

# You Matter! *Know What to Expect and Know Your Rights*

## Ostomy and Continent Diversion Patient Bill of Rights<sup>©</sup>

The Ostomy and Continent Diversion Patient Bill of Rights is a tool produced by United Ostomy Associations of America, Inc. for patients to self-advocate for their own care and improve outcomes. 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. It outlines evidence based recommendations for best in practice quality ostomy care for medical professionals\*.

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 health care settings. Counseling, care, and educational instruction as outlined in the patient bill of rights should be provided by a certified health care professional such as a Certified Wound Ostomy Continence Nurse, Certified Ostomy Care Nurse, Ostomy Management Specialist, or Ostomy Care Associate.

*Disclaimer: The following rights/standards of care may be limited or compromised due to instances when surgery is emergent.*

### Patient Bill of Rights Standards of Care

***The patient shall be involved in all phases of the surgical experience and shall receive:***

#### ***During the preoperative phase:***

Preoperative stoma site marked by a certified health care professional following the standards of care established by the Wound, Ostomy and Continence Nurses Society with the American Society of Colon & Rectal Surgeons and the American Urological Association

Explanation of the surgical procedure and the rationale for surgery

Education provided on living with an ostomy/continent diversion and self-care post discharge

Information about the impact of surgery on daily activities including adapting physically and emotionally and lifestyle changes such as clothing choices, exercise, diet and sexuality

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, care and educational instruction in a language and at a level of understanding suitable for the patient. Communication will be culturally sensitive and delivered in a dignified manner

#### ***During the operative phase:***

A stoma that can be fit with a reliable pouching system

A stoma that is well-positioned for the patient's unique body shape and medical condition

#### ***Postoperative nursing care specific to ostomy/continent diversion type and include the patient as well as their designated advocate. Preparation for discharge will include:***

Individual instruction in ostomy care including patient return demonstration of emptying and changing pouch

Ways to troubleshoot difficulties with basic skin and stoma issues including skin irritation, stoma blockage, hernia, and prolapse

Dietary guidelines and strategies to prevent dehydration given both verbally and in a written format

Information on the variety of product choices available from manufacturers

Information about the supply ordering process

Resources for obtaining supplies specific to patient circumstances (e.g., uninsured/underinsured)

Information about manufacturers' post-discharge support programs

Providing information about organizations that support and advocate for patients living with an ostomy or continent diversion such as United Ostomy Associations of America and their Affiliated Support Groups.

Providing the most current educational materials based on ostomy type

#### ***During the lifespan of the ostomy or continent diversion, access to ongoing care and support that includes:***

Health care professionals with knowledge specific to the care of an ostomy/continent diversion in *all* health care settings, including telemedicine

Reevaluation of ostomy management and supplies following changes in medical condition, aging and social/economic status

Ongoing emotional and social support

Specific and individualized ostomy supplies chosen in consultation with a health care professional to achieve and maintain a reliable fitting pouching system

*\* For references see Ostomy and Continent Diversion Patient Bill of Rights: Research Validation of Standards of Care at ostomy.org*

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

*\* Learn more in the "Expect More Take Control of Your Healthcare" toolkit at ostomy.org*

**Advocates for a Positive Change** [www.ostomy.org](http://www.ostomy.org) 1.800.826.0826

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