

## **IBD reflections – thinking about my patients thinking about their journey**

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### **Abbreviations**

IBD – inflammatory bowel disease

Hi Doc – I have pain in my abdomen. Sorry to hear this I reply. Can I examine you? Sure. My examination reveals nothing. I can't feel a mass and they are not peritonitic. Their pain is elsewhere. Much deeper clearly. Can you check my ferritin please. Sure. Yes its low. Yes Doc I can tell as I feel tired. Is it purely a low ferritin causing his tiredness I think...

Let me review your medications. So you have tried infliximab and are now on ustekinumab. Yes Doc but I don't think its working. Note to self it hasn't been so long but then maybe it isn't working. I can modify its frequency and more tests will help me to decide... His CRP is certainly raised.

So you need to provide us some stool samples please so we can see where we are in terms of your inflammation. Sure Doc will do. I look back at previous letters. There is a theme. 'Unfortunately you have not provided us a sample so we would be grateful if you can.' Shall I probe the topic or just take his word for it. We want their stool but do our patients want to provide us such....

So by the way Doc I don't want a colonoscopy. It hurt the last time and I don't want it. My mind is racing with all the possibilities on AI based detection. My bias creeps in. Yet I also know endoscopy does hurt. The mismatch between patient and provider wants.

I am planning to bring your case to our MDT. Physicians/ Surgeons and Nurses. Ah the discourse. Imagine if I invited him to the MDT. Why do we not do that I wonder? Surgeons. They view biologics as smarties. They like to cut. Physicians view biologics as the only option. How come?

Doc I have a question. Sure go ahead. These fortisip drinks. They taste awful. What else do you have. Imagine having IBD and being asked to drink something that tastes as it does. The word stoic comes to mind. Not a word of my choosing but because it seems to be a thing within the medical community. I don't like this word. It doesn't do patients justice.

So out of interest. What are you doing at the moment I ask. Studying chemistry Doc. Woah I think. All this and studying Chemistry. How does he do it. How's it going I ask. Yes fine. I'm on course to do well. Although when I get tired it slows me down. But I force myself to continue. Fascinating I think.

Doc I have a final question. Do all these drugs work? My neighbour was on one of them and his bowel burst. He got rushed to hospital because of it. The realization sinks in. I know deep down they can work but not always. All we can do is try I reply. We have good data out there but it is far from perfect...

## Acknowledgements

To all my patients suffering with IBD – thankyou for sharing your journey