

# Communicating your IBD

## Introduction

It can sometimes be difficult to talk about your IBD to other people, including your family, friends and even your healthcare practitioners. IBD can be isolating, so it really is important that you feel comfortable and confident in talking to others about your condition, whether that be the details of your symptoms and how these affect your day-to-day life, or what support you require from others (including your employers) in order to successfully manage your IBD.

- Any conversation you have will be dependent upon a number of things:
- The level of disclosure are you happy with
- The level of disclosure your audience is comfortable with
- What is/is not appropriate to talk about
- How much the person you are talking to understands about IBD
- The relationship you have with the person you are talking to (e.g. friend, family, teacher/tutor, acquaintance, work colleague)

These considerations can be very variable, and will depend a great deal upon your personal needs and priorities. Therefore the bulk of the content of this module will give you advice on how to approach any conversation, rather than providing the specific content of any conversation.

The objectives of this module are to help you:

- **talk** to people about your IBD
- feel **able to control** any conversation you have about your IBD
- feel **comfortable talking** to others about difficult topics
- **minimise any frustration** you feel if people don't realise what an impact IBD can have on your life and how severe IBD really can be
- **know what to include** in your conversations, whether that be as a person who is newly diagnosed, or as someone who has had IBD for a long time who is wanting a discussion with a new contact, or perhaps a deeper conversation with an old friend
- **have an appropriate vocabulary** to use, depending on the situation and your audience (for example, family members may use "poo", "wee-wee", "pee" as toilet expressions, but such a vocabulary may not be the best for other audiences, who may use "bowel movement", "diarrhoea", "stool", "urinate" or similar words)
- be **aware of the likely influencers** on any conversation – both sides need to be comfortable with the topics of conversation, depending (in part) on social background, age, gender, etc.
- be aware that **the same conversation can be had in several different ways**, depending on who is being talked to (partner, friend, family, employer, new contact just met in hospital), as no single conversation, or approach, fits all
- be aware of the **knowledge** of the person you are talking to (many people have never heard of IBD, and do not have reasonable knowledge about the gastrointestinal tract, digestive system, IBD symptoms). People who are unsure about any 'medical' vocabulary will need a different approach to those who know more
- realise that **being embarrassed is OK**, especially if you are newly diagnosed! Most people are embarrassed talking about personal issues – it isn't unique to IBD, it doesn't make the person with IBD different. However, you must not let embarrassment isolate you, and stop you from communicating appropriately to the people you need to talk to about your IBD.

## Top tips

- Build a support network which works for you
- Build a support network which identifies the different roles that your partner, family, friends etc. will play in supporting you
- You may communicate with your partner, friends, colleagues about the same topics, but depending on the degree of disclosure you are comfortable with, and your relationship with the listener within your support network, what you tell them; how you tell them and when you tell them will be different.