

For many people, going back to work after their surgery is an important milestone. The whole routine of waking up, rushing to get ready, getting annoyed sitting in traffic and coming home worn out, signifies a welcome return to 'normality'. It is also a reminder of just how far one has come since those early post-op days.

But it is not quite as simple as just turning up in the office on Monday moming. Instead, the whole thing can be a source of anxiety. Should you tell people you have a stoma? What happens if you have a leak, or your stoma makes a noise in a meeting? I recently caught up with Pete, who like me is a Colostomy UK volunteer, to compare notes. Everyone's situation will be slightly different, but hopefully sharing our experiences and tips will be helpful.

The first thing we discovered was we had many similarities, even down to the type of surgery we had. We also both decided to take a positive attitude in how we dealt with a diagnosis of rectal cancer and to be open about it with friends and colleagues. Both our employers were supportive, which makes a huge difference. I probably benefited from there being more awareness and information available when I

returned to work three years ago compared to Pete's experience nine years ago. I was also provided with more information from the stoma nurse and directed to Colostomy UK, whereas Pete said that although the support he received in hospital was excellent, he was not given any information on support groups or charities. He also said the importance of avoiding parastomal hernias and information on prescription ordering and the ability to mix manufacturers was lacking.







- » Tidings Editorial Board Volunteer three years.
- » Works in public sector audit, 300+ employees, desk-based, modern building.
- » APR* keyhole surgery and formation of a colostomy + chemotherapy.
- » Stoma nurse gave info about Colostomy UK, hospital physio advised Pilates.
- » Returned to work Sep 2020, five and a half months post-op, one-month post-chemo, age 48.
- » Exercise: walking, Pilates, cycling.
- » Psychological support: Maggie's Centre.

WHAT WORKED WELL:

"I was extremely lucky I had such understanding colleagues who gave me all the support I needed.

I requested early on for the accessible toilet to be made stoma friendly, which they agreed to do. It takes the stress out of changing my bag at work if I need to."

WHAT WE WISH WE'D DONE DIFFERENTLY:

"I underestimated how long it would take me to get back to working full-time hours. I suffered fatigue for about a year after I finished chemotherapy and I definitely tried to increase my hours too quickly.

I was referred to an occupational therapist through my work who made me realise I was putting too much pressure on myself and not to rush things."



- » Helpline Volunteer 18 months.
- Worked in printing business, 70 employees, on shop floor/ up and down stairs, old building.
- » APR open surgery and formation of a colostomy.
- » Not aware of Colostomy UK, no advice about exercise or return to work.
- » Returned to work in 2014, four weeks post-op, age 61.
- » Exercise: walking, yoga, swimming.
- » Psychological support: counselling via GP referral.

WHAT WORKED WELL:

"I told everyone, it made it easier, and it felt like the right decision.

I even had a 'kiss my arse goodbye party' before my surgery! When I went back to work, I made a point of saying early on that my stoma might make noises in meetings."

WHAT WE WISH WE'D DONE DIFFERENTLY:

"I definitely went back to work too early, I should have taken a few more weeks."

"And I didn't ask or do anything about the situation with the toilets, which was a mistake and would have helped. Being built in the 1950s, the factory only had a small toilet. I just used the top of the loo for organising my supplies, but it wasn't ideal."

*APR: abdominoperineal resection surgery – removal of the rectum and lower part of the colon, and formation of a colostomy

Tips for returning to work:

» Gradually introduce gentle
exercise to build up your fitness
before returning to work –
walking is an easy way to do this,
increasing distance and intensity
over time. Pilates and yoga are
also good for strengthening your
core. Improving your fitness is
important for recovery generally
too. Colostomy UK's booklet
Active Ostomates: Sport and
Fitness After Stoma Surgery
is well worth a read. It's available



» Speak to your employer about any adjustments you might need e.g., a comfortable chair with good support, a standing desk (sitting for long periods may be difficult at first), making the toilet stoma friendly, working from home if possible. Stoma-friendly toilets were covered recently in Tidings (summer 2023). See also: www. ColostomyUK.org/campaigns as you could download a copy of the guidelines for your employer.

- » Check your entitlement in relation to sickness absence and pay. You may be able to use annual leave if you need to extend your time off or use it to allow you to work reduced hours for a while (annual leave will build up if you are off for an extended period).
- » Arrange a phased return to work, do half days initially if possible, and later starts to give you time to change your stoma bag (you may still be getting used to your stoma, it takes several months to settle down).
- » If you have a more physical job, ask for lighter duties or a temporary change in duties until you are back to full fitness.
- » Take regular breaks, depending on how long you have been off work and the treatment you've had, as fatigue may be an issue for a while.





» If you feel comfortable telling your colleagues about your situation it can make it easier to cope at work and you can make light of your stoma making unexpected noises.



- Think about your mental health, as well as your physical health, and consider counselling.
- » Irrigation may be something to consider if you have a colostomy, giving you more control over your stoma and confidence at work (although you will probably have to wait several months after surgery before being able to do this). Pete started irrigating after 12 months and said it make a big difference for him not having to worry about changing his bag at work and he has no issues with wind or noises. To find out more about irrigation contact

Colostomy UK and ask for a copy of their irrigation booklet or visit their website where you can download it for free.



If you haven't already - register with Colostomy UK at www.ColostomyUK.org/join-us for a wealth of information and support!

