



Safe digital resources for ostomates

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ORIGINAL

Living with stom...

Living with stom... A phenomenological study

Res P... 2011;11:06-12

ABSTRACT

AIM: It is to understand the experience of living with stom...

DESIGN: Descriptive study with a purposive sampling method.

SETTING: 19 patients hospitalized in the "Emergency" Department.

PATIENTS: One interview with 19 patients.

RESULTS: One series of an interview.

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CLEANSING BALM

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1. Introduction

As Stoma Care Nurses working in a digital age, we need to embrace new genres which will enable us to inform and support our patients effectively. These need to be reliable and accurate; there are many ways for patients to source information about stomas, surgery and products as well as adapting to life with a stoma, therefore a stoma resource guideline which has been approved and vetted will give Stoma Care Nurses a safe starting place when offering online and digital support.

Many of these resources are developed, written and filmed by people living with a stoma, their lived experiences and top tips to coming to terms with their stoma and living their life to the full.

This document will allow the Stoma Care Nurse to offer supportive and reliable websites in the knowledge that patients will be receiving valuable, correct and reliable information about all aspects of life with a stoma. The list is not exhaustive, but having a 'go to site' is always a good place to start.

2. Pre-stoma surgery

Coloplast: <https://www.coloplast.co.uk>

Before stoma surgery

- How your stoma might affect daily life
- Why do I need to wear an ostomy pouch?

<https://www.coloplast.co.uk/stoma/people-with-a-stoma/before-stoma-surgery/>

Urostomy Association: <https://urostomyassociation.org.uk/>

What is a urostomy?

<https://urostomyassociation.org.uk/information/urostomy/>

Living with a urostomy

<https://urostomyassociation.org.uk/information/living-with-urostomy/>

2.1. Your operation

Bowel Cancer UK: <https://www.bowelcanceruk.org.uk/>

Your operation (PDF download)

https://bowelcancerorguk.s3.amazonaws.com/Publications/Your_Operation.pdf

2.2. Colonoscopy through the stoma

Colostomy UK: <http://www.colostomyuk.org/>

Colonoscopy through the stoma (PDF download)

<http://www.colostomyuk.org/wp-content/uploads/2018/06/Colonoscopy-through-the-stoma.pdf>

2.3. Disease-specific information

Bowel Cancer UK: <https://www.bowelcanceruk.org.uk/>

About bowel cancer

<https://www.bowelcanceruk.org.uk/about-bowel-cancer/>

Crohn's & Colitis UK: <https://www.crohnsandcolitis.org.uk/>

About Inflammatory Bowel Disease (IBD)

<https://www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease>

Bladder & Bowel Community (B&B): <https://www.bladderandbowel.org/>

Bladder conditions and symptoms

<https://www.bladderandbowel.org/bladder/bladder-conditions-and-symptoms/>

Bowel conditions and symptoms

<https://www.bladderandbowel.org/bowel/bowel-problems/>

Squeezy – The NHS physiotherapy app for pelvic floor muscle exercises

<https://www.bladderandbowel.org/news/squeezy-the-nhs-physiotherapy-app-for-pelvic-floor-muscle-exercises/>

Macmillan Cancer Support: <https://www.macmillan.org.uk>

Signs and symptoms of bladder cancer

<https://www.macmillan.org.uk/information-and-support/bladder-cancer/invasive-bladder-cancer/understanding-cancer/signs-symptoms-bladder-cancer.html>

3. After stoma surgery and going home

Coloplast: <https://www.coloplast.co.uk>

After stoma surgery

- How do I learn about adjusting to life with a stoma?
- What will the stoma look and feel like after surgery?

<https://www.coloplast.co.uk/stoma/people-with-a-stoma/after-stoma-surgery/>

3.1. Who and how to tell

Coloplast: <https://www.coloplast.co.uk>

After stoma surgery

- Who to tell and what to say about your stoma

<https://www.coloplast.co.uk/stoma/people-with-a-stoma/after-stoma-surgery/>

3.2. Showering with a stoma

Patient stories and perspectives

Thaila Skye – Showering with your ostomy

<https://www.youtube.com/watch?v=A-lhxBoeViE>

3.3. What is ballooning?

Patient stories and perspectives

Thaila Skye – What is ballooning?

<https://www.youtube.com/watch?v=AN5bYUG8zw8>

3.4. Dealing with irritated or sore skin

Coloplast: <https://www.coloplast.co.uk>

Irritated sore skin

<https://www.coloplast.co.uk/stoma/people-with-a-stoma/living-with-a-stoma/irritated-sore-skin/>

3.5. Stoma bag leakage

Coloplast: <https://www.coloplast.co.uk>

Stoma bag leakage

<https://www.coloplast.co.uk/stoma/people-with-a-stoma/living-with-a-stoma/stoma-bag-leakage/>

Coloplast Charter: <http://www.coloplastcharter.co.uk>

Coloplast Charter Telehealth Support

Patients registered for this service can get trusted advice and support from CQC-registered telehealth specialists and access to exclusive online content.

3.6. Diet

Coloplast: <https://www.coloplast.co.uk>

Food and beverage

- What to eat and drink with a stoma
- Be prepared for dining out
- Advice on ballooning and pancaking
- Diarrhoea and food blockage advice

<https://www.coloplast.co.uk/Stoma/people-with-a-stoma/living-with-a-stoma/food-and-beverage/>

Patient stories and perspectives

Thaila Skye – Food and dining out with an ostomy

<https://www.youtube.com/watch?v=9Wk-k14-xDU>

4. Living with a stoma and life's milestones

Coloplast: <https://www.coloplast.co.uk>

Living with a stoma

- Overcoming common issues you may face with your stoma
- Travelling with a stoma
- Diet
- Intimacy
- Staying away from home
- Going back to work

<https://www.coloplast.co.uk/stoma/people-with-a-stoma/living-with-a-stoma/>

Bowel Cancer UK: <https://www.bowelcanceruk.org.uk/>

Real life stories - Listen to our podcast:

<https://www.bowelcanceruk.org.uk/how-we-can-help/real-life-stories/podcast/>

4.1. Travelling

Coloplast: <https://www.coloplast.co.uk>

Travelling after ostomy surgery

- Get a travel guide, travel certificate and packing list
- Stoma tips in the heat, when travelling and when swimming
- Travelling by plane with an ostomy
- Sun safety

<https://www.coloplast.co.uk/Stoma/people-with-a-stoma/living-with-a-stoma/travelling-with-an-ostomy/>

4.2. Sex and intimacy

Coloplast: <https://www.coloplast.co.uk>

Sex and intimacy

- Coming to terms with a changed body after ostomy surgery
- Intimacy-related complications

<https://www.coloplast.co.uk/Stoma/people-with-a-stoma/living-with-a-stoma/intimacy-and-sexuality/>

4.3. Fertility and pregnancy

Coloplast: <https://www.coloplast.co.uk>

Fertility and pregnancy when having an ostomy

<https://www.coloplast.co.uk/Stoma/people-with-a-stoma/living-with-a-stoma/intimacy-and-sexuality/>

4.4. Christmas

Patient stories and perspectives

Thaila Skye – Christmas with an ostomy

<https://www.youtube.com/watch?v=t2Je6gJYpUo>

4.5. New Year resolutions

Patient stories and perspectives

Thaila Skye – New Year's Resolutions

<https://www.youtube.com/watch?v=OFd9QrZu2uA>

4.6. Summer holiday

Patient stories and perspectives

Thaila Skye - Preparing for vacation

https://www.youtube.com/watch?v=_ws1x8jcjQY

Thaila Skye - Packing for the perfect getaway

<https://www.youtube.com/watch?v=MDec1saxRis>

Thaila Skye - Travelling to your holiday destination

<https://www.youtube.com/watch?v=oa01QGZM1sA>

Thaila Skye - Enjoying your vacation

https://www.youtube.com/watch?v=ZHM8A_I5AH4

4.7. Returning to work

Patient stories and perspectives

Thaila Skye – Returning to work with an ostomy

<https://www.youtube.com/watch?v=1T9myOrqp8U>

4.8. Irrigation

Colostomy UK: <http://www.colostomyuk.org/>

An introduction to irrigation (PDF download)

<http://www.colostomyuk.org/wp-content/uploads/2017/09/CA015-04r01-An-Introduction-to-Irrigation.pdf>

4.9. Regaining bowel control

Bowel Cancer UK: <https://www.bowelcanceruk.org.uk/>

Regaining bowel control (PDF download)

https://bowelcancerorguk.s3.amazonaws.com/Publications/Regaining_Bowel_Control.pdf

4.10. Dating, intimacy and body image

Patient stories and perspectives

Intimacy for ostomates

<https://www.youtube.com/watch?v=uJRYVlqfKXM>

Ostomy and dating

<https://www.youtube.com/watch?v=PBE3SXY24GI>

Katryna Thomas-Shell – online dating

<https://www.youtube.com/watch?v=eAc9avEhLXg>

The IBD and Ostomy Support Show

- Body image after IBD diagnosis

<https://www.youtube.com/watch?v=BxNvFDfpx5o>

5. Online forums and patient advocates

There are online forums for people to share their experiences and talk to others who have gone through similar experiences:

Colostomy UK

Facebook Page: <https://www.facebook.com/colostomyuk/>

Closed group: <https://www.facebook.com/groups/colostomyassociation2011>

IA Support - Ileostomy and Internal Pouch Association

Forum: <http://forum.iasupport.org/>

Facebook page: <https://www.facebook.com/iasupport/>

Macmillan

https://community.macmillan.org.uk/cancer_experiences/ileostomy_and_colostomy_discussions/

Meet An Ostomate

<https://www.meetanostomate.org/>

United Ostomy Associations of America (UOAA)

<https://www.uoaa.org/forum/viewforum.php>

Patient advocates

You are not alone – honest, open and supportive work from people like you, living life with a stoma

Rachel Jury (two stomas - one ileostomy, one urostomy)
<http://rocking2stomas.co.uk/>

Thaila Skye (colostomy, used to have an ileostomy and mucous fistula)

<https://www.coloplast.co.uk/thailaseries>
<http://www.thailaskye.me.uk/>

Katryna Thomas-Shell (ileostomy)
<http://katsbagofcrap.blogspot.com/>

GetYourBellyOut (IBD and Ostomy Community Interest Company)
<https://getyourbellyout.org.uk/>

6. Patient Associations and NHS resources

Colostomy UK
<http://www.colostomyuk.org/>

IA Support - Ileostomy and Internal Pouch Association
<https://iasupport.org/>

Urostomy Association
<https://urostomyassociation.org.uk/>

Macmillan Cancer Support
<https://www.macmillan.org.uk/>

NHS
<https://www.nhs.uk/conditions/colostomy/> <https://www.nhs.uk/conditions/ileostomy/living-with/>
<https://www.nhs.uk/search?collection=nhs-meta&query=urostomy>

7. Apps

Essential Stoma Care App

Apple: <https://apps.apple.com/gb/app/stoma-care/id1327330303>

Android: <https://play.google.com/store/apps/details?id=com.speedagency.stomacare&hl=en>

Macmillan Organiser App

Apple: <https://apps.apple.com/gb/app/my-organiser/id905915003>

Android: <https://play.google.com/store/apps/details?id=com.macmillan.myorganiser>

You can find an electronic version of this document at
www.coloplast.co.uk/stoma-links

Alternatively it can be found as a resource on the ASCN website
<https://ascnuk.com/>

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