

Rosie Campbell



Ferring Pharmaceuticals have reviewed these slides for technical content

Diagnosis and Surgery:

- Complex treatment refractory Crohn's Disease (Oral Oesophageal, Ileocolonic, Perianal)
- March 2005 Colostomy formed
- Numerous EUA's
- Treatment Refractory disease course with penetrating phenotype – completion proctectomy after subtotal colectomy – permanent ileostomy
- Perianal wound discharge with retained sepsis – MRI scan 2015 shows prescra cavity and draining sinus tract
- Previous MRSA colonisation
- August 2016 reconstructive surgery flap by plastic surgeons (Mr Shibu) further reconstructive Feb 2017
- Cutaneous Vasculitis – Query Aza related
- Intolerant to Infliximab, refractory to Adalimumab, intolerant to Methotrexate
- Oesophageal stricture, treated by scheduled dilatation every 4 – 6 weeks

Looks can be deceiving:



Treatment:

- 5-ASA
 - Azathioprine
 - Methotrexate
 - Infliximab
 - Humira
 - Stelera – Current
 - OGD every 4-6 weeks under GA
 - Ustekinumab – Currently been on 2 years
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- Accepted for Stem Cell 2011 – Declined and had total colectomy 2011
 - Steroids
 - Calcium supplements
 - Several diets
 - Folic Acid
 - Antibiotics
 - Iron Infusions
 - Blood transfusion



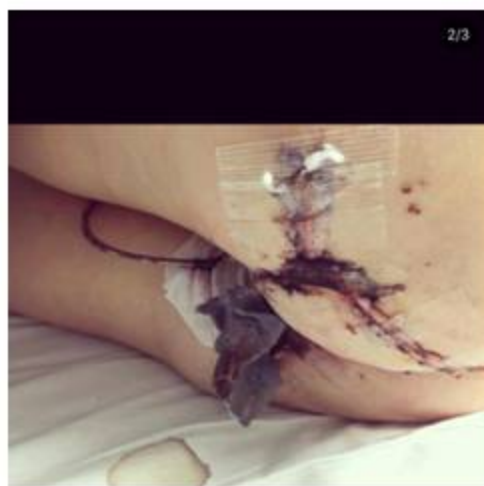
Day in the life of me:

- Waking up several times in the night with the fear the bags leaked
- Sore stomach from stoma site
- Sore bum and having gauze and pads on constantly for leaking from peri-anal wound
- Narrow throat – unable to eat properly
- Fatigue
- Avoiding certain foods
- Body pains
- Feeling like the weight of the world on your shoulders
- Anxiety

Clinic/ED/Bloods/Drugs/Symptoms

- Clinic wait times
- Clinic for patient's like me with no IBD like symptoms currently – where do I fit in?
- Do the ED teams need more training on these types of illnesses?
- Constant blood tests
- Side effects of different drugs, and being disheartened when they don't work thinking what next? Then the fear sets in
- Symptoms

Highs and Lows





We are thrilled to receive a grant of £75,000 over 3 years from [@WestonFdn](#) towards our IBD Nurse Specialist Programme. #IBD Nurses are the single biggest influence on patients' with #Crohns and #Colitis experience of care.

Your support will have a tremendous impact. Thank you!



What we need from our IBD Teams:

- Someone to listen
- Support with all that life throws at us
- IBD Nurses
- Awareness
- Joint Clinics with Surgical teams



Achievements:

- Speaker at ECCO and PIBD conference this year 2019
- Part of the IBD nurse funding campaign for Crohn's and Colitis UK
- Ran a Bupa 10 for Crohn's and Colitis
- Work full time
- My story shared in the mail online and the sun online
- Travelled to many different countries



Being a 29 year old Women with Challenging IBD:



Support

From friends and Family as well

