

# Helping ostomates and amputees adapt to their new circumstances

Learn how to help patients cope with psychosocial challenges, body-image problems, and sexuality concerns.

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**I**n most cases, amputation (removal of an extremity, digit, or other body part) is a surgical intervention performed to remove tissue affected by a disease and, in some cases, to provide pain relief. Fecal and urinary diversion surgeries also are considered amputations. Amputations and fecal or urinary diversions (ostomies) require extensive rehabilitation and adaptation to a new way of life, with physiologic and psychological impacts. Although diversions and ostomies usually are less visible to others than other types of amputations, they call for similar patient education, rehabilitation, and life-long counseling.

The primary goal of therapy for ostomates and amputees is to resume their presurgical lifestyle to the greatest extent possible and to adapt to their new circumstances. Preoperative assessment and training interventions have proven valuable. Having a clear understanding of the surgical intervention helps reduce postoperative anxiety and depression, which can pose roadblocks to patients' adaptation or response to their new situation. Successful interventions should be done by health-care professionals who are trained in caring for ostomates and amputees.

Ostomates and amputees experience similar psychosocial challenges, body-image problems, and sexuality concerns. This article focuses on these three issues. For a summary of other issues these pa-



tients may experience, see *Other problems amputees and ostomates may face*.

## Psychosocial challenges

Ostomates and amputees may experience depression, anxiety, fear, and many other concerns related to the surgical procedure—concerns that center on whether they'll be able to resume their presurgical lifestyle.

### Other problems amputees and ostomates may face

Amputees and ostomates may experience problems related to:

- age
- complications from ill-fitting prosthetics
- medical complications
- cost of supplies
- loss of wages.

Many worry about social isolation and loss of income. Some fear both the primary disease process and the lifestyle changes induced by surgery. Anxiety may impede their social interactions and lead to significant psychological problems. Appropriate and effective counseling and therapy must be planned and provided. (But be aware that untrained or inexperienced healthcare professionals may not be able to provide the guidance the patient needs to feel comfortable; some may be unable even to offer information about available support systems.)

These patients also may find themselves socially isolated, in part due to loss of employment or the socioeconomic consequences of a decreased income. Some experience fear and worry when anticipating lifestyle changes caused by loss in or change of function, adaptation to the prosthesis, and treatment costs.

Maintaining social contact after surgery is extremely important to recovery and adaptation to the amputation or ostomy. The United Ostomy Associations of America and the Amputee Coalition encourage patients to maintain social involvement. Both groups suggest patients discuss their feelings, thoughts, and fears with a trusted family member, friend, or partner. Both or-

ganizations sponsor and encourage support-group involvement. In some cases, emotional support from other amputees or ostomates with a similar experience may be appropriate; some patients may be more comfortable sharing thoughts and asking questions in a group of people with similar experiences. Resuming presurgical social events and activities can enhance patients' adaptation to a new way of life.

Help your patient find a support group at the website of the United Ostomy Associations of America: [www.ostomy.org/supportgroups.shtml](http://www.ostomy.org/supportgroups.shtml).

### Body-image problems

Ostomates and amputees have to cope not only with changes in physical appearance but with how their body functions and how they feel and perceive their body.

They're keenly aware of their changed appearance and are concerned about others' perceptions of them. They may feel anxious and depressed related to body image; the degree of anxiety and depression may relate directly to their presurgical body image and activities. Many become anxious and fearful as they adapt to the prosthesis. (See *Stages of grief*.)

## Stages of grief

Postoperatively, ostomates and amputees must deal with loss of a body part, similar to the grief a person experience after losing a loved one. Healthcare professionals must be aware of this before, during, and after the patient's initial hospitalization so they can provide the best care possible. To adapt to their situation, patients typically go through the five stages of grief.

- The first stage is *denial*, as when a patient refuses to engage in teaching or counseling sessions.
- During the second stage, *anger*, patients may direct anger at the healthcare team.
- Patients in the third stage, *bargaining*, may find excuses to postpone or refuse to participate in care. They may seem helpless and dependent on others for care.
- During *depression*, the fourth stage, patients feel hopeless and may express sadness and despair.
- Ultimately, patients may reach *acceptance*, the final stage, and are ready for training. At this stage, they commonly seek counseling, training, and interventions for problems.

However, be aware that not all patients go through each stage, and some may go through the stages in a different order than that described above.

Compared to amputees, ostomates may have more concerns about body image with sexual partners, because the stoma is, in a sense, a hidden amputation. In most cases, the stoma and pouch can be obscured visually from others. The amputee, on the other hand, has fewer options for hiding the missing body part.

To help patients cope with body-image problems, care providers must offer education, therapy, and counseling to help the patient accept and successfully adapt to the body-image change. The first step in this process may simply be to have the patient look at the stoma or stump, progressing to participation in prosthesis care.

### Sexuality concerns

Many ostomates and amputees have difficulty resuming sexual activity after surgery. Although the stoma usually remains hidden from others, it's observable to the ostomate and sex partner. Most patients require an adjustment period before they feel comfortable with a sex partner. They may fear that:

- the partner will reject them or no longer find them attractive
- they will experience loss of function and sensation
- they will experience pain or injury of the stoma.

They also may feel embarrassed, caus-

### View: Patient insights



Hear patient insights about ostomies in this video from the United Ostomy Associations of America.

A longer version is available at:

[www.ostomy.org/living\\_with\\_an\\_ostomy.shtml](http://www.ostomy.org/living_with_an_ostomy.shtml)

ing them to avoid sex. However, counselors can help couples discuss these concerns and resume a satisfactory sexual relationship. Ostomates and amputees and their partners may need counseling to resume a satisfactory sexual relationship. If they continue to have adjustment difficulties, referral to a trained sex counselor or psychologist may be indicated. Several studies show that appropriate counseling can help prevent complications and allow amputees and ostomates to continue to express their affection physically. (See *Talking to patients about sexual problems*.)

Resuming sexual activity may be easier if the ostomate or amputee had a sex partner before surgery. However, males who experience postsurgical erectile dysfunction are less likely than other males to resume sexual activity. Counseling encourages postsurgical patients to focus more on the pleasurable feelings they and their partners feel, rather than on sexual per-

### Talking to patients about sexual problems

- Bring up the topic instead of waiting for the patient to do so. Open by saying something like, "Many patients with a new ostomy worry about how it will affect their sexual relationship with their partner and what adjustments they'll have to make when having sex. How has this been for you?"
- Schedule time to discuss sexuality. You don't want to rush your conversation.
- Establish a rapport before raising the topic of sex. Don't wait until the last minute, but don't bring it up as the first topic, either.
- Be open and nonjudgmental. Patients may have sexual practices that vary from your own.
- Give specific tips for dealing with practical problems such as controlling gas or odor.

formance. Body-image problems and inadequate sexual adjustment go hand in hand. (See *Helping ostomates resume sex.*)

## Team approach to patient education and counseling

In many parts of the country, a designated healthcare team manages amputees' care and rehabilitation. But until recently, nurses were the only professionals certified to participate in ostomates' care and rehabilitation. In fact, ostomates may represent a significant underserved population. A 2012 study found many ostomy patients didn't

receive consistent training and counseling from ostomy certified nurses. Only 13% of respondents reported they had regular visits with an ostomy certified nurse; 32% said they'd never received care from an ostomy nurse. Just over half (56%) indicated they saw an ostomy nurse when they thought it was necessary. The study also reported that 57% hadn't seen an ostomy certified nurse in more than 1 year.

A team with specialized training to address ostomates' physical and psychosocial needs might be able to provide the specialized care these patients need. The primary

## Helping ostomates resume sex

To help patients and their partners resume sex after an amputation or urinary or fecal diversion, recommend they do things to help them get ready for sex—things that make them feel sexy, whether it's showering, shaving, slathering on the aftershave or perfume, or wearing something skimpy. For others, it's soft lights, champagne, candlelit dinners, and romantic music. Sometimes people with a stoma feel they need to do a little more. The following advice may help you feel more comfortable in the bedroom.

- Always practice safe sex (foams, lubricated condoms, or other forms of contraception).
- Focus on your feelings, not on the pouch.
- Empty the pouch before engaging in sexual activity.
- Make sure the pouch is secure. Reinforce it with paper tape around the edges.
- If you wear an ostomy pouch belt, make sure it's clean.
- Make sure you're clean. Better yet, jump in the tub or shower with your partner.
- If you're concerned about the pouch's appearance, use a pouch cover or a pouch you can't see through.
- Use a "passion pouch" during sex. This is a smaller, closed-end, disposable pouch that's shorter and less bulky than standard drainable pouches. Many brands are available.
- The side-lying position for sex may work better on the stoma side, because the pouch will fall away and not come between you and your partner.
- If you have a colostomy and you irrigate, irri-

gating it just before sex might allow you to wear a small patch or "security pouch" during that time.

### Hints for women



- Use personal lubricants to minimize vaginal dryness. You can buy these in most grocery or drug stores.
- Hormone creams or vaginal suppositories are sometimes prescribed for vaginal dryness. Talk to your physician about them.
- Consider wearing crotchless panties, teddies, or a short slip or nightie or something with a snap or cut-out crotch.
- If the pouch or other stoma covering seems to be in the way or causes pain during intercourse, experiment with different positions.
- You might not reach orgasm the first time you have sex after surgery. Don't worry; this is normal.

### Hints for men



- In the man-on-top position, lean a little toward the pouch-free side of your stomach.
- Consider wearing a cummerbund around your midsection to prevent the pouch from flapping.
- Try wearing attractive boxer shorts if you're concerned about exposing the pouch.
- Talk to a healthcare professional if you continue to have problems, such as inability to get or maintain an erection. Don't panic. Solutions exist for almost every sexual problem.

Source: United Ostomy Associations of America, Inc. *Intimacy After Ostomy Surgery Guide*. [www.ostomy.org/ostomy\\_info/pubs/uoaa\\_sexuality\\_en.pdf](http://www.ostomy.org/ostomy_info/pubs/uoaa_sexuality_en.pdf).

# Feeling comfortable with the prosthesis is essential to adapting to a “new normal”.

medical caregiver or general practitioner would serve as team leader and make appropriate referrals. The team should include a surgeon, ostomy- and amputee-trained nurses, a prosthetist or other healthcare provider trained in selection and fitting of prosthetic equipment and devices that affect function, a physical therapist, an occupational therapist, a social worker, a vocational counselor, a psychologist, caregiver or family members, support groups, and (last but not least) the patient.

The team approach might reduce hospital stays and promote patients' return to their home environment. It also might encourage independence and enhance the success of long-term adaptation.

## Focus on the future

Healthcare providers should encourage ostomates and amputees to focus on the future, not the past. Feeling comfortable with the prosthesis—the amputee's artificial limb or the ostomate's pouching system—is essential to adapting to a “new normal” way of life. Maintaining social relationships is important to adaptation as well. Mastering basic skills and adapting to changes in body function help improve the patient's quality of life. Follow-up visits, phone contact, and access to a team of well-trained healthcare providers for patient education, rehabilitation, and long-term management are crucial to these patients' successful adaptation and quality of life. ■

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