



OSTOMY TORONTO

Charitable Registration #11907 1009 RR001

CASE STATEMENT 2004/2008

Dedicated to assisting all persons facing life with an Ostomy

There is probably no surgical procedure that produces more misunderstanding and fear than an “ostomy”. For the few members of the public who have actually heard about ostomies, they hold the negative stereotype of people wearing a “bag”. They believe that once someone has an ostomy they will become invalids or social pariahs as a result.

In recent years the time spent in hospital after an ostomy has been shortened to typically three to five days. This is time for some healing, but not enough for adjustments to the emotions and new physical challenges. This is where the visitors and resources of Ostomy Toronto play a vital rehabilitation role in a patient’s road back to an active and productive life.

1. What is an Ostomy?

An “ostomy” is a surgically formed opening on the surface of the abdomen, called a stoma, through which bodily wastes are eliminated. A discreet odour-proof pouch and adhesive flange (ostomy appliance) is attached to the body around the stoma to collect the body’s wastes. A number of conditions call for this procedure as part of treatment and recovery. These include cancer of the colon and rectum, cancer of the bladder, physical trauma, congenital disorders, bowel obstructions and complications of Ulcerative Colitis and Crohns disease.

There are an estimated 40,000 people, young and old, living with an ostomy in Canada.

The most frequently used ostomies are:

Colostomy: The damaged or diseased portion of the colon and/or rectum is removed and the healthy part of the colon is brought to the abdominal surface and a stoma is formed. Conditions which may require a removal of part of the colon and/or rectum include diverticulitis, cancer, trauma, inflammatory bowel disease or birth defects. A colostomy may be temporary or permanent, depending on the reason for surgery.

Ileostomy: In a permanent ileostomy, the colon and anus are removed and the stoma is created from the last portion of the small bowel, which is called the ileum. Conditions that may require an ileostomy include inflammatory bowel disease (Ulcerative Colitis or Crohns Disease), Familial Adenomatous Polyposis, cancer, trauma or congenital disorders. An ileostomy may be temporary depending on the reason for surgery and may be the first of a series of surgeries that result in an internal reservoir created or “pelvic pouch” which eventually eliminates the need for needing an external pouching system.

Urostomy: This is a surgically created opening to divert urine from its normal route. The surgery is necessary when the bladder must be removed or bypassed.

In children who have birth defects, many urostomies are temporary, but in adults the procedure is usually permanent. The most common reasons for doing urostomies in adults are cancer of the bladder, tumours, spinal cord trauma resulting loss of bladder control, or neuromuscular diseases such as multiple sclerosis.

What is a Stoma? This is the visible part of an ostomy. The location of the stoma on the abdomen will vary, depending upon where in the colon the colostomy is created, or in the case of a Urostomy usually on the right of the abdomen slightly below the navel. In most ileostomies the stoma will also be on the right side of the abdomen. The stoma is soft, moist and red in colour, similar to the tissue inside of the mouth. The average size of a stoma is 2.5 to 5 cm (1” to 2”) in diameter. The stoma may bleed slightly when wiped or rubbed, since blood vessels are very close to the surface. There is no feeling in the stoma; it does not hurt when touched or when a stool, or gas or urine is passed. You cannot control the movement of stool, gas or urine through a stoma.

A variety of pouching systems are available to suit individual needs. Today’s pouches are odour resistant, light weight, comfortable, low profile and attach snugly around the stoma.

2. The problems facing Ostomates:

There are over 4,000 children, youth and adults living with ostomies in the GTA. Ostomy surgeries are undertaken at all of the active treatment hospitals of the GTA, as well as Southlake in Newmarket and North York in Richmond Hill.

When a physician first mentions an ostomy, every patient without exception, has negative feelings. Generally the younger the patient, the harder it is to accept an ostomy. Patients who have been diagnosed with Cancer for instance, may never have been sick up until that point, and are often in shock throughout the diagnosis and surgery period. The medical staff, in most cases, cannot advise the new ostomate on the practical day-to-day routines for life with an ostomy. Those undergoing surgery are in the hospital for much shorter stays than in the past, and they are sent home with only limited knowledge of living life as an ostomate. They are still dealing with the stress of the surgery itself and not thinking of how they will cope with the practical matters of living with an ostomy. Neither are their spouses or loved ones helped to understand the outcomes of this operation nor how they can become helpful and supportive. Parents of child ostomates feel all alone in the world.

New ostomates emerge with a number of important unanswered questions such as: Where do I buy supplies? Is there anyone else like me? Who is speaking on my behalf? Can I get back to the quality of life I've been used to? Can I be independent? Will I be able to afford the ongoing costs of supplies? Is there a support group?

The general community is not only largely unaware of ostomy procedures and their results, but those who do are likely to be misinformed about how to respond appropriately to someone who is living with an ostomy. Very few people, even work colleagues, will know that someone has had this operation unless the patient chooses to tell them.

Whether others are told or not is entirely up to the patient. They might feel uncomfortable about revealing the fact, fearing negative attitudes.

After surgery a patient wakes up with a pouch attached to the surface of their abdomen, and a head full of questions, and emotional fears, as to how they are going to cope, or recover their normal way of life. Most hospitals provide immediate assistance through a trained enterostomal therapist (ET) nurse who show patients how to manage their stoma and the pouch. The patient needs time to heal, to manage the ostomy, and to mentally adapt to these changes in their physical life.

Contrary to common fears, an ostomy almost always improves the quality of life for the patient by correcting the previous serious or debilitating condition. Tens of thousands of ostomy patients attest to the fact that they lead active, stimulating lives, with near normal diets, sex and travel habits. Over time most agree that they would rather have the ostomy than their previous medical conditions.

3. Ostomy Toronto assists people living with Ostomies:

Ostomy Toronto is dedicated to assisting all persons facing life with an Ostomy, in the Greater Toronto Area, by providing emotional support, instructional and information services through its visiting, resource and membership programs.

Ostomy Toronto is a volunteer based chapter of the United Ostomy Association of Canada Inc. (UOAC), an organization constituted in June 1997. Prior to this Canadian chapters had been affiliated to The United Ostomy Association based in the United States. The Toronto chapter has been in existence since 1958 and was registered as a charity in June 1975. We serve the GTA primarily but include areas North to Barrie, East to the Oshawa border and West to Mississauga and the Halton-Peel Region. Our purpose is to help ostomates and their families or caregivers, by making sure they have access to literature, videos, and trained ostomy visitors. We also provide monthly meetings which feature guest speakers from the medical community.

Ostomy Toronto, as with all other chapters came into being as a result of local ostomates' experiences, both before and after surgery. They saw the need to provide emotional support, reassurance, information and practical advice to those facing and recovering from ostomy surgeries. As a result of cutbacks in both hospitals and nursing organizations, ostomates are

less likely to have contact with an enterostomal therapist (ET). Ostomates are now limited to the number of “funded” ET visits and may be required to pay a fee for specialist care.

Our Mission and long-term goals are:

MISSION STATEMENT OF OSTOMY TORONTO

A service-based organization of caring volunteers, dedicated to assisting all persons with ostomies as a result of gastrointestinal or urinary diversions. Ostomy Toronto provides emotional support, experienced practical help, and education to the family unit, caregivers, and the general public.

LONG-TERM GOALS OF OSTOMY TORONTO

- a. Provide caring programs of emotional support and assurance, with experienced and practical help, information and instructional services, to all individuals in the Greater Toronto Area (GTA) who are about to have, or have, gastrointestinal or urinary diversions (ostomies).
- b. Provide programs of emotional support and assurance, with experienced and practical help, information and instructional services, to family members, parents or caregivers of ostomates.
- c. Build a community network of caring and contributing members, young and old, either ostomates or family members/caregivers who will be both served by practical and informational support and in turn provide voluntary services to the organization, its beneficiaries and its supporters.
- d. Develop a diverse, sustainable and adequate resource base in support of the organization’s service programs and administration costs.
- e. Build positive and practical relationships with the medical community, that keeps them aware and abreast of the services offered by the organization; and that draws on their cooperation, advice and support.
- f. Develop positive relationships with local retailers of ostomy supplies to increase and build rapport.
- g. Raise awareness with the general public concerning the benefits and challenges of living with and ostomy, dispelling fears and negative stereotypes.
- h. Continue to operate a committed, accountable and trustworthy organization, dedicated to serving the GTA community with effective service, administration, financial stewardship and resource development programs.

- i. Continue to develop positive relationships with the relevant local government departments, and their representatives, in a way that increases their knowledge and understanding of the needs of ostomates, the services provided by the organization and the resource needs of both ostomates and the organization.
- j. Serve the mission and goals of the national organization The United Ostomy Association of Canada Inc. Maintain open communications with the intent of sharing and learning best practices from other Canadian chapters.

4. Our program of services to Ostomates:

Ostomy Toronto steps in to fill the gap by providing programs of emotional support and assurance, with experienced and practical help, information and instructional services, to ostomates and their families or caregivers. This is offered through a trained visitor program, the most comprehensive Ostomy Resource Centre in the GTA, and regular membership activities and newsletters.

4.1 The Trained Visitor Program:

Ostomy Toronto has a team of 25 voluntary visitors on whom to draw. This pool of trained support will be increased by five by June 2005. Each visitor has undergone an ostomy surgery and is living a productive and happy life. They may be a fashion model, a corporate manager, an athlete or homemaker, young or old. Many trained visitors are individuals who themselves benefited from the visiting program, and others are recruited from the organization's members. They are well equipped to answer non-medical questions and help patients through their adjustment period.

Over the past 48 years Ostomy Toronto has visited over 3,500 patients, in hospitals or their homes in the GTA.

As the organization is currently structured and resourced, we are only able to provide this service to 50 patients a year, a very small percentage of those who need our services. Promotion is needed to make both the medical profession, patients and their families or caregivers, and the general public aware of the services provided by Ostomy Toronto. While our team of visitors are volunteers the organization has to carry the logistical, resource and support costs of this service.

4.2 The Resource Centre Program:

Located at the corner of Bloor Street West and Spadina (Fifth Floor) is the Ostomy Toronto Resource Centre. This provides a comfortable, private setting where people who have had or are about to have ostomy and related surgery can obtain information. Literature provided by the medical profession is available as is a library of books on these subjects. There are videos to view and a trained ostomy visitor on hand to answer questions or provide advice on how to live with an ostomy.

We provide free internet access so that patients can look up a variety of ostomy-related websites to research the latest medical information on either ostomies or the illnesses that result in the need for ostomies. They can learn about events and reach other ostomates through bulletin boards.

4.3 The Membership Program:

Ostomy Toronto is a membership based organization. The members are made up of those who have had ostomy or related surgery and others who have an interest in the association such as relatives and friends, physicians, E.T. and other nurses.

Apart from receiving the support and resource services of OT, members are kept informed of matters related to ostomy through a monthly magazine, a bi-annual national magazine, and monthly meetings from September to June. Guest speakers from the medical community or related fields address these meetings, where members also have the opportunity of meeting and relating to others who have survived ostomy surgery. Members are encouraged to become trained volunteers.

4.4 Collaborations:

Ostomy Toronto works in collaboration with other organizations in the field, on behalf of our members and patients. We can direct them towards enterostomal therapists who work with organizations such as Community Care Access Centre (CCAC) and ostomy supply manufacturers or retailers, after their initial recovery and when new questions and problems arise.

These organizations are: United Ostomy Association of Canada; Friends of Ostomates Worldwide; Canadian Cancer Society Inc.; Canadian Association for Enterostomal Therapy; Crohns and Colitis Foundation of Canada; Canadian Spina Bifida Association; Canadian Paraplegic Association; Community Care Access; and Community Nursing Agencies.

5. Ostomy Toronto Leadership:

Ostomy Toronto is a registered not-for-profit charitable organization of members. Members are those who have had ostomy or related surgery, and others who have interest such as relatives and friends, physicians, ET nurses, other nurses or any other interested persons. Paid-up members have rights and privileges including the right to elect a Board of Directors. The Board meets monthly, except in July and August, and currently consists of:

Dielwen (Di) Bracken	– President and Visiting Coordinator
Lorne Aronson	– Vice President and Bulletin Editor
Ranjit Hira	– Treasurer
Carol Rodda	– Secretary
Deb Pelletier	– Past President
Muriel Kinnear	– Social Convener
Helen Kizer	– Director

Paula Nixon – Director
Dan Pelletier – Fundraising Coordinator
Robert Wychers – Program Coordinator

In addition the Board maintains a medical advisory panel made up of physicians, nurses and community care providers. These medical specialists provide coaching, education and guidance to Ostomy Toronto.

Dr. Marcus Burstein – General surgeon specializing in colorectal surgery and Associate Professor of Surgery at the University of Toronto
Dr. Gary Sibbald – Dermatologist internist, Associate Professor and Director of Continuing Education at the University of Toronto
Dianne Garde – Enterostomal Therapist (ET) Advisor, GTA
Dawna Knowles – RN Enterostomal Therapist (RN-ET) Advisor, GTA

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