrition. Dietitians offer advice on healthy eating habits to help people improve their health and well-being. For a child with SBS, the dietitian plays a critical role by creating tailored nutrition plans and monitoring the child's growth
Nurse Practitioner or Physician Assistant	A healthcare provider helps physicians manage patient care and can prescribe treatment
Registered Nurse	A healthcare professional who helps care for a patient in the hospital and at home. They may administer medicine, nutrition, and fluids. They may also help coordinate home care needs and patient education
Pharmacist	A healthcare professional who fills prescriptions and helps manage the medicines, nutrition, and fluids prescribed. They review all medications the patient is taking to be sure they all work safely together inside the body and provide education about these prescriptions, such as how they should be taken and what may be expected
Social Worker	A professional who offers practical assistance using community resources to help children and caregivers receive the support they need. One example is by helping with the discharge process and making sure the children and caregivers are informed on continuation of care. Some social workers, such as those with a Master of Social Work (MSW) degree, may be licensed to also offer counseling to support emotional and mental health
Speech Language Pathologist	A therapist who evaluates and assists with feeding problems the child may be having due to trouble swallowing, or not being able to move the muscles in and around their mouth properly
Occupational Therapist	A therapist who evaluates and treats people with injuries, illnesses, and disabilities. They can help children meet goals to develop, recover, improve, and maintain skills needed for daily living and working. For people with SBS, they can help with feeding issues, fine motor skills and sensory problems that may arise
Physical Therapist	A therapist who evaluates and assists with delays in development that may arise and helps the patient improve strength, mobility, and gross motor skills
Psychologist	Mental health professional who supports the emotional and mental health of patients by providing strategies to help them cope. One of the main ways that psychologists do this is through counseling
Psychiatrist	Mental health professional who diagnoses and treats emotional, behavioral, and mental health disorders, sometimes with medications
Caregiver	Plays a pivotal role as a loving and supportive partner throughout the journey, providing direct care to the child and helping them manage their disease, nutrition, medications, and daily activities at home. They also advocate for the patient's needs and offer emotional support and education

LIST OF POSSIBLE MEDICATIONS/SUPPLEMENTS

Your MDT may prescribe different medications/supplements to help manage symptoms. Here are some examples:

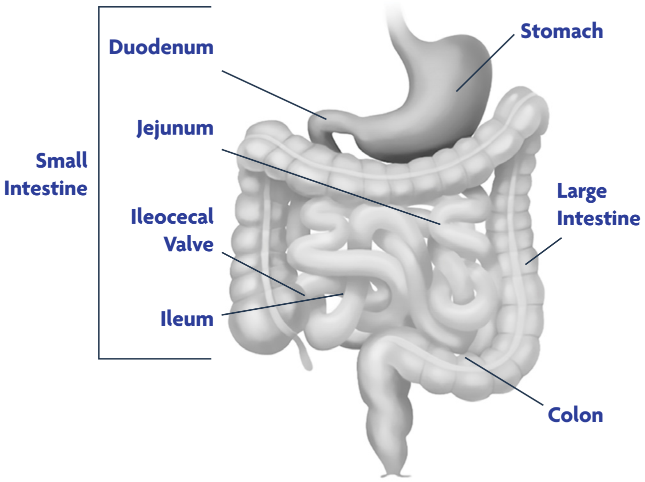
Medications/Supplements	Purpose
Antibiotic	Prevents and treats bacterial growth
Antimotility agent	Slows down the time it takes food to move through the intestines (this helps your intestines absorb more fluids and nutrients)
Anti-secretory agent	Reduces stomach acid in the intestines
Bile acid binder	Prevents diarrhea from bile acid
Histamine-2 (H2) blocker	Decreases stomach acid production
Intestinal hormonal agent	Improves how well the intestines absorb nutrients
Pancreatic enzyme replacement therapy	Helps with digestion
Probiotics	Helpful in fighting short bowel bacterial overgrowth
Proton pump inhibitors	Decreases stomach acid production
Vitamins and mineral supplements	To make up for low intake or low absorption of vitamins and minerals from food

Not intended to be a complete list of possible medications/supplements nor to describe approved indications or all potential uses of these medications/supplements as they may be used for symptom management in other conditions as well. **Always talk to your child's/adolescent's doctor about all possible medications or supplements before trying anything new.**

ANATOMY WORKSHEET

This worksheet can be used with your surgeon or gastroenterologist. Ask them to fill in the diagram below, marking which of your anatomy was removed, and noting what percentage or what length in centimeters of the intestines *remain*. Ask your doctor to keep a copy for their records and reserve a copy for yourself. You can use this document to inform other doctors, including emergency department staff. After any additional procedures ask the surgeon or gastroenterologist to update the diagram.

Keep your diagram up to date as things may change!



Patient Name:

Date:

Percentage or Centimeters Remaining:

Ask your surgeon to take any notes or make illustrations in the space below

NUTRITION

Nutrition Catered to Short Bowel Syndrome (SBS)

Short bowel syndrome (SBS) impacts the intestine's ability to absorb nutrients and fluids. Each person with SBS is affected differently. They will have different nutritional needs and ways of receiving nutrition. For example, some may drink special formulas or beverages, eat special diets, or have feeding tubes, and some may receive nutrition and fluids through the bloodstream. While each person will face their own challenges, nutrition is essential to managing SBS. Talk to your child's doctor regarding diagnosis, treatment, and medical advice, especially before trying anything new, such as new diets.

Individualized nutrition can help:

- Ensure that the specific nutritional needs of your child are being met
- Prevent **dehydration** (when your body doesn't have enough fluids)
- Minimize symptoms such as excessive diarrhea, bloating, cramping/stomach pain, signs of dehydration, and malnutrition
- Enable the intestines to better adapt to changes following surgery

Work with your child's medical team, which may include a dietitian, to discuss goals and create a nutrition plan that is right for your child. Remember that as your child grows and their intestines **adapt**, (ie, the remaining intestines change so that they can properly digest nutrients and fluids) this plan should be revisited and revised.

Types of Nutrition Therapy

Let's start with an overview of the different methods of administering nutrition. Following surgery, your child might be on **enteral nutrition (EN)** (tube feeding), **parenteral nutrition (PN)** (intravenous [IV] feeding), or both for a period of time in order to meet their nutritional needs. Your child may need PN and EN *in addition* to **oral nutrition** (by mouth) to ensure they are nourished and to help their intestines heal after surgery. The amount of time on PN or EN varies and depends on your child's needs.

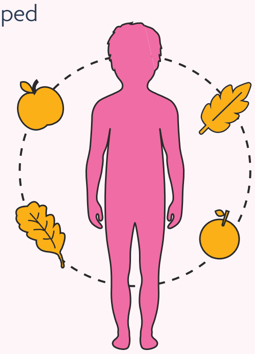
Let's take a look at the characteristics of these two types of nutrition therapy:

Characteristics of Enteral Nutrition:

- A liquid form of nutrition given through a feeding tube. This includes breast milk or formula, homemade food blends, or a combination of the above depending on your child's age and type of nutrition therapy
- Feeding tubes can either be inserted:
  - Through the nose and then into the stomach (**nasogastric tube**) or small intestine (**nasoenteral tube**)
  - Right into the stomach (**gastrostomy tube** [commonly referred to as a **G-tube**]) or small intestine (**jejunostomy tube** [commonly referred to as a **J-tube**]) through the skin
- It can be reduced or gradually stopped with the help of a healthcare team
- It can help intestines adapt over time

Characteristics of Parenteral Nutrition:

- A liquid form of nutrition given directly into the bloodstream, since the intestines are not working properly
- It may be reduced or gradually stopped with the help of a healthcare team
- It does not help intestines adapt
- Although life-saving, long-term use of PN can result in complications. Talk with your child's healthcare team about potential problems



To help promote intestinal adaptation and to reduce dependence on PN, oral or EN should be encouraged when possible.

Nutritional Considerations

Understanding how the things your child eats and drinks makes them feel can help you make decisions related to nutrition (ie, what to choose and what to avoid). A food journal can be a helpful tool when confusing symptoms occur. After eating, write down what, when, and how much your child ate. Track how they reacted to the food (eg, they felt good afterward or they had gas). It's important to continue to do this over time, as your child's ability to handle different foods may change. As your child gets older and more independent, encourage your child to keep a food journal for themselves. And be sure to share this information with your child's healthcare team and dietitian (if you have one).

Additional considerations to try while building an SBS nutrition plan include:

General Guidelines

- For infants, breast milk is the preferred milk, when possible, as it has been shown to improve the tolerance of the digestive system
- To prevent **oral aversion** (the fear or hesitation to eat or drink), if deemed safe by your child's healthcare team, it is recommended for children to eat food orally and discover various flavors and textures
  - If your child eats minimally by mouth, provide taste exposures for 5 minutes at a time, two to three times daily on days leading up to tube feeding
    - For infants, try giving them a pacifier dipped in breast milk or formula to introduce them to the taste
  - **Talk with your child's healthcare team before starting any oral feeding or taste exposure routine**

- Balance oral eating skill development with EN. Talk with your child's healthcare team to ensure when and if it is safe and appropriate to introduce foods by mouth to help with developing oral motor and sensory skills. **Talk with your child's healthcare team to ensure it is safe and appropriate to do so**
    - After 6 months of age, **complementary foods** (foods other than breast milk or formula that help provide needed extra nutrition as they grow) can be started, if appropriate and safe as instructed by your child's healthcare team. This also helps to prevent oral aversion
- Eat slowly and chew foods well to help break them down. This makes it easier for the intestines to absorb nutrients and help stop blockages as food passes through the intestines
- Eat six to eight small meals or snacks per day to put less stress on the intestines
- Avoid sugary foods and drinks
- Drink **oral rehydration solution** (ORS), which is a balanced mixture of salt, sugar, and water. This helps the intestines absorb more fluids
- To help prevent diarrhea, eat food before drinking liquids at each meal and limit the amount of liquids consumed during a meal
- Eat **protein** at every meal such as meat, fish, eggs, nuts, milk, yogurt, and tofu
- With SBS, salt can be difficult to absorb and retain. Eat salty foods such as deli meats, salted pretzels, and cheese. It is okay to add salt to foods
- It's hard to get enough calories when you have SBS. Consider adding **calorie boosters** such as corn starch, crushed saltines, avocado, or hummus to foods
- If instructed by your healthcare team, take a multivitamin

Guidelines based on your child's anatomy (as we learned in section 1 of this guide, your child's anatomy may also impact the types of foods they can eat and the way different foods affect them):

- **If their colon IS connected:**
    - Eat starchy carbohydrates (eg, bread, bagels, potatoes, rice, pasta, chickpeas, and lentils)
    - Don't limit fat. It helps them get the right amount of calories
    - Eat sparingly foods high in **oxalates**, which are found in coffee, tea, chocolate, nuts, and soy products. Oxalates can cause kidney stones
    - Eat foods and take supplements that contain fiber

- **If their colon IS NOT connected (child has an ostomy instead):**
    - Don't limit carbohydrates, as their body needs them for energy
    - Eat plenty of fat in order to ensure they're getting enough calories. Also, try replacing saturated fats for unsaturated fats
    - Don't worry about eating foods high in oxalates

For a more detailed breakdown and description of the different nutrients found in food, what they do, and how they might affect your child, see "A Kid's Guide to Short Bowel Syndrome" (information provided on the **Additional Resources card** found in this guide).

The Trouble With Eating is...

As discussed above, there are numerous strategies to help your child to get the nutrients and fluids they need to be healthy. But absorbing nutrients and fluids is not the only challenge that may impact your child. For some children, eating or drinking by mouth can be challenging:

- Some children may have problems chewing and swallowing. Food and liquids may "go down the wrong pipe" into the lungs
- Your child may feel self-conscious or embarrassed about the special food and fluids they need to eat around others
- Your child may develop an oral aversion. This can happen when they don't like the feel or taste of food, for example. They might also connect eating and drinking with belly pain or diarrhea, especially if this is something they've experienced in the past

If your child has any of these eating problems, they're not alone. Occupational therapists as well as speech language pathologists can help your child develop the skills they need to take in more food by mouth over time, decrease their fear of eating, and be more accepting of foods. These things may take a while and that is totally okay! Remember, a food journal can be a helpful tool in noticing your child's responses to foods over time.

Work together to modify your child's diet to avoid troublesome foods and fluids, reduce pain after eating or drinking, and reduce the likelihood of bathroom emergencies.

If your child shares with you that they are embarrassed to eat around others, be supportive. Listen without judgment and let them know that it is okay for them to feel that way. Encourage them to talk with you, their medical team, a counselor, or a specialist who can offer ways to deal with these feelings. Let them know that no matter what, they are amazing, they are brave, and they are doing the best they can.

The Right Nutrition Plan Is a Moving Target

No matter how your child receives their nutrition, the right plan is one that lets them live their life in the fullest way possible. It should be one that nourishes them, helps them grow, makes them feel good, and adapts to whatever life brings them. **Always talk to your child's doctor before trying anything new OR any nutrition plan.**

ADDITIONAL RESOURCES

The resources compiled below contain information on all things short bowel syndrome (SBS). They are broken down into categories to help you easily locate the topic you want to explore. For quick access, website links are included for each resource, apart from the names of various books. This list is not all-encompassing. For additional resources, please talk to your healthcare team.

This information is provided as a resource and is not an endorsement, and Takeda is not responsible for their content.

Books

- ***A Kid's Guide to Short Bowel Syndrome*** by Tegan Medico, MS, MPH, RDN, CNSC
- ***When Jeremy Jones' Stomach Stopped Working*** by Anne E. Reckling
- ***Henry Imagines: An Adventurous View of Short Bowel Syndrome*** by Joseph L. Bowes
- ***The Adventures of Team Super Tubie*** by Kristin Meyer

Enteral, Oral, and Parenteral Nutrition

- The Oley Foundation: **oley.org**
- Staying Hydrated With Oral Rehydration Solution (ORS): **www.shortbowelsyndrome.com/Content/pdf/Recipe_Book_DIGITAL.pdf**

Health Insurance

- Boston Children's Hospital, A Young Adult's Guide to Health Insurance: **childrenshospital.org/sites/default/files/media_migration/00d61248-ab4b-477e-9061-43726aa59670.pdf**

Medical Abbreviations and Acronyms

- Short Gut Syndrome: Patient, Family & Professional Support Groups: **shortgutsupport.com/abbreviations.php**

Ostomies

- United Ostomy Associations of America (UOAA): **uoaa.org**

Rare Disorders

- National Organization for Rare Disorders (NORD®): **rarediseases.org**
- Angel Aid: **angelaidcares.org**
- Global Genes®: **globalgenes.org**

Short Bowel Syndrome

- The Gutsy Perspective: **thegutsyperspective.org**
- SBS Strength Inside: **www.shortbowelsyndrome.com**
- Short Bowel Syndrome Foundation: **shortbowelfoundation.org/**
- The Youth Rally: **youthrally.org**
- *American Gastroenterology Association*, short bowel syndrome (SBS): **patient.gastro.org/short-bowel-syndrome-sbs/**

Transitions of Care

- Kinberg S, Verma T, Kaura D, Mercer DF. Optimizing transition from pediatric to adult care in short bowel syndrome and intestinal failure [published online ahead of print, 2023 Apr 2]. *JPEN J Parenter Enteral Nutr*. 2023;10.1002/jpen.2499. doi:10.1002/jpen.2499: **aspenjournals.onlinelibrary.wiley.com/doi/epdf/10.1002/jpen.2499**
- Connected Care SickKids®: **connectedcare.sickkids.ca**
- Got Transition®: **gottransition.org**
- Short bowel syndrome (SBS): From teen to adult care: **patient.gastro.org/short-bowel-syndrome-sbs-teen-to-adult-care/**

Video

- Emergency Central Venous Access Device (CVAD) Procedures: **youtu.be/B5hYzaCpOwo**
- SickKids® Intestinal Failure: Video for Adult Caregivers: **youtube.com/watch?v=QAYI8z11uIA**
- SickKids® Intestinal Failure: Video for Classmates: **youtube.com/watch?v=LBUM3QZjJWA**

GLOSSARY

Advanced practice providers (APP): These include **physician assistants (PAs)** and **nurse practitioners (NPs)**.

Antibiotic: Prevents and treats bacterial growth.

Antimotility agent: Slows down the time it takes food to move through the intestines (this helps your intestines absorb more fluids and nutrients).

Anti-secretory agent: Reduces stomach acid in the intestine.

Aseptic non-touch technique (ANTT): Using a specified clean method of completing a procedure to make sure there is no contamination with germs in order to prevent infections.

Bile acid binder: Prevents diarrhea from bile acid.

Biofilms: A group of bacteria stuck to each other and a surface.

Calorie boosters: Complex carbohydrates (starches) and/or fats that mix well into food and fluids such as corn starch, crushed saltines, avocado, or hummus that are added to foods to help the person receive an adequate amount of calories.

Caregiver: Plays a pivotal role as a loving and supportive partner throughout the journey, providing direct care to the child and helping them manage their disease, nutrition, medications, and daily activities at home. Also advocates for the child's needs and offers them emotional support and education.

Central lines: Catheters inserted into a vein used to deliver parenteral nutrition, intravenous (IV) fluids, and/or medicines into the bloodstream.

Central Venous Access Device (CVAD): Also known as a central line, is a thin, soft, flexible tube. This long tube, also called a catheter, is placed in a vein that leads to your heart.

Complementary foods: Foods other than breast milk or formula that help provide extra nutrition as infants grow.

Continuity of care: Continuous coordinated healthcare for a patient, which is ongoing without disruption.

Crohn's disease: A disease that causes swelling in the intestines that can lead to blockages.

Dehydration: When your body doesn't have enough fluids to maintain regular functions.

Dietitian: A healthcare provider who has special training in diet and nutrition. Dietitians offer advice on healthy eating habits to help people improve their health and well-being. For a child with SBS, the dietitian plays a critical role by creating tailored nutrition plans and monitoring the child's growth.

Duodenum: This is the first and smallest section of the small intestine. This is where important digestive juices used to break down food mix together: bile and digestive enzymes. It is the main location where iron and other important nutrients are absorbed.

Electrolytes: Minerals such as salt and potassium that are important for normal functions of the body, such as heart and muscle activity.

End-jejunostomy: Surgery where the colon, ileum, and some of the jejunum is removed. The doctor then connects the rest of the jejunum to the belly.

Enteral nutrition: A liquid form of nutrition given through a feeding tube. This includes breast milk or formula, homemade food blends, or a combination of these things depending on the person's age and type of nutrition therapy.

Feeding tubes: They can be inserted through the nose and go into the stomach (**nasogastric tube**) or small intestine (**nasoenteral tube**). They can also be inserted right into the stomach (**gastrostomy tube** [commonly referred to as a **G-tube**]) or small intestine (**jejunostomy tube** [commonly referred to as a **J-tube**]) through the skin.

Gastroenterologist: A healthcare professional who specializes in disorders and diseases of the digestive system. They oversee the treatment and care strategy for a person with short bowel syndrome (SBS).

Gastroschisis: When the intestines stick out of the body through the belly button.

Gut motility: How well food moves through the intestines.

Histamine-2 (H2) blocker: Decreases stomach acid production.

Healthcare transition (HCT): The structured process of moving from one healthcare team to another.

Hirschsprung's disease/intestinal aganglionosis: A condition where some nerve cells are missing in the large intestine, preventing it from working properly. This can lead to blockages in the intestines.

Hydrated: Consuming and absorbing enough fluids for the body to function properly.

Ileocecal valve (ICV): This valve connects the last part of the small intestine to the large intestine, and it acts as a gatekeeper between the two. It helps keep nutrients in the small intestine longer, allowing more nutrients to be absorbed, and it keeps the contents of the large intestine (digested food and bacteria) from making their way back into the small intestine.

Ileum: The last and largest section of the small intestine, which is responsible for absorbing important vitamins such as B12. It is also where fluids that aid in digestion are taken back to be reused by your body.

Individualized education plan (IEP): A written plan outlining individual specialized education accommodations and services to help students overcome potential educational barriers created by their condition.

Intestinal atresia: When the intestines haven't formed correctly.

Intestinal failure (IF): When the intestines cannot digest and absorb enough nutrition for normal functions. SBS most commonly leads to IF due to the removal of a large part of the small intestine.

Intestinal hormonal agent: Improves how well the intestines absorb nutrients.

Intestines: Tube-shaped organs that connect your stomach to your anus. They are responsible for digesting food, absorbing nutrients, and taking in water and minerals.

Jejunocolic anastomosis: Surgical connection of the jejunum and the colon. Sometimes, the ileum is removed.

Jejuno-ileal anastomosis: Surgery where the doctor removes parts of the jejunum and ileum. The colon stays unaffected.

Jejunum: The middle section of the small intestine, which processes nutrients and the medicines you take.

Large intestine: This is often referred to as the **colon**. It is responsible for taking in water and remaining nutrients, including **electrolytes** (such as salt and potassium) not absorbed by the small intestine. It is also responsible for **transforming** or changing broken down food from a liquid state to a more solid state known as **stool**.

Malabsorption: This means your body has trouble absorbing nutrients from the food you eat.

Malnutrition: When your body doesn't have enough nutrients.

Malrotation: When the intestine doesn't fully rotate into its normal position at birth.

Midgut volvulus: When blood supply to the middle section of the small intestine is completely cut off.

Multidisciplinary team (MDT): An extensive team of healthcare professionals formed for the purpose of providing more individualized and better coordinated care.

Necrotizing enterocolitis: When the lining of the large intestine becomes swollen, causing some of the tissue to die.

Nurse practitioner (NP): A healthcare provider who helps physicians manage patient care and can prescribe treatment.

Occupational therapist: A therapist who evaluates and treats people who have injuries, illnesses, and disabilities. They help children meet goals to develop, recover, improve, and maintain skills needed for daily living and working. For people with SBS, occupational therapists can help with feeding issues, fine motor skills, and sensory problems that may arise.

Oral aversion: The fear or hesitation to eat or drink.

Oral nutrition: Nutrition obtained by the body from consuming food by mouth.

Oral rehydration solutions (ORS): A balanced mixture of salt, sugar, and water that can help the small bowel wall absorb more fluids when dehydration occurs.

Ostomies: Surgical openings created from a place inside the body and leading to outside the body so that waste can leave your body.

Oxalates: Can cause kidney stones and are found in coffee, tea, chocolate, nuts, and soy products.

Pancreatic enzyme replacement therapy: Helps with digestion.

Parenteral nutrition (PN): A liquid form of nutrition given directly into the bloodstream (intravenous [IV] feeding), because the intestines are not working properly.

Patient assistance programs: These programs can help with the costs associated with SBS care, such as by covering the cost of medicine or providing a discount.

Pharmacist: A healthcare professional who fills prescriptions and helps manage the medicines, nutrition, and fluids prescribed for a child. They review all medications the child is taking to be sure they all work safely together inside the body and provide education about these prescriptions, such as how they should be taken and what may be expected.

Physical therapist: A therapist who evaluates and assists with delays in development that may arise and helps the patient improve strength, mobility, and gross motor skills.

Physician assistant (PA): A healthcare provider who helps physicians manage patient care and can prescribe treatment.

Probiotics: Helpful in fighting short bowel bacterial overgrowth.

Protein: Complex substances that are needed for many body functions. They can be found in foods such as meat, fish, eggs, nuts, milk, yogurt, and tofu.

Proton pump inhibitor: Decreases stomach acid production.

Psychiatrist: Mental health professional who diagnoses and treats emotional, behavioral, and mental health disorders, sometimes with medications.

Psychologist: Mental health professional who supports the emotional and mental health of patients by providing strategies to help them cope. One of the main ways that psychologists do this is through counseling.

Registered nurse (RN): A healthcare professional who helps care for patients in the hospital and at home. They may administer medicine, nutrition, and fluids. They may also help coordinate home care needs and patient education.

Short bowel syndrome (SBS): A rare, serious, and lifelong disorder. SBS prevents your body from absorbing nutrients, water, and electrolytes effectively. SBS can occur when part of the intestines is missing, removed, or damaged, and the intestines may not work properly.

Small intestine: Where digestion and absorption of nutrients occurs. It is divided into three main parts: the **duodenum**, **jejunum**, and **ileum**.

Social worker: A professional who offers practical assistance using community resources to help children, caregivers, and other people receive the support they need. One example is by helping with the discharge process and making sure the child and caregiver are informed about continuation of care. Some social workers, such as those with a Master of Social Work (MSW) degree, may be licensed to also offer counseling to support emotional and mental health.

Social work services: Services provided by social workers who can assist with accessing community resources and navigating insurance coverage.

Speech language pathologist: A therapist who evaluates and assists with feeding problems the patient may be having due to trouble swallowing or not being able to move the muscles in and around their mouth properly.

Stoma: Surgical opening from a place inside the body to the external of the body.

Stool: Broken down and digested food from a liquid state to a more solid state that leaves the body as waste.

Support groups: These groups can provide emotional support and give practical advice from people in similar situations.

Surgeon: A healthcare provider who specializes in surgery. They determine if surgery is needed at any point during the child's journey and carry out the procedure if needed.

Transfer of care: The moment when the care responsibility moves from one provider or healthcare team to another, such as from the pediatric healthcare team to the adult healthcare team.

Trauma: Injury.

Urine output: How much you pee.

Vitamin deficiency: When your body has fewer vitamins than it needs for normal functions.

Vitamins and mineral supplements: To make up for low intake or low absorption of vitamins and minerals from food.

504 accommodation plan: Formal plan that schools develop outlining accommodations for kids with qualifying disabilities, such as short bowel syndrome (SBS). This law ensures they can learn alongside their peers in a regular classroom.

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SBS
SHORT BOWEL SYNDROME
STRENGTH INSIDE