

Every Child Matters!

Pediatric Ostomy Patient Bill of Rights[©]

United Ostomy Associations of America (UOAA) recognizes that pediatric ostomy care should be child and family-centered and should involve communication between all members of the healthcare team including doctors, nurses, ostomy nurses, child life specialists, nutritionists and social workers. The Pediatric Patient Bill of Rights is a statement of the rights to which infants, children, teens and their families should receive when facing ostomy surgery. It is a tool to empower parents/legal guardians to advocate for their child during all phases of care. The following rights are meant to ensure a positive patient experience and best outcomes to achieve a desirable quality of life for the infant, child, or teen living with an ostomy and their family. These are in addition to standard (hospital) patient rights and specifically relate to having an ostomy.

You have the right to:

Receive preoperative counseling that ideally includes:

- Working with a child life specialist to offer explanations of the surgical experience which is developmentally and age-appropriate; include sibling(s), if applicable
- Opportunity to see and touch ostomy appliances
- Education by an ostomy nurse; include sibling(s), if applicable, to include the impact of surgery on activities of daily living such as clothing and physical activity
- Have stoma site marked pre-operatively by an ostomy nurse or medical professional following Standards of Care (established by the Wound, Ostomy and Continence Nurses Society, American Society of Colon & Rectal Surgeons and American Urological Association position statement) (Note that this may not be possible in emergent situations)

- Explanation of stoma type to be created in surgery and expected output
- Mentorship with a family who has been through ostomy surgery
- Discussion of the emotional and developmental impact of surgery on the child and family

Receive during the operative phase:

- A stoma that can be fitted with an effective functional pouching system
- A stoma that is appropriately positioned for your child's unique body, needs and comfort (if medical condition allows)

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You have the right to:

Receive postoperative care and education from a trained ostomy nurse. The child should be included when appropriate. Information should prepare the family/legal guardian for caring for the child at home.

- Receive care that is specific to ostomy type
- Recognition that you are the expert in your child's care and your needs and what is best for your family should be acknowledged
- Individual instruction in caring for your child's ostomy including a hands-on demonstration of emptying and changing pouch
- Discuss changes to the stoma and abdomen during the healing process and effect on wear of the pouch
- Ways to troubleshoot difficulties with basic skin and stoma issues (e.g., skin breakdown and stoma blockage)
- Pediatric dietary and fluid guidelines given both verbally and in a written format (work with a nutritionist)
- Information on the availability of supplies and product choices
- Information about the process for ordering supplies
- Resources for obtaining supplies specific to patient circumstances (e.g., uninsured/underinsured)
- Information about personalized assistance programs through ostomy manufacturers
- Resources to organizations who educate, support and advocate for infants/children/teens/ living with an ostomy

- Help with connecting to families with similar experiences including pediatric-specific organizations (such as Pull-thru Network (PTN), Youth Rally and Facebook: Parents of Kids with Ostomies)
- Follow-up appointment dates/time and who to call in case of an emergency

Receive through adulthood ongoing support and care to include:

- Access to healthcare professionals with knowledge specific to the care of an ostomy in the outpatient setting (ostomy nurses including WOC nurse, OMS, OTA)
- Reevaluation of care with changes caused by growth and change in medical status
- Information on new ostomy technology
- Ongoing emotional support for child and parent/legal guardian as the child advances through developmental stages (It is common for children/teens to experience readjustment to their ostomy as they age and as developmental concerns change)

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