

# You Matter! Know What to Expect and Know Your Rights Ostomy and Continent Diversion Patient Bill of Rights

*The Ostomy and Continent Diversion Patient Bill of Rights is a tool for patients to advocate for their own care. It is meant to empower those who live with an ostomy (temporary or permanent) or a continent diversion. It identifies the needs and expectations for those needing this type of surgery and for the community of people who are currently living with an ostomy or continent diversion. In order to achieve a desirable quality of life, a person undergoing ostomy or continent diversion surgery must have access to high-quality care in all healthcare settings. Counseling and Care in the patient bill of rights should be provided by a trained medical professional such as a Certified Wound Ostomy Continence Nurse (WOCN), Ostomy Nurse, Ostomy Management Specialist (OMS), or Ostomy Care Associate (OCA). The patient shall be involved in all phases of the surgical experience except in emergent situations and shall:*

## Receive preoperative counseling that must include:

- Preoperative stoma site marked by a 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)
- Explanation of surgical procedure and the rationale for surgery
- Discussion of ostomy/continent diversion management
- Impact of surgery on activities of daily living such as physical adaptation, clothing choices, exercise, possible changes in sexual activity and treatment, and dietary needs
- The opportunity to talk with someone who has been through ostomy or continent diversion surgery
- The opportunity to discuss the emotional impact of surgery
- Counseling in a language and at a level of understanding that is comfortable for the patient

## Receive during the operative phase:

- A stoma that can be fit with a quality functioning pouching system
- A stoma that is appropriately positioned for their unique body, needs and comfort (if medical condition allows)

**Receive postoperative nursing care** specific to ostomy/continent diversion type and include the patient as well as their designated advocate (if any). Preparation for discharge will include:

- Individual instruction in care of ostomy including demonstration of emptying and changing pouch
- Ways to troubleshoot difficulties with basic skin and stoma issues including blockage and hernias
- Dietary and fluid guidelines given both verbally and in a written format such as UOAA's Ostomy Nutrition Guide
- Information on the availability of a variety of supply and product choices
- Information about the supply ordering process
- Resources for obtaining supplies specific to patient circumstances (e.g., uninsured/underinsured)
- Concierge services through ostomy manufacturers
- Resources to organizations who support and advocate for patients living with an ostomy or continent diversion
- Educational materials (such as UOAA's New Ostomy Patient Guide)

**Receive during the lifetime** of the ostomy or continent diversion the patient/designated advocate will benefit from ongoing support and care to include:

- Access to healthcare professionals with knowledge specific to the care of an ostomy or continent diversion in the outpatient setting
- Recognition of the need for reevaluation of care with the changes caused by aging and change in medical status

***If you believe your rights are not being met, speak up - be a force for change!***

**Advocates for a Positive Change**

[www.ostomy.org](http://www.ostomy.org) 1.800.826.0826

