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‘Managing difficult conversations’ podcast series

Episode 2:
Questions patients are too afraid to ask

*We brought together Consultant Gastroenterologist **Dr Gareth Parkes**, IBD Nurse Consultant **Cath Stansfield** and Founder and Director of the patient advocacy resource ‘The Bottom Line’ and ‘IBD Women’ **Rachel Sawyer** to hear their perspectives on how to discuss IBD-related cancer, surgery and sexual function with patients with IBD. Listen to the full episode on our Expert insights page and read Rachel Sawyer’s thoughts below, which are based on her experience as a patient advocate living with IBD.*

Rachel Sawyer, Founder and Director of patient advocacy resource ‘The Bottom Line’ and ‘IBD Women’

“Receiving a diagnosis of IBD heralds an important first step in a patient’s relationship with their healthcare team. For some patients it is startling news, while for others it provides a sense of relief and validation that the cause of their symptoms has finally been identified.

But as with many chronic conditions, IBD presents a series of difficult conversations between a patient and their healthcare team. Fears of cancer, surgery and the impact on one’s sexual function are just a few examples, and how these conversations are managed is vital to a patient’s ongoing health and relationship with their HCPs. As someone who has lived with IBD for many years, I would like to offer my perspective – plus a few tips along the way – on how best to manage these difficult conversations.

Let’s start with a look at one of the major fears for many patients with IBD: the risk of developing cancer. To mitigate this risk, it is recommended that patients have regular surveillance colonoscopies and adhere to their treatment plan.

But the invasive nature of colonoscopies can mean that some patients do not adhere to this surveillance schedule. To counter this, I believe we need to ‘rebrand’ colonoscopies and the negative imagery that surrounds them. Regular colonoscopies give us a real chance to prevent disease progression with the early removal of polyps. In this regard at least, us patients with IBD have an advantage over the general population in terms of bowel screening frequency, and HCPs should reinforce this as a positive to their patients.

How we understand risk as patients is vital. So often there are two parallel conversations going on in the clinic: the one the patient thinks they are having with their HCP and the one the HCP thinks their patient is having with them. Using visual aids to explain risk can be useful here, as patients may not always remember a series of recited figures, but they may be able to recall an infographic. Similarly, showing a patient a photograph from their colonoscopy that demonstrates their active disease can be a useful way of helping patients to understand the gravity of their disease. This is particularly useful for the disconnect that often occurs between symptoms and disease activity in IBD.

Referrals for surgery can be a frightening prospect for patients with IBD, often triggering anxiety about recovery times, fitness to work or ability to look after family. Recently, patients with IBD have been great drivers of conversations on surgery as an early treatment option, mainly due to them wanting to reclaim their quality of life at the earliest opportunity. Treating patients as equal stakeholders in healthcare decision-making is a great way to help patients to invest in their own health and strive for the best outcomes.

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Without doubt, one of the trickiest topics to negotiate between patients and their HCPs is the subject of intimacy. "We don't ask and patients don't tell" is a remark often heard by HCPs and it can lead to a frustrating impasse, particularly for patients who often suffer in silence.

The person who is best placed to raise the subject of sexual function likely depends on the individuals involved. But asking patients if there are matters that they would like to discuss about an aspect of their life with IBD, including intimacy, is a gentle and matter-of-fact way to introduce this topic into clinical discussions. Even if an HCP cannot directly resolve the problem that their patient faces with intimacy, they can at least point them in the right direction: perhaps a referral to a surgeon for physical challenges with sex, or a mental health specialist for those needing psychological support to regain a healthy sex life.

The most important factor here is to take the opportunity to air the discussion; to not raise the subject is an opportunity missed.

Early investment in managing difficult conversations with patients will provide the reward needed: it creates more relaxed patients who engage better with the challenges that their IBD brings, which in turn gives their HCPs the best opportunity to help them achieve good clinical outcomes."

"I truly believe that once the conversation is started and all the stakeholders are coming together to help in that conversation, then things do get better."

Rachel Sawyer, Founder and Director of patient advocacy resource 'The Bottom Line' and 'IBD Women'

Keen to hear the HCPs' perspective on how to manage these difficult conversations in IBD? Check out the full podcast episode on our Expert insights page. For more tips on how to facilitate open communication with patients with IBD, visit our Hot topics page to listen to the discussion between IBD Clinical Nursing Specialist Kay Greveson and Advanced IBD Clinical Nurse Practitioner Aileen Fraser.