

Online Solutions: Closing the Gap in the Continuum of Care

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Online Solutions

Introduction

Stoma surgery is a life-altering event, but many people with ostomies and their loved ones have little time to adapt. With increasingly shorter hospital stays, some people are left feeling unprepared to cope with the physical and lifestyle adjustments after ostomy surgery. Although support services and groups exist to help transition patients when they are discharged, people with ostomies still may face many challenges.

In the United States, more and more people are seeking health and wellness information online. Social networking websites also have emerged, where like-minded individuals can meet and connect with people in similar situations. Many different groups have formed online communities to provide a safe and anonymous place for their members to interact.

Lifestyle community websites have now surfaced, where people with ostomies can communicate with one another and provide and/or find information and comfort. This presentation is on one such online community¹. It features the site's impact on several people with ostomies and clearly illustrates the ongoing need for information, support, and connections.

Challenges Individuals May Face Before and After Ostomy Surgery

- Difficulty finding information and support preoperatively
- Less time for learning stoma care due to reduced hospital stays
- Feelings of being overwhelmed
- Ongoing inability to access information at the ideal time and pace
- Difficulty finding others who understand their situation
- Embarrassment about their private condition
- Increased social isolation and individual frustration

Internet Trends

- Older Americans are online, with over 60% of people over 50 using the Internet²
- The audience for online health information has grown 21% during the past year – more than four times faster than the total US Internet audience³
- In the US, 97% of people over 40 are seeking health and wellness information online⁴
- 75% of consumers consider the Internet their most trusted source for researching drug information⁵
- Growth of health-related websites, such as WebMD, Yahoo!® Health, and MayoClinic.com
- 34% of US online consumers visit social networking sites (up 40% from previous year)⁶

Answering the Challenge: A Community-Based Website for People with Ostomies

- Provides ostomy-related information
- Encourages peer-to-peer connection
- Offers another avenue in the care continuum to help with pre- and post-surgery adjustment
- Provides an anonymous means of open communication
- Offers access to information and support 24/7
- Connects those with common interests and ideas
- Offers access from the comfort of home

Website

One successful community-based website¹ for people with ostomies allows visitors to access information on a variety of lifestyle topics, ostomy-related issues, products, and news and events. They can also pose questions through the “Ask the Clinician Panel” feature, share their thoughts and experiences with peers on an interactive forum, and submit other content including personal stories, photos, and videos.



Home Page – Ostomy Online Community

User Experiences with a Community-Based Website for People with Ostomies

The following profiles highlight the positive experiences that people with ostomies can have if they are willing to venture onto an ostomy online community, such as this one. Many participants on the site's¹ Forum prefer the anonymity of using an avatar (a computer user's representation of himself/herself) to represent them on the site.

threeedogmedia – Brinnon, Washington | 56 years old



The site¹ had a big impact on Karen, otherwise known by her screen name, threeedogmedia. “Frankly, when I first heard I had colon cancer and was going to have an ostomy, I wanted to kill myself,” she admitted. “I was so depressed, but then I found this site and came up with the biggest belly laugh! I think I must have read every Forum post I could get my hands on. It was an immediate turnaround in my attitude. These were people who had a sense of humor. They talked frankly about having an ostomy; there was nothing that was taboo. I started to post and I got some immediate responses. It was a turning point for me – the site saved my life.”

Threeedogmedia said she would recommend the site¹ to other people with ostomies. “It is chock full of information and any questions you can possibly come up with have been answered there. Nothing's too stupid to ask. There are people on the site that are in worse shape than you are, and they still have a sense of humor. It brought me back into a mode where I'm able to laugh. I never thought I could smile again.”

Avatar for Don Wallbaum – Logan, Ohio | 55 years old



For Don Wallbaum, the site¹ is a way to connect with people like himself. “It's good to be with others for whom your ostomy needs to be neither explained nor justified – it simply is,” said Don. “While an ostomy certainly affects the way I live in the world, it does not affect who I am. Those on the site understand that, and we go on.”

Don also views the site¹ as a way to help others. “There are new people coming on who just had their surgery. They're in kind of an emotional shell shock. Their whole world has collapsed around them and they don't see their way out. I think it's good to have someone who's been around say, ‘It's not as bad as you think. You will get through this; there is help available. We're all here and it's not the end of the world.’ You have people on this site who have worked through tremendous adversities to come out the other end, and they are incredible role models. The new folks cling onto the information, advice, and support of these people – it's critical for them to have those links to normalcy.”

Avatar for Happy – Woodbury, Minnesota | 64 years old



As a retired WOC Nurse with an ostomy, Happy thinks the site¹ is a great way to stay informed. “It keeps me on top of things,” she said. “It's good for me to see what other people's issues are. And, of course, there are certain things – like intimacy and other issues – that interest me too, given that I'm a young 64-year-old lady.”

Happy also uses the site¹ to help others. “It is very rewarding to reach those people who are absolutely paralyzed at home because they're afraid to go out and have their ostomy leak. I can help that person realize, ‘While you're having a leak you think the whole world knows, but actually nobody does.’ I also like the flexibility of being online, as opposed to guaranteeing every Tuesday or Thursday that I'm going to be available. I feel like I'm doing something and I get a lot out of it.”

Wendy – Oxfordshire, UK | 43 years old



The anonymity of the site¹ is what really appeals to Wendy. “It's anonymous, but at the same time it has a friendly feel,” she said. “It's nice to talk to somebody else, but it's much nicer to talk to somebody else anonymously because you can really open up then. Everybody on there is so glad they've found the site.”

Wendy said the site¹ has become her source for interaction with other people with ostomies. “I used to go to a support group organized by people at the hospital, but they stopped having it saying we shouldn't group people together like that and allow everyone to be individuals,” she said. “It's silly – we need people to talk to that have something in common with us.”

Conclusion

People with ostomies are frequently searching for information, support, and connections with others in similar situations. An online community is a powerful and evolving tool that can help close the gap in the care continuum, and provide individuals with the help they need to live their lives to the fullest.

¹ www.C3Life.com

² Source: TNS Compete and the Consumer Electronics Association joint study, 11/2008.

³ Source: comScore, Inc. study, based on number of unique visitors, 7/2007 vs. 7/2008.

⁴ Source: ThirdAge and JWT BOOM, “Boomers, Healthcare and Interactive Media,” provided to eMarketer, 6/2/08.

⁵ Source: Analysis conducted by acquisition solutions firm Prospectiv®, and published in “TheInteractiveGuide”; Internet, accessed 7/31/08.

⁶ Source: North American Technographics® Media and Marketing Online Survey, Q2 2008 and North American Social Technographics Online Survey, Q2 2007.