

Paul.....

My Mental health pathway with crohns and an ileostomy.

My name is Paul and I am 54 years old. I have been a YOU member for 30 odd years.

Like many others I was diagnosed with CD as a teenager after a lengthy period of fluid, blood and weight loss. I eventually made it through Tech College and was in my 4th year of shift work when I was rushed to hospital. A bowel obstruction had gone toxic and I awoke with a stoma. I didn't even know what such a thing was. Anyway, I learned to live with it and my CD was generally controlled with medication. However, a few years after the initial loop ileostomy was performed my Dr's informed me that my large bowel was 'knackered' (their term!) so in 1989 all of my large and a fair chunk of my small bowel were removed. Since then I have had a large number of complications resulting in many, many surgical and other invasive procedures. I have literally lost count of how many I have had, the latest being a stoma prolapse repair in 2019. Funnily enough the CD itself has been in remission for over 15 years- it's all been physical issues. Hernias, prolapsed stomas, obstructions, structures and a couple of alarming bleeds. I certainly know my local Ambo's!

I have always dealt mentally with all this through humour. Even actually after being placed on an operating table I'd still be acting the fool. This 'method' worked for me for years until a couple of years back when I was booked for (yet more) surgery to try and correct a recurring hernia. I had by now become a professional Tour Guide and I was enjoying life more than I had been for years. I had also become a grandpa and was volunteering at my hospital and enjoying giving something back.

My surgeon reckoned I'd be in for maybe a week tops to fix the hernia with a few weeks recovery then back to work. However things began to sour. After returning to my 'usual' ward (I have been blessed with being looked after by the same staff in the same ward for over 20 years, some are now like family to us)

I had the usual pain/no food etc. for a couple of days and then I began to get obstructions just behind the stoma. The surgeon inserted a catheter in it to hopefully 'clear' it but after a day or two this wasn't working. Even I was shoving it back in during the night when it would come out. The dramas continued until things turned ugly and I ran a huge fever. So back to theatre I went at 1am. The next morning I was back in the ward and I believe this was the moment my current mental issues began.

One of the PSA's came in to mop the floors and joked with me about 'my mess' I looked to see a pool of blood. I called a nurse in and it was simply a suture or two had come out so no big deal but for some reason this really overwhelmed me. I lost it and started to cry. The nurse, whom I'd known for years sat with me for hours whilst I emotionally fell apart. When my wife came in that evening I felt shame and weak for losing control like that. The recovery period was long and arduous. 3 months off work, nurse around daily for dressings, wound breakdown blah blah. But eventually I returned to work.

I was only back at work a short time when I finished a tour and walked out to my car to go home. Next I know I'm in an Ambulance and the word 'Stroke' is being mentioned. I had

been found lying on the street next to my car. I was admitted to Neurosciences Ward and the usual battery of tests were a bit inconclusive. Possibly a stroke possibly massive seizure. Either way this has changed my life. I have had other seizures since and periodically cannot drive so rely heavily on sparse public transport to get to work. I was placed on anti convulsants and anti-depressant medications which had a profound effect on me. I had been slipping into depression since the 'suture' incident but now I had spiraled to a new low. The medication was causing me to hallucinate, be incoherent unfocussed and worst of all changed my nature from one of a happy person to one who was angry and resentful of everyone and everything. It has literally almost ended my 20 year marriage to my beautiful wife who has been a steady hand on the tiller and my number one supporter. But this new addition of mental health issues was one cross too much to bare. We had actually decided to separate and were making the arrangements when at the 11th hour we decided to have one last try and as I write this things are going ok. I am still having quite serious mental problems some of which are medication induced and getting through a day at work or simply existing day to day is bloody hard. I see a Neurologist for the medical side of things. As for the rest, once I began becoming an angry person I took myself to a psychiatrist and I have found that a great help. I also have rediscovered things I had let loose from my life years ago- writing, poetry, visiting the church and reflecting. I have returned to transcendental meditation. In addition to all that I find playing my Bass guitar and photography help give me back my 'gentle mind' I'm not there yet but I'm on the right road I'm sure.

Amie.....

I found that having a good mental health doctor helped and taking the right medications. But most of all, support from family and friends. Not being made to feel like a "different" person. YOU helped immensely. Having people to talk to who know what it's all about is invaluable.

Kaitlin.....

Positivity, laughter, a good support network and groups like this to get tips on issues that people around you wouldn't understand. Perspective as well I think to recognize that things could be worse. I had my bowel removed, a stoma for 5 months while I did chemo while still working and looking after 2 toddlers. It was hard but there are many people who were/ are worse off than me. It was the things I mentioned above that helped get me to the other side . You can do it

Margaret.....

**Amongst other things, but probably top of the list of what had helped me has been wonderful support, caring and information I have been blessed with via this support site!
Bless you all !**

Julie

From the perspective of the parent of a child with chronic health problems -

1. Reach out the clinicians with any of your mental health concerns and ask them what support they and the hospital can offer in house.
2. Prior to and during hospital admissions organize a child life specialist (used to be called a play therapist) to help your toddler, child, teenage to navigate admissions, deal with painful procedures or to scaffold the steps necessary for learning to do regular procedures
3. Engage with the in-house mental health Team where possible and appropriate.
4. Listen to your child and validate their concerns.
5. Help your child retain some control by asking them what they want.
6. Get pain relief under control.
7. Have a management planned protocol specific to you prior to leaning on hospitals so there are no "what if" or "what do I do now?" moments and concerns.

Jane

I've learnt ways to look after myself as someone with a stoma but also a carer. Mindfulness – using apps like Smiling Mind, setting realistic goals and celebrating them. The importance of exercise at whatever level is appropriate, establishing support networks by knowing who to tell, how much and when.

Toni

I've had issues with my mental health my whole adult life. But when my physical health took a turn a few years back now I felt that my mental health took a turn too.

Things which have helped me immensely with y mental health is having a good rapport with my GP and taking medication as prescribed. But there is a whole other area of support that helps. Groups such as YOU help because you can talk to people who have been there done that. People who know more of what you are going through so in saying that things which have helped me which aren't medical intervention are online support groups.(it's good to be able to talk to people who understand what it's like to have your skin on fire like the burn of a thousand suns), friends and family (even though they don't fully understand, they sure do try. They empathise with you the best they can). Also, for me. The other thing that has really helped is moving out of a very toxic situation and getting a kitten. Jus the change in where I live has made massive difference to

both my mental and physical health. My kitten is my friend/ fur baby / nurse. He know when I'm not well and look after me.

Sarah.....

I am more than happy to share my struggles. After the impact of meningococcal had ravaged my body I was tired of fighting. I mentally and physically didn't want to go on. It was hit after hit. Constantly fighting for my life. I made a decision that I wanted to withdraw care and stop dialysis which is all that's keeping me alive. It was told without it, I would be dead in less than a week. It took a lot, but I decided to continue. I learnt from this that no matter what your illness is, circumstances etc that your left is still purposeful and that I am extremely loved and lucky that I am alive, even if it's hard.

Hope this help someone xxx

Jules...

Yep my battle wasn't easy with two operations to get the stoma to work, then chemo and then adjust to what we have to consider is a normal life. Every day is a challenge, the mind must be positive. Keeping humour in my world has kept me sane, having my closest friends support me with no matter my issue or situation is. Keeping active, fit and goals to achieve is the way through it.

Tony.....

I have coped by having a "never let it beat me attitude". That includes facing every challenge head on as it arises and doing what I need to do to look after myself and get myself back on track. I was sooo lucky to have found YOU not long after my ostomy surgery. This was living proof right in front of me that ostomy surgery didn't have to stop me living but it could in fact help me to live.

Helen....

The things that worked for me to alleviate stress and anxiety when I was initially told I would have surgery are :- I educated myself on what a stoma was which was really

difficult to do without the internet back then but I picked my surgeons brain to bits. He actually organised for one of his former patients to come in and visit me as there were no supports groups at all so he was very forward thinking which helped. I had an "I can do this" attitude too, as I remember a nurse telling me that healing and coping all depended on my attitude which I did believe.

Amber

My name is Amber and I have had my stoma for pretty much my whole life. My stoma was formed when I was 8 years old at the RCH. I missed out on a lot of my schooling due to being in and out of the hospital for procedures with my stoma and bowel obstructions. It was hard to catch up with school work but the teachers were always there to help me when I needed it. I would also miss out on doing things on school holidays if I had surgery scheduled around that time.

The hardest part about having a stoma in my teens was it interfering with what I wore and sometimes being visible under my clothes. To combat this problem I had the stoma moved down lower on my abdomen to a more discreet place and this was enough for me to be comfortable. I never had an issue about telling my friends that I had a stoma as they were always very supportive of me no matter what.

Now I'm an adult having a stoma is like second nature to me and I would not have it any other way. I don't really have any major problems with it and I am able to live and enjoy my life as I see fit.

Carmel ...

My son got his Hartmann's colostomy at age 9. It was done that way as we didn't know if it would be permanent or not. He has a myriad of other issues including non verbal autism. He grew and gained weight after he got his stoma which he had not done for 3 years prior. Now, at age 20, he is 6 feet tall and healthy. In the adult system now, the verdict is that to reverse his colostomy would be more trouble than it is worth. It doesn't stop him doing anything, he and his carers are managing just fine. If he hadn't got his stoma he would not have survived.

Josie....

Having my ostomy at such a young, tricky age was hard, no doubt about it ... But it was definitely for the better and I'm so much better off with it. My friends were all understanding and accepting of it which was great ! Ostomies can come with problems but if you have a good stoma nurse, surgeon and supportive friends and family who understand what you are going through, then you should be good and the ostomy will be the start of a better life.

Bonnie.....

I was diagnosed with UC when I was about 20. I am 33 now, and it has been a mixed journey for me. My main mental health issues have been -

- body image
- anxiety

My body is not nice. Years of medications (mainly steroids) have given me stretch marks, thin hair, bad joints, acne, and a plethora of other complaints. I was ashamed of my body for a long time and in denial about my illness.

I coped with this with a mix of things, including supportive friends and family and learning to be accepting of the skin I am in. I realised I was pushing people away rather than letting them in, and once I started to open up and be positive, my relationship with others and with myself changed. By the time I was in my mid 20's, I loved myself again and have had good self esteem since.

My strong sense of self and the ability to love myself meant that when I eventually had my surgery, I was able to more quickly accept the changes to my body. It still isn't nice - its flabby and has a poo bag attached to it, but I can do all the things that anyone else can, and can do a million more things than when I was sick. I have a healthy relationship with my partner, who has been nothing but supportive throughout the entire ordeal. I care more about the bag than he does! I used to cry because it sounded like an empty chip packet crunching when we have sex, but now I just try not to think about it. Mainly I just think of it as annoying because I am uncomfortable when I lie on my belly - this is the worst of my problems! I used to sleep on my tum, and now I have to sleep on my side or back.

I have always had mild anxiety, but as an adult the bulk of it stems from my UC. In the lead up to my surgery I was basically incontinent, in constant pain and was underperforming at work. I had run out of sick leave, and was so stressed about the time I knew I needed to recover. I couldn't travel far in the car, as I needed bathrooms so frequently. I was 32 and wore nappies daily as I had no ability to "hold on". It was impacting my relationships without even realising.

Stress and anxiety and bowel disease are a circle, where one feeds off the other. The more stressed I was, the worse my condition was. I was honest with my boss, and spoke to HR, and we organised a return to work plan. I was able to use leave without pay, and take annual leave at half pay so I still had some money coming in.

I was very sick by the time I had my surgery. I had complications and was in ICU for a while before even having the big op. But after the surgery I started to feel better quickly, and recovered pretty well. I had issues post surgery with the stoma site and some ulcerations, but my mental health improved a million times. I was no longer stressed about bathrooms, what I was eating, or getting toxic mega colon and dying in my sleep. I was able to take my dog for a walk around the block. I have since started yoga, go away on trips, and have been hiking - all things I haven't done in years. My work went above their legal obligations in making me feel comfortable about taking time off and coming back to work. My boss regularly pulls me aside and asks how I am and checks on my stress levels.

I still get anxiety, and I still have body image issues. But on balance all things have improved since my surgery. I would like to have the reversal surgery, but i have been re-diagnosed with crohns, so I don't know how realistic that is. This was a big shock, and I am still kinda processing it.

My biggest concern now is having babies, but that has to do with the surgery AND that I am 33. I am worried my eggs are going bad haha.

Some of my tips for coping with all this -

- Talk about your experience with anyone and everyone. Use it as a way to connect with family and friends.
- Fake it till you make it - it is hard to feel confident in your body when it is attacking you. Dress up and go out somewhere safe with people who care about you. The more you push yourself, the more comfortable you will feel. OWN YOUR BAG.
- Blogging. This one I have done throughout my journey. I am active on social media and write about my experiences honestly and often. I post stuff on FB, Insta, Twitter and wherever else I feel like it. Everyone knows about me pooping myself!
- Be honest with your workplace if you feel comfortable to do so. People may surprise you with their compassion and care. Same goes for friends and fam.
- If someone dismisses your concerns, they suck. If your friends stop calling in, get new friends. If a boy/girl stops dating you because of your illness, they are doing you a favour - you don't need that kind of person in your life. Dating sucks both with and without a bag, we aren't special haha. All people have body image issues that make us nervous to date and be intimate.
- If you are nervous about surgery, remember what you are missing out on. While you are sick on the couch, people with bags are outside living life.
- Have a pity party for yourself, but only for 1 day. I still get overwhelmed sometimes and just want to stay in bed. So I stay in bed and watch crap TV, and

then the next day I get up and get back into life. Allow yourself time to process, but don't dwell.

- If you feel that your anxiety or depression is getting the better of you, get help from a doctor. Break the stigma of mental health issues, there is nothing wrong with medication or therapy. It is how we treat any illness.
- Get a dog. They give you a reason to get up in the morning, and love you no matter what you look like.

I am a town planner. I work for State government with the Department of Environment, Land, Water and Planning. My main role is helping local councils with their land use planning, and interpreting and changing their planning schemes. This year I have also been involved in the bushfire emergency response team as part of the Public Information Unit. My role is to draft and update messages for the Vic Emergency app. I have recently spent a lot of time in Bairnsdale and Orbost working in the Incident Control Centres.

I work full time, and always have. I am guilty of pushing myself too hard and not taking my health seriously, and I sometimes wonder if I had just gone part time, maybe I would have been able to keep my bowel. Did I need to go back to uni and stress? Did I need to get that new job? Did I need to move to a regional town, away from friends and family? Probably not. But I have never let my condition stop me from doing anything. Has my health defined me? Yes, it has. But there is nothing wrong with that, as it has also made me more resilient, compassionate, empathetic and kind. I wouldn't wish bowel disease on anyone, but it is hardly something that has ruined my life.

Dave.....

While I feel it's important to be surrounded by family and friends, I felt the key to coping mentally with a stoma was education. I feel this is especially true for new ostomates who may be struggling.

Firstly: I found the best way to alleviate stress/anxiety was to learn as much as i could regarding the illness that led to my stoma (in my case crohns disease) and try to understand it. Having the "how & why" knowledge brought about a much quicker acceptance of a stoma for me.

Secondly: I found personal interaction with others was important. One of the best tools an ostomate can have is support from groups such as Y.O.U. and fellow ostomates. I've always believed the more questions we ask in life, the more we learn. Having fellow ostomates close at hand for advice is the best way to learn which in turn leads to a greater knowledge and can put our minds at rest. As any experienced ostomate will tell you, there are no stupid questions, just informative answers :)

Tracie.....

I have coped with my stoma by accepting that it saved my life. I had C diff infections that were killing my large intestine, family was told I had 72 hours to live. Once I accepted that my stoma saved my life, I was able to take control and move on with looking after my stoma in hospital then at home.

Declan.....

I was born with B.E. and had lots of operations in my first three years and then had to wear pull-ups until I was 7, kids used to tease me and call me baby in prep because of the pull-ups so I use to go to the toilet and try to wee like other boys.

When I was 7 years old I had a Mitrofanoff Stoma made and now catheterise through the stoma 5 times a day. I do this at school and if we go on excursions I take a small Catheter bag with me. I go on School camp and my Teacher makes sure I have privacy.

I do not do sleepovers with school friends but other stoma kids and relatives stay here. I am very private about my condition, my closest school friends don't know, I go to their birthday parties but only stay the 3 hours. I play sport and ride my Motor Bike.

I have my Stoma for life and I realised very early with Mum's help I have to accept it and work with it.

Mandy.....

My daughter got her colostomy at just 1 day old. As a first time parent, finding out at birth (not before) that your child has a serious medical condition (that you had never heard of before) is all extremely overwhelming. Instincts take over, you go into auto pilot mode, listen to the doctors (a lot of which goes in one ear and out the other because of the information overload scrambling

everything in your brain), learn as much as you can and take as best care of your baby because she needs you. My daughters colostomy was reversed 1 week before her first birthday following some major surgery at 6 months old to correct the malformation. However she never gained control of her bowels, so at 11 she got an appendicostomy (MACE) for bowel management. We had a lot of support going into the MACE surgery, my daughter had full understanding of it all. Finally she had control.

Numbers to call if you feel you need professional help in **Australia**

Beyond Blue - www.beyondblue.org.au Ph: 1300 22 4636

Free 24/7, aims to increase awareness of depression and anxiety and reduce stigma

Be You - part of Beyond Blue for pre schoolers (contact Beyond Blue)

Kids helpline - www.kidshelp.com.au Ph: 1800 55 1800

Free 24/7, confidential and private counselling service specifically for children and young people aged 5 to 25

Lifeline - www.lifeline.org.au Ph : 13 11 14

Provides 24 hour crisis counselling support groups and suicide prevention services

Mensline Australia - www.mensline.org.au Ph: 1300 78 99 78

Free 24 hour counselling service for men needing emotional support or in crisis.

Black dog institute - www.mycompass.org.au

The black dog Institute provides a 24 hour free mobile phone / computer based programme to assist those with mild to moderate depression, anxiety and stress.

CHIPS (Chronic Illness Peer Support) - Ph: 9345 6616

Covers all chronic illnesses for ages 12-25. Royal Children's Hospital Melbourne
