International Ostomy Association

Visitor Training Guidelines

an IOA initiative
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Preface

“The well being of the ostomate is the ultimate goal of the partnership between the surgeon, stoma nurse and the trained ostomy visitor.”

The International Ostomy Association of member countries is dedicated to the complete rehabilitation of ostomates through aiding each other.

Where does all this begin? With the trained visitor! The trained visitor is the heartbeat of the organization. Visitors vary in age, gender, jobs and cultural background. They may be business people, athletes, or homemakers, young and old alike; but they all have a common bond. Having undergone ostomy surgery or alternate procedures, they are now living normal lives.

It is even more comforting to talk to someone who has had the same surgery. The visitor comes prepared to share positive experiences and non-medical information to help the ostomate recover physically and mentally. The visitor is a member of the rehabilitation team, which consists of doctor, stoma nurse, and volunteer visitor. The visitor is uniquely qualified to share non-medical information and to help in the psychological and social rehabilitation of the ostomate.

Rehabilitation means the ability of the ostomate to return to an active role in the family and society.
Introduction

The Objectives of an IOA Visitor Training Session:
• Understand the purpose of the Visitor Program
• Learn the role and responsibilities of a visitor and basic visiting policies
• Review the anatomy and physiology of intestinal and urinary diversions
• Recognize psychological and social issues of ostomates

Training
It is recommended that the ostomy group/club/association hold classes periodically.

Guidelines
Visitor Program Guidelines are provided to assist with each training session and help develop the Ostomy Association’s credibility with the healthcare community.

Training Session Agenda:
The training session is divided into four segments:
Segment 1: Basic Visiting Steps
Segment 2: Types of Ostomy Surgery
Segment 3: Psychological and Social Issues
Segment 4: Basic Visiting Skills

The IOA Visitor Program is a very important service that is being provided by the ostomy group/club/association.

You Are Making a Difference!
SEGMENT ONE

Basic Visiting Steps

Objectives
• Understand the purpose of the visit
• Learn the roles and responsibilities of a visitor
• Gain knowledge of the basic visiting steps

Introduction
The Visitor Program is an important program of the International Ostomy Association (IOA). This service offers person-to-person support to those people who have undergone ostomy or related surgery, so that they may adjust to living with a stoma and have a good quality of life. This program also offers support for the spouse, significant others, family members and parents of children with ostomies.

Purpose and Objectives of IOA Visitor Program

Although visits happen in different places, they all serve the same purpose. Some visits may be made in the hospital or home. Some may be telephone visits and many visits are made at support group meetings.

The following steps should be used in any visit.

The purpose of a visit:
• Offer reassurance, understanding, and practical information
• Help the ostomate renew his/her self confidence
• Support ostomates and their families to adjust to living with a stoma
• Provide information about local services that can help

In addition, the IOA Visitor Program allows family members to become visitors of family members of other ostomates.
Role of a Visitor

Even though doctors and nurses are very helpful to the new ostomates, it is even more helpful for the ostomate to meet with another ostomate. The visitor is a good example of someone who has adjusted well to an ostomy.

The following outlines the visitor's role.

The Visitor's Place in the Team
The visitor must respect the relationships between the ostomate and the members of the healthcare team. The visitor's role is not to give medical information.

Behavior
Every visitor should behave in a respectful way. Professional behavior is necessary if the Visitor Program is to be accepted as a valuable part of the rehabilitation effort. The visitor is not required or expected to show his/her own stoma.

Visitor Training
Visitors must attend the training classes before making any visits.

The visitor should:
• Have accepted their own ostomy
• Remember the purpose of the visit
• Make the visit as promised and on time
• Keep up to date with new information about ostomies
• Follow the basic visiting steps established for the IOA visitor
• Not share any information about your meeting with the ostomate
• Let the person who arranged the visit know that it has taken place
**Basic Visiting Steps**

**Permission**
Approval of the ostomate is always necessary. If the meeting is arranged in a hospital/outpatient clinic, the health authority, including the doctor, must accept the Visitor Program. For visits away from the hospital, doctor approval is not necessary.

**Privacy**
Ostomates’ names are always kept confidential and should not be discussed with anyone outside the healthcare team. Be aware of the requirements used by that hospital facility. Do not talk about any information shared in the meeting with the ostomate.

**Medical Advice**
The visitor should not initiate discussion regarding the ostomate’s diagnosis or give medical treatment advice. If the ostomate asks for medical advice, always refer them to their doctor or stoma nurse. The visitor should inform the doctor or stoma nurse about any requests by the ostomate for medical advice.

**Stoma Care**
Stoma care is not permitted. Visitor should not recommend any manufacturer’s bags or ostomy products. Visitor should not show his/her stoma and bag. There will be exceptions. The ostomate MUST be helped.

**Listen**
Don’t talk too much about your personal surgery experience; spend time listening to the ostomate.

**Other Considerations:**

**Role of the Stoma Nurse**
In communities where there is a stoma nurse, the nurse can pick out a bag system and supplies, and teach the ostomate how to care for the stoma.

**Religion and Politics**
The visitor shall not discuss religion, politics and other sensitive issues and respect the beliefs of the ostomate.
Types of Visits

You may be asked to visit an ostomate at different times during his/her care. The things you talk about may change at different times.

Review the following visiting techniques.

<table>
<thead>
<tr>
<th>Situation/Location</th>
<th>Visiting Steps</th>
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<tbody>
<tr>
<td>1. Before Surgery</td>
<td>Before surgery, visits should be short to give basic answers to ostomate’s questions. Refer any medical questions back to their doctor or nurse. Avoid talking about the operation. Offer to come back after the surgery. Your job is not to talk about medical information.</td>
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<tr>
<td>2. After Surgery in Hospital</td>
<td>Be sensitive to the fact that the ostomate may be medicated and therefore not as responsive. Respond quickly when asked to make a hospital visit. Make the visit short, limited to 15-30 minutes depending on the ostomate’s condition. Answer questions factually and to the limit of your own experience.</td>
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<tr>
<td>3. At Home</td>
<td>A home visit is a more relaxed one. There may be more distractions in a home visit because of the family setting. The ostomate may be feeling better and the visit is more relaxed. However, the home may be very busy with activities. The home visit may be an opportunity to include interested family members in the discussion.</td>
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<tr>
<td>4. By Telephone</td>
<td>A telephone visit allows for a contact with the ostomate with no added stress on the ostomate or the visitor. Offer to meet the person in a follow-up visit.</td>
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<tr>
<td>5. At Support Group Meetings</td>
<td>Going to a support group might be helpful before surgery for some. For some new ostomates, it may be the first opportunity to meet with other ostomates.</td>
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Privacy Issues

**Follow National, Local or Hospital Rules about Privacy.**
The Visitor should be aware of The Charter of Ostomates’ Rights but it should not be used for discussion with the ostomate, particularly in the early visits. Awareness about the rights of ostomates should be given to new patients later.

**Charter of Ostomates Rights**
This Charter of Ostomates Rights presents the special needs of this particular group and the care they require. They have to receive the information and care that will enable them to live a self-determined and independent life and to participate in all decision making processes.

It is the declared objective of the International Ostomy Association that this charter shall be realized in all countries of the world.

The ostomate shall:
• Receive pre-operative counselling to ensure that they are fully aware of the benefits of the operation and the essential facts about living with a stoma.
• Have a well-constructed stoma placed at an appropriate site, and with full and proper consideration to the comfort of the ostomate.
• Receive experienced and professional medical support, stoma nursing care and psychosocial support in the pre-operative and post-operative period both in hospital and in their community.
• Receive support and information for the benefit of the family, personal carers and friends to increase their understanding of the condition and adjustments which are necessary for achieving a satisfactory standard of life with a stoma.
• Receive full and impartial information about all relevant supplies and products available in their country.
• Have unrestricted access to a variety of affordable ostomy products.
• Be given information about their National Ostomy Association and the services and support which can be provided.
• Be protected against all forms of discrimination.

**ISSUED BY THE IOA HOUSE OF DELEGATES, September 2004**
Objectives
• Learn about the most common kinds of ostomy
• Understand what kind of discharge each ostomy has and how to take care of it

Introduction
• Although ostomates and visitors will be matched by type of ostomy, age, and gender, if possible, it is important that visitors know basic information about different ostomies and how they are cared for

Type of Ostomies

1) Permanent ostomies are made when the rectum, the colon, or the bladder have been removed or bypassed. They will always be there.

2) Temporary ostomies may be placed in the small or large intestine or the urinary tract. Some ostomies are only made for a period of time and later can be reversed.

The Digestive System

The digestion and absorption of nutrients, as well as the storage and elimination of fecal waste, take place within the gastrointestinal system, or the GI tract. Digestion starts in the mouth as you chew your food. Food then passes through the esophagus to be digested in the stomach. Digested food moves into the small intestine, where nutrients are absorbed. The remaining undigested portion solidifies as water is reabsorbed in the large intestine or colon, forming solid fecal matter or stool. Stool is then passed to the rectum, where it is stored until it is excreted through the anus. (Fig. 1)
Types of Fecal Diversions

1) **Sigmoid Colostomy** (Fig. 2)
Waste:
• Stool may be formed and look like normal bowel movement
• The kind of bowel emptying can be controlled in some persons

Care:
• Either irrigation or natural bowel movement
• Protective covering or closed end bag if well controlled, otherwise, open drainable bag

2) Loop Colostomy (two holes) (Fig. 3)

Waste:
• Semi-solid
• Unpredictable drainage/may empty often
• May be irritating to the skin

Care:
• Skin protection
• Drainable bag
3) **End Ileostomy** (Fig. 4)

**Waste:**
- Liquid or paste
- Unpredictable drainage/will empty often
- Very irritating to the skin

**Care:**
- Skin protection
- Open-end, drainable bag
4) **Temporary Loop Ileostomy** (two holes) (Fig. 5)

**Waste:**
- Liquid or paste
- Unpredictable drainage/will empty often
- Very irritating to the skin

**Care:**
- Skin protection
- Open-end, drainable bag
Urinary System

The kidneys, ureters, bladder and urethra make up the urinary tract. The kidneys, two bean-shaped organs located just below the ribs toward the back, produce urine by filtering water and harmful waste from the blood. Urine drains from the kidneys through two small tubes called ureters into the bladder. When you are ready to urinate, the urethra releases and urine passes out of the body. (Fig. 6)
Types of Urinary Diversions

1) Ileal-Conduit (Fig. 7)

Waste:
• Urine
• Some mucus
• Drains all the time

Care:
• Skin protection
• Drainable bag with tap
• Adaptable to night drainage/may be connected/hooked up to larger bag or bottle at night
2) **Ureterostomy** (Fig. 8)

**Waste:**
- Urine
- Drains all the time

**Care:**
- Skin protection
- Drainable bag with tap
- Adaptable to night drainage/may be connected/hooked up to larger bag or bottle at night
3) Nephrostomy (Fig. 9)

Waste:
- Urine
- Drains all the time

Care:
- Skin protection
- Drainable bag with tap
- Adaptable to night drainage/may be connected/hooked up to larger bag or bottle at night
Types of Double Stoma

1) Urostomy and Colostomy

In some medical conditions, it may be necessary for doctors to make two stomas; one for stools and one for urine. (Fig.10)

Waste:
- Stool from a colostomy
- Urine from a urostomy

Care:
- Skin protection
- Urine bag and colostomy bag
2) Colostomy/Ileostomy and Mucus Fistula

In some medical conditions, connection may be impossible with/without removal of the colon and it may be necessary to make a colo/ileostomy and a fistula for mucus from the rectum or the inactive side/stoma. (Fig.11)

Waste:
• Mucus from the inactive side/stoma
• Working side drains stool

Care:
• Skin protection for the working stoma
• Small bag covering, or dressing changed daily
Objectives
• Understand the stages of recovery
• Learn appropriate answers to these stages
• Review ostomates’ concerns

Introduction
A visitor may meet the ostomate when they are scared about what will happen in the future, concerned for the family, worried over money, their jobs, and their ability to adjust to living with the stoma.

Having an ostomy may cause concern about how a person looks. Although body image (or the mental picture of one’s appearance) is changing constantly, a time lag exists between the actual change in the body and the mental acceptance of it. It would take time for the person to adjust to the changes to their body; the time it takes is different for everyone.

Reactive Stages
Almost every ostomate goes through four stages of recovery following an accident or illness that leads to a loss or change to an important part of the body. These stages may have different names, but they have the same meaning.

Stage 1
Shock or Disbelief
The first stage deals with shock, disbelief, or impact of having ostomy surgery. The ostomate may rely on denial for coping and may reject explanations about their condition or any attempts to teach self-care. The ostomate may not believe that they have had ostomy surgery.

Visitor Response
Listen. Restate correct information as known. Indicate that they understand the ostomate’s difficulties.
Stage 2
Retreat or Defensive
In this stage the ostomate may become angry or irritable or they may ask “why me?” The ostomate may emotionally withdraw. They may be upset about the change to their body and having to live their life with a stoma.

Visitor Response
Let the ostomate show their anger. Many people feel this way after they have had ostomy surgery. Over time, ostomates adjust to living with an ostomy.

Stage 3
Acceptance
The ostomate is no longer angry and finds their own way of coping. As the ostomate works through this stage, he or she may feel sad or cry.

Visitor Response
Say you understand what has happened and how he/she feels. Do not just talk about the stoma, talk to the ostomate about how they will go on with a normal life in the future.

Stage 4
Adjustment
This is the stage when the ostomate begins to adjust to living with an ostomy. The ostomate may still need some help but is starting to be independent.

Visitor Response
Let the ostomate know that they are doing really well becoming independent.
Ostomates’ Concerns about Surgery

Ostomates may fear that others may not accept them as they did in the past.

**Telling Others**
The ostomate should decide if they are conformable about telling others about their surgery. In some cultures and social environments, it may not be correct to tell others that you have an ostomy. If the ostomate decides to tell others about their surgery, they should give a short simple explanation.

They should also decide who the right people to tell are.

Ostomates should be prepared to explain their surgery with a few brief statements. For example, “An ostomy is a surgical procedure for the diversion of the bowel (or bladder).”

**Sexuality**
Discussion of this topic may vary by culture and it may be better to refer the ostomate to the doctor or nurse.

**Pregnancy**
Often younger female ostomates are worried about becoming pregnant and having a child. In this case, refer to their doctor or nurse.

**Returning to Work**
Going back to work may worry the ostomate who may be concerned about sharing a toilet and how and when to change or empty bags.

**Social/Medical Welfare Systems**
These are different from country to country. If there are programs in the country, the visitor should give the contact information about the local ostomy association to the ostomate.
A good visitor should:

1. Be introduced, or introduce him/her self
2. Be friendly
3. Be honest
4. Be a good listener
5. Be able to deal with emotion
6. Be considerate of the ostomate
7. Be observant of hospital policies and procedures
8. Be respectful of the ostomate’s privacy
9. Be on time and keep promises
10. Be proactive and give information about the local ostomy association
11. BE YOURSELF!
**Common Ostomy Terms**

**Anastomosis** – Surgical connection between hollow organs

**Appliance** – Bag used to collect the waste

**Collectomy** – Removal of all or part of the colon

**Continent Ileostomy** – Surgical procedure whereby internal storage of stool is made possible. Operation is restricted to carefully selected ostomates

**Diverticulitis** – Inflammation or outpouching of sac arising from bowel wall

**Electrolytes** – Salts and minerals needed by the body for health

**Familial Polyposis** – Rare disease that runs in families. The colon and rectum contain many polyps. Has strong tendency to malignancy

**Fistula** – An abnormal channel or connection between an organ, to a body cavity, or to the skin

**Hernia** – Abnormal bulging or extrusion of part of an organ through tissue opening/failure that contains it

**Ileitis** – Inflammation of the small bowel

**Ileo-anal** – Joining of small bowel to the sphincter of the anus

**Ileostomy** – Surgical opening from the ileum (next definition) to the surface of the abdomen to form a stoma

**Ileum** – Lower half of the small intestine that ends at the beginning of large intestine in lower right part of abdomen

**Kock Pouch** – Surgical technique of constructing an intra-abdominal pouch from part of the ileum, referred to as “continent ileostomy”

**Nephrotomy** – Diversion of urine away from the ureter and the bladder by inserting a tube into the kidney. This may be done in one or both kidneys

**Obstruction** – A blockage or occlusion of a structure, often the intestine and the ureter

**Ostomy** – Surgically created opening into the intestine or urinary tract, through the abdominal wall, for discharge of bowel or bladder wastes
**Perineal Wound** - Opening where the anus/rectum was removed, new tissue fills area

**Prolapse** - An outward telescoping of the bowel

**Revision** - Removal of a part, such as intestine

**Retraction** - A pulling in the stoma so it is below skin level

**Stoma** - An opening or mouth

**Stenosis** - A narrowing along a segment of stoma due to scar tissue

**Stricture** - A narrowing along a segment in the tract such as the bowel, the ureter, and so on

**Urinary Diversion** - Any one of a number of surgical procedures that divert the urine away from a diseased or defective urinary organ
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