

# Communicating your IBD

## What to think about when communicating your IBD

### Top tips

- There is no such thing as a 'normal' conversation: each person is unique, and has to be treated as such.
- As an individual with IBD, you need to be very aware about the level of intrusion/disclosure there may be in any given conversation. How much trust and confidence do you have in the person you are talking to?
- The (ideal) aim of any conversation is to have the listener understand your IBD, accept and support you with no judgement. *(This is a difficult objective to achieve for any conversation, so do not aim too high – keep trying!)*.
- A principle of 'give and take' is important – both yourself, and whoever you are talking with will need to respect each others' boundaries. The person should be respectful of your motivation for talking to them about IBD, and you should be respectful of their curiosity and learning process.

### General considerations

As the person with IBD, you will have a unique set of communication needs depending on who you are, your age, your personal circumstances, the stage of your disease, the severity of your disease etc. Do you have a job? Do you have the support of a family to fall back on? Do you have a close friend? How many people know about your illness? In short, as you are an individual, a unique person, you will need to think about how to personalise your own approach to talking about your IBD to different audiences. In other words, only you will be able to judge what you need to say about your IBD, and to whom you need to say it.

However, while your communications will be based upon you as the individual with IBD, you will have a number of communication issues in common with other people with IBD irrespective of your age, severity of disease, etc. For example, you will probably need to think about how to communicate about the following:

- What is IBD? (it is not IBS)
- How your disease affects you
- How your symptoms change over time
- What your motivations are for talking about your IBD – do you need another person to provide help, support, or just an understanding ear?

This means that, when you communicate with others, you will need to consider different approaches for different people, depending upon your relationship with them. Only you can identify what these specific approaches are, based on any particular situation. Remember, you own all the information about yourself – what you decide to disclose is your decision.

As a general guide, you need to be aware of:

- your own personal boundaries, and the personal boundaries of the listener
- your spectrum of trust with your audience (how much do you trust them?)
- your levels of disclosure with the listener (how much do you want to tell them?)
- what vocabulary to use (so you are not only listened to, but also understood).

Different people have different comfort levels – there is no ‘one size fits all’. Each person with IBD has to learn what they are comfortable talking about, and what the person they are talking to is comfortable with listening to.

### **General ignorance about IBD**

If you are lucky, some people you speak with may have heard about IBD, and some may know the challenges you face. Others will know very little, while others may have heard about the ‘bowel’ aspects, and maybe flares.

You know that IBD is much more than that, but that is your communication challenge! You also have to think about how to communicate the wider issues that accompany your IBD, rather than just the ‘bowel’ issues. Your audience may not be aware of your IBD or have been involved previously with a person who has IBD and therefore may have a low level of knowledge that could be frustrating. Topics which are of significance to you might not even appear on their ‘radar’!

So, you will need to decide how best to tell them about a number of topics, such as:

- any alterations you have to your body image (for example, if you have a stoma)
- the significant weight loss due to disease/surgery (it is not anorexia nervosa)
- the side-effects of steroids (for example “moon” face)
- the mood swings
- the fatigue
- admissions to hospital

Once you start a conversation, understanding and accepting that you will most probably (regularly) need to explain things that exasperate you (e.g. that IBD is not having ‘irritable bowels’) may help you feel less frustrated. As you explain things, and people understand more, they will ask fewer questions that you might find silly, irrelevant or rude. But that is what the communication is for – to educate your listener, so they can become more understanding and supportive of you.

Similarly, the ‘smaller’ topics (stomach cramps, constipation, diarrhoea, tiredness) may seem unimportant in themselves to your audience (after all some may think “we’ve all had a bit of constipation or diarrhoea haven’t we – so what’s the problem?”). But you will have to think about how you can get across that a mixture/combination of these symptoms, as well as their severity, together with the other emotional aspects of IBD, can sometimes have a major impact on your quality-of-life, and your ability to participate in day-to-day activities.

These issues will cause frustration from your side. But, communicating about the impact these items have on your day-to-day existence can only help your audience gain a better understanding of the challenges you face. Do not shy away from these – to many audiences they are not even things they would associate with IBD.

Also, remember, that (unfortunately) some illnesses are generally deemed more ‘socially acceptable’ (broken arm, sports injury) than others (depression, bulimia). So, discussions concerning bowels, faeces, toilets, etc. may be more difficult for some people to have/accept than others. This has to be taken into consideration during any conversation.

IBD is sometimes called an ‘unseen illness’, because it is not outwardly obvious to other people. Flares don’t show like a plaster cast does – and symptoms (tiredness, short-temper) may be mistaken for moodiness or bad temper and misinterpreted as such (especially among teenagers). So, communications to pre-empt/manage such situations will be necessary.

### **Communicating clearly about your needs**

What does this mean?

To give an example, living with IBD sometimes means having to prioritise your health over other activities. This means that there might be times where you will have to communicate with family/friends/peers/partners/work colleagues about not being able to participate in previously agreed tasks or activities, for example. This can be difficult. However, it is important to be assertive and clear so

that the person you are communicating with knows a little about the situation, your reasons, and that it is not appropriate to coax or cajole you into changing your mind.

Consider the following statements:

(a) "I'm not sure whether I can go out tonight. It's just that I'm not feeling well, would you mind if I didn't go?"

(b) "Something has come up, I am not feeling well and I need to stay at home this evening. I'm disappointed, but have a good time without me".

(c) "I just can't go. You never understand, just leave me alone!"

You can see that the statements are different. The first statement is a little vague and passive, and would probably lead to someone trying to convince you to still go out, which is not what you need. The second is more assertive and clearly states what is needed. The third is more aggressive and probably won't win you many friends!

Try to remember to aim to be **assertive** (definition: *someone who behaves confidently and is not frightened to say what they want or believe*) – not **passive** (definition: *someone who accepts or allows what happens or what others do, without active response or resistance*) and not **aggressive** (definition: *someone who is unduly forceful or belligerent*). This is a hard thing to do especially when you are not feeling well, and already feeling bad that you have to back out of agreed plans. Practicing possible statements can be useful. Also, think of times when you have successfully and unsuccessfully communicated your needs to others, and try to remember why it worked or did not work out so well.

## Hurdles to overcome

A person who is newly diagnosed with IBD may have more difficulties in communicating/talking about various topics, compared with someone who is more experienced with their illness. You should not be afraid of acknowledging that it is difficult to talk about some aspects of your disease, and it may be difficult to talk to some people about certain aspects at all. Do your best to accept this. Have the confidence to be able to choose what you want to say, and when you want to say it, and to whom.

Remember though, that out of all your contacts, you need to be confident in your ability to talk to your healthcare practitioner – they will be very aware of the potential embarrassment levels of a person with IBD, especially with members of the opposite sex. They are trained to put you at your ease, so try to gain the confidence to be open and honest with them during your consultations.

Despite this, it can still be difficult (awkward even) at first with health professionals – nothing is perfect; however, their role, is to gain your trust and confidence and be able to talk with you about your IBD, so over time this awkwardness should not be such a big issue. It may help to remember that IBD specialists see people with IBD every day, and so will already be experienced with the difficult or embarrassing aspects of IBD.

## How to raise a difficult subject

Some topics of conversation are difficult to talk about, and uncomfortable to introduce into a conversation. Waiting for the right time to say something can be challenging, as there may never be a 'right time'. One useful strategy is to proactively make time with someone to discuss an important topic.

For example:

*"There is something that I wish to discuss with you. I wonder if we can do this over dinner tonight."*  
That opens the conversation and gives you time to build confidence about what to say.

Another strategy is to highlight that you are about to say something that is difficult. For example:  
*"I need to tell you something that is very difficult for me to talk about/difficult to say."*

You will find that the person listening will stop what they are doing and listen to you, which can make it easier (or sometimes harder) to continue. But you are helping them understand that you are going to say something important, which will facilitate good communication.

You might also want to make the situation easier for you both by telling them what you would prefer them to do. For example:

“I want to tell you something really important, and I want you to listen to everything I say before you respond, to make sure that I cover everything first”.

Some people find it easier to talk about important issues when they are engaged in another activity, such as when they are driving, cooking, playing golf, etc. This can be helpful if you find you don't like the intensity of a serious discussion, but be aware of the place that you select to ensure that you have privacy or that it is appropriate (i.e. it will be difficult to drive if you get very upset).

## **Who should you talk to?**

There are some people with whom it is strongly advisable for you to have a conversation with about your illness. However, this means that you have to think about the unique challenges you will face communicating to each of these groups of individuals. This is important, as these people will become your support network. However, your conversation with each one of these people will be different.

For example:

- **your spouse/partner/parents**, as they will be part of your closest support network.
- **your healthcare practitioner**, as their job is to offer you the best treatment without judgement.
  - Importantly, although it may feel intrusive at times, you need to communicate openly with your healthcare practitioner. Your illness and its associated topics are not unusual to them, and they will/need to ask you questions about your IBD which may sometimes embarrass you; however, your healthcare practitioner should put you at your ease.
- **your employer** may need to be aware of your illness (e.g. when in remission, you can work OK, but if you need to regularly take time off for treatment, or you cannot work because of flares etc.) in order to offer you a sympathetic and supportive work environment. Think about any advantages or disadvantages of telling your employer – you might wish to seek advice about ‘working with IBD’ first.
- **your friends**, because true friends will not define you by your disease