

American Pediatric Surgical Nurses Association Inc. Safety and Excellence in the Surgical Care of Children

PATIENT AND FAMILY INFORMATION SHEET

Ileoanal J Pouch

What is a J Pouch?

A J Pouch is a surgery that involves removing the large gut (sometimes called the large intestine or colon) and the anus then making an inside pouch that can hold stool/ "poop". The inside pouch is often called a J Pouch and is made by using some of your child's small gut. An ostomy (stoma) is a piece of gut joined to your skin where stool will pass into a stoma bag while the J pouch heals. The surgery can be done in one, two, or three operations known as "stages" based on your child's state of health.



How is the decision made that surgery is needed?

Here are some of the symptoms your child may have:

- Surgery may be needed when different medical treatments and medications have been tried and the ulcerative colitis symptoms do not improve.
- Surgery may be recommended when your child has a family member that was diagnosed with Familial Adenomatous Polyposis (FAP). In FAP, polyps slowly form throughout the colon and rectum and may be inherited.

Preparing for Surgery

- *Before surgery,* your child will need to clear out their bowel (intestines) from stool (poop). This is called a bowel prep. It is important to follow your healthcare team's instructions on how to do a bowel prep the day before your child comes to the hospital for surgery.
 - Your child will be limited to a clear liquid diet. Ask your healthcare team what liquids are ok for your child to drink.
 - $\circ~$ Some children may be allowed to do a bowel prep at home depending on their ability to drink the required fluids or the age of the child.
 - $\circ~$ Ask your healthcare team, if this is an option for your child.
- Based on your child's condition your child may be admitted to the hospital the day before surgery for a medicine (polyethylene glycol) to clean out their intestines.
 - There is a possibility that the child may have a nasogastric tube or an "NG tube" placed. This is a tube that is placed through a nostril, down the esophagus and into the stomach. That way the child does not have to drink large amounts of the bowel prep medicine.
 - Your child may be on intravenous fluids (IV Fluids) for hydration.
 - Your child's healthcare team may also do blood testing.



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Surgical Procedure: Based on your child's state of health, the operations can be one, two, or three separate surgeries often called "stages" to make a J Pouch. Each surgery can take many hours. Here is a review of the different surgical procedures:



In general, the colon is removed, a stoma is made, a J Pouch is created, and the stoma is later closed.



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3 Stage Procedure

1st stage: Colectomy (removal of gut/large bowel) and temporary ileostomy stoma is made

2nd stage: Ileoanal J pouch is made and new ileostomy stoma is made

3rd stage: lleostomy stoma closed





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After the Operation: Post op Care

- As soon as your child wakes up after surgery, someone from the recovery room will call you so you can be with your child again.
- Your child will receive IV fluids for hydration and pain medications for comfort.
- Your child may not be allowed to drink or eat for a day or so after surgery.
- Your child may have a tube in their nose called a nasogastric tube to remove gas/fluids from their stomach until he/she is ready to drink or eat. This helps to prevent vomiting.
- Your child will be allowed to eat when they are passing stool or gas from their ostomy or bottom.

What does my child need to do after the surgery?

- After the surgery, your child will need to:
 - o Do deep breathing exercises.
 - Get out of bed, sit in a chair and walk around with help.
 - \circ \quad You and your child will learn to take care of the new ostomy

When can we go home?

- Your child will stay in the hospital until he/she is eating well, can keep down fluids, is peeing well and pain is controlled with pain medicines by mouth.
- You and your child will need to be able to care for your new ileostomy. You will learn how to empty stool from the pouch and changing the pouch—this can take about 5-7 days after surgery.

Diet recommendations after J pouch surgery:

- You child may need to make some changes to their diet. These changes may be temporary or permanent.
- It is important to have a well-balanced diet that has vitamins and minerals, and has foods from all the major groups (grains, vegetables, fruit, milk, and meat and beans).
- Your child should eat regularly and not skip meals. Be sure your child drinks plenty of fluids to not get dehydrated. Empty bowels or gut can make gas and make your child uncomfortable. When adding new foods to your child's diet, try a little bit with other foods you know will be easy to digest. Small, frequent meals are best. You should tell your child to always chew fully.
- You and your child will need to know about diet rules that are recommended when you child has an ileostomy. This can mean foods to skip that may cause blockage, gas or odor.
- A nutritionist or dietician may meet with you and your child after surgery to give you guidance.



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How do I care for my child at home?

- You and your child will need to care for the stoma while the stoma is in place. Stoma care supplies will be ordered to be delivered to your home.
- Some children require prescription pain medication at home. Give your child all medications as directed by your healthcare team. Over the counter Tylenol[®] and/or Motrin[®] are usually used to help with pain at home.
- Your child may shower after discharge and bathe as directed by your healthcare team.
- Your child should walk around but avoid sports, gym, swimming, rough play, or bike riding until cleared by your child's surgeon.
- Your child can typically return to school in 1-2 weeks from after surgery. Your child's surgeon will tell you when your child can return to school.

When should I call the office?

If your child experiences any of the following, please call our office:

- Vomiting or not able to drink fluids or eat food
- Stomach pain or bloating that doesn't get better
- Fever (Temperature > 101°F (38.3°C)
- Redness, drainage or swelling from the incisions
- The ostomy stoma appears dark maroon or pale
- Irritation to the skin around the stoma or difficulty keeping stoma pouch on
- Bloody stools
- Rectal pain
- More or less stool output than normal.

Your child will need to follow up with the surgeon. You will receive specific instructions for follow up when your child is discharged.

Please don't hesitate to call our office if you have any problems or concerns.

Surgical provider: _____

Office Number: _____

After hours number, if applicable: ______

Thank you for allowing us to care for your child.