An ostomates experience of COVID19

As the Coronavirus continues to be part of all our everyday lives, here at Coloplast we will continue to provide help and support to our customers.

To ensure we all learn from experts by experience during this time we would like to share key information that enables ostomates to plan and cope with Covid19. This document will provide insight into one of our customers' personal experiences of the coronavirus and shares valuable insights, hints and tips that we believe will support fellow ostomates in the community.





This article includes Brian's written story for you to read and refer to and includes links to resources available from Coloplast that can be shared with patients.





Brian's story begins

It's the cough. It's like a constant tap on the door. Cough, cough cough. Cough, cough, cough. Please. Let yourself in. The door's open. I can't...cough, cough.

Every ostomate will know that internal groan you make at 4am when you've got to leave the warmth of your bed and do a bag change. Cough. I stumble out of bed. Cough cough cough. Barely awake. Everything is laid out in the bathroom. I can do this in my sleep. I reach for the black disposal bag and put it in the Tippee bin. Cough, cough, cough, cough, cough, Something's wrong. I can't seem to breathe. I get the replacement bag ready. Spray the adhesive. Breathe. The coughing makes the output pour out. I catch it. And change. And the coughing paces up. I cry out for my wife. Magqie. I'm in trouble.

I think I'm going to die. She rushes in. Startled. I'm sobbing now. The coughing has its own relentless energy. I know I have to breathe. Later when the surgery opened i rang to make a phone appointment. Later when the surgery opened I rang to make a phone appointment with the nurse and the GP called back. He took my history. I recounted my symptoms. Cough (obviously), sore back, night sweats, fatigue that is hard to describe, breathlessness, headache. Diarrhoea. No fever though. I thought that was the clincher. The get out of Covid card. Nah. It doesn't work that way.

It's been weeks now. I've learned how to manage, how not to be fearful. I have got mild symptoms. I've not been hospitalised or been tested. I did have to go to the Covid Assessment Centre in Inverness one day. I had an excruciating pain in my back. I'd damaged my intercostal muscles from coughing.

My dose is mild. But not mildly terrifying at times. And as an Ostomate it has thrown up a whole bundle of issues. I think we need to consider them. There will be more. But these are mine.

I have a <u>parastomal hernia</u> (PSH). I'm used to comforting and supporting my stoma. I place my hand over it. The gentle heat helps. And the pressure when I let out a 'normal' cough, is reassuring. But the Covid cough is fairly relentless. I know many ostomates who don't have a PSH dread developing one. With good reason. I think this is the time to keep the support belts and garments handy and use them.

One of my fears was being rushed into hospital. Would the stoma nurses even be there? Have they been moved to the front line? Who would manage my stoma if I became unconscious? Would the staff know what to do? I filled my 'emergency pack' with more bags, adhesive remover and gauze.

'Sounds very like Covid-19.'

I've been drinking copious amounts of water to combat the sweating. Meaning I have to pee more. That's okay for me but others with an ileostomy or urostomy this maybe more problematic. I've been going through a lot of stoma bags. More than normal, I'd say. I don't know why this is. Occasional diarrhoea still hits me. But even if it's not that the output is fairly relentless.

I need to talk about mental health too Hmmmm lockdown can mess with your head. Having Covid, I've found myself being glued to my phone and to the radio. Every mention of the disease and I'm on it. Every announcement or press conference. I'm constantly tuned in. I'm in an unhealthy cycle of anxiety, hyper vigilance and catastrophic thinking. What if my supplies run out? What if I have a blockage? How long is this going to last?

Some of my fears, although heightened, actually have a sound basis. Many people in the NHS are now saving 'where have all the (non Covid) patients gone?'. If I have a non Covid incident I don't really understand what to do. The GP has said they don't really want me in the practice. So, let's say I do have a blockage, other than dial 999, I actually don't know how I'll be assessed or treated at this precise time. 111 seems to be entirely about Covid. Ostomates frequently have a range of conditions. I'm not sure I understand the pathways to have them dealt with because I have Covid.

I'm getting better now. Slowly and gently.

Stay well and safe, Brian



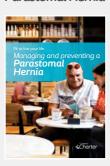
Resources available:



For concerns over bag adhesion and problems with sweating please use the Trouble Shooter

Click to Open **Trouble Shooter**

Managing and preventing a Parastomal Hernia



Click to read

An introduction to the Core 4



An introduction to the Core 4

Click to read

Information Sheet - High Output



Click to read

Healthy Eating with a Stoma



Click to read

Q Resources available:

Coloplast advice and support

To read the latest update and advice on the services and support Coloplast provides please visit or refer patients to:

https://www.coloplastcharter.co.uk/coronavirus-update/

Government advice and support

As well as the advice that you can find on the stoma sections of our website about managing your condition, there is also some expert advice from the NHS and Government. You can view the most up to date links below:

NHS - Non-Covid related advice

https://www.nhs.uk/health-at-home/

NHS England

https://www.nhs.uk/conditions/coronavirus-covid-19/

GOV.UK Information for the public

https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public

GOV.UK - Information for stay at home guidance

https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance

COVID-19: guidance on shielding and protecting people defined on medical grounds as extremely vulnerable.

https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19



