

# Communicating your IBD

## The Communication Pyramid

### Top tips

- With any illness, and especially with IBD, there are a number of communication challenges, especially around intimate and/or embarrassing issues.
- However, you need to have the confidence to communicate to some people, some of the time, about these topics.
- Other topics may be easy for you – but will no doubt be harder for other individuals.
- Before you are able to successfully communicate with anyone about your IBD, you will need to trust them.
- Depending on that trust, you will feel you are able to say (disclose) certain things to certain people, while you will feel uncomfortable telling other people the same information.
- Once you have decided to communicate with someone, you need the right words. The vocabulary you use will depend on you, on them, and on what you want to say.
- As you are an individual there will be a personal element to your communications which only you will know.
- **Remember, you are in control of what you say, to whom, and when.**

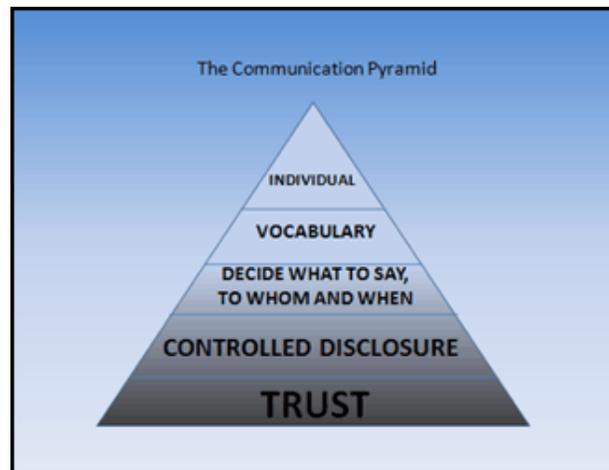


Figure 1. The Communication Pyramid

### **Level 1. Trusting**

You should envisage your communications as a pyramid (see Figure 1) with trust the bedrock upon which everything else is built. Without **trust** (definition: *to have belief or confidence in the honesty, goodness, skill or safety of a person, organisation or thing*) it will be difficult to communicate effectively about IBD. You may trust some people implicitly, others may take longer to gain your trust, but without that trust, you would be unwise to disclose anything about yourself or your IBD.

### **Level 2. Disclosing**

Once you feel you have a level of trust in someone (such that you want to disclose information about yourself to them), you have to make your mind up how much you actually want to tell them about your IBD. Such controlled disclosure just means that you are judging the sort of relationship you have with them, before you tell them anything.

### **Level 3. Considering what to say**

Once you have decided to share information about your IBD, you need to work out what you want to say, to whom and when. For example, you may have an urgent need to tell one particular person all about your IBD, the challenges you face, the concerns you have, the support you require. With another person, you might only want to tell them a little bit about one particular topic, or a couple of topics, meaning that you do not want to disclose as much to them as you were willing to do to the first person. Alternatively,

with another individual, you may want to tell them something, but choose to wait a little while (for example, after you have seen your doctor, or spoken to another of your contacts). In this way you are also deciding when the best time to give out some information might be.

#### ***Level 4. Vocalising***

Now you need to consider how you want to/should say things. This is where the correct vocabulary comes in; the words you use might be different for one person compared with another. This does not just apply to IBD it happens in many other situations. A physician will use certain words with other doctors, while using more common words with a patient (for example, a physician may describe a subcutaneous haematoma to a colleague, but describe it as a bruise to a patient). Similarly a car mechanic will use different words to a customer than he/she would to another mechanic, while a solicitor talking to another solicitor will converse differently than with a client.

Thus, you need to consider what vocabulary to use; this will very much depend on the context in which you are having the conversation, the audience's knowledge, and how comfortable they are in hearing what you want to tell them. Be aware that certain words will mean different things to different people ('cold' can mean the 'flu, or just under the weather, or just not very warm; 'quite sick' may mean poorly, or vomiting, or generally very ill. What does 'tired' mean to you? Is it extreme fatigue, or is it needing a cat-nap or sit down?). So, you need to choose your words carefully, to avoid misunderstanding. Also, be aware that some people are very embarrassed about hearing or using 'toilet-type' words. In most people this goes right back to their childhood, and toilet-training. Comfort words and family words might be appropriate to use with your own family, but may not mean anything to someone outside this circle; for example, using words like 'faeces' or 'bowel movement' may be lost on a child, or indeed some adults. We all know 'street' words, or 'rude' words to describe stools for example, but they may not be appropriate in the conversation you are having with friends or family members, as they may offend or distract the listener from what you are trying to say.

So vocabulary is important! Your audience needs to understand what you are trying to say, and the words you choose will be important in getting your communication messages across.

#### ***Level 5. Individualising***

On top of the complexities of any particular situation in which you find yourself when talking to someone, and the challenges you face in making yourself clear, each conversation you have involves you as an individual. You have certain personal requirements, and certain individual priorities, which make each conversation unique. This is where the individualisation of your conversation will occur. Your themes, topics, facts, thoughts, concerns and ideas might be the same as have taken place in previous conversations. Indeed these may be similar to the themes, topics, facts etc. that a number of people have. However, it is the individual that you are, and the individual circumstances under which you are having the conversation, which will mean these topics are vocalised in a unique style, and in a unique way. This is something that only you can decide on, and is something you must be comfortable with.