

## IBD Insights: living with the disease

### Patient-to-Patient tips on disease management

Our first *IBD Insights: living with the disease* focuses on tips on managing the disease from the patient's perspective. Our PPI panel members - all with diverse experiences and backgrounds - share their viewpoints on what works best for them regarding disease management, diet, and lifestyle when living with IBD.

#### Top Tips

- When you have an IBD, the disease is yours to keep as it is in your body, so you are part of the team managing the disease.
- Be an empowered patient by being an advocate for yourself and your disease:
  - Be curious! Ask your health care team plenty of questions, no matter how small, large, stupid or complicated they might seem.
  - Learn and educate yourself about the disease and treatments.
  - Trust your healthcare team but don't be afraid to challenge their decisions if you are not happy with them.
  - If you don't understand or feel comfortable about advice being given, challenge it and ask questions to understand it so you can make informed decisions for yourself.
  - You are a key team member in any discussions and decisions about your disease.
  - Know your own body and trust your intuition, particularly if major life changing decisions are being made about you and your treatment options, eg. surgery.
- Look after your general health and fitness.
- Be regimented about your medication. Take it as prescribed and try not to forget it. Even when you are feeling well and symptom-free, do not stop taking your prescribed medication, unless advised to do so by your healthcare team.
- Learn and know about your medication. You will potentially be on it for a long time:
  - What type is it? (eg NSAID, 5-ASA, biologic, steroid etc)
  - How is it given? (orally, though IV etc)
  - What dosage are you on?
  - How often do you have to take it?
  - How does it work?
  - Is it taken before, after or with food?
  - Any side effects to be aware of?
  - What other medication options are available as alternatives to what you are on?

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- Avoid taking advice from unqualified sources such as online forums, unknown websites, other sick patients in hospital, random acquaintances (eg, “my brothers, neighbours, cousin also has UC and says you should...”).
- Find out who your assigned nurse practitioner is (if you have one) and get acquainted with them. They are an invaluable resource for answering questions you may have and for helping you out if you start to experience a flare up.
- Learn, be aware and understand the disease symptoms. There are many.
- If you have newly developed IBD symptoms contact your healthcare team or GP and get it checked out. They could be early stage indicators of a flare up.