

Communicating your IBD

Communication exercises

Scenario practice

Before you communicate about your disease with anyone, work out (plan ahead, visualise) what you want the outcome of that conversation to be. That outcome will be different for different people. Here are some scenarios for you to practice with:

- Visualise them going well – what did you say and do?
- Visualise them having gone badly for you
- What went wrong?
- What would you do differently next time?

Scenario practice

- I have just started with some new symptoms which I find distressing, and means I cannot go out with my friends tomorrow.
 - What do I say to my best friend?
 - What do I say to my partner who was coming with me?

Scenario practice

- I have just started with some new symptoms which I find distressing.
 - What do I say to my physician?

Scenario practice

- My boss, who knows about my IBD, has asked whether I would like to travel away with work. I am in remission.
 - What do I say to him?
 - What do I say to my work colleague with whom I was sharing a room?

Scenario practice

- My college course requires me to go away on a field trip. I am having a flare-up:
 - What do I say to my tutor?
 - What do I say to my project team who I am working with?

Scenario practice

- I am having Sunday lunch at my parents. My mother knows about my IBD, but my father has difficulty in accepting it. The conversation comes around to my illness and what IBD symptoms can mean.
 - What do I say to my father?
 - What do I say to the uncle who has also come for lunch?

Scenario practice

- I am going on an all day journey
 - What do I tell my partner who is worried I will be OK?
 - What do I tell my parents who don't think I should go?
 - What do I say to the driver/conductor/guard before I travel?

Scenario practice

- You have spent all day preparing a meal for your partner's work colleagues. During the meal you feel tired and unwell.
 - What do you tell your partner?
 - What do you tell your guests?

Scenario practice

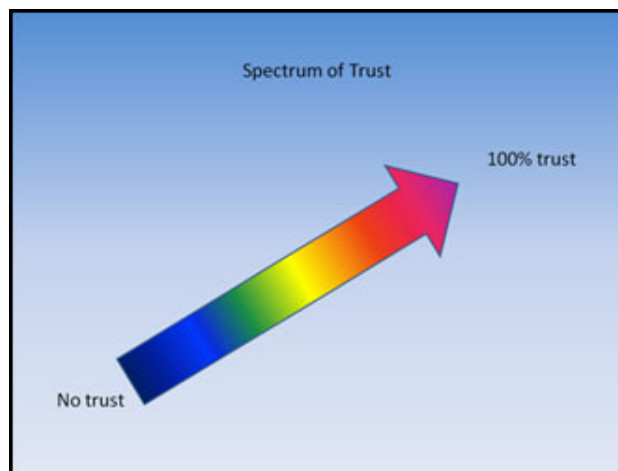
- Before you tell anyone, you overhear one of your guests saying to their colleague that you seem very stuck-up.
 - What do you say to your partner?
 - What do you say to the guest(s)?

Spectrum of trust

Trust is a very complex, dynamic thing – something which takes time to build and be comfortable with. It requires confidence in you, yourself and in other people. Similarly trusting your tutor, or your employer, about an aspect of your illness may be different to your trust in your partner, or your doctor.

Before you communicate about your disease with anyone, work out (plan ahead, visualise) what you want the outcome of that conversation to be. That outcome will be different for different people:

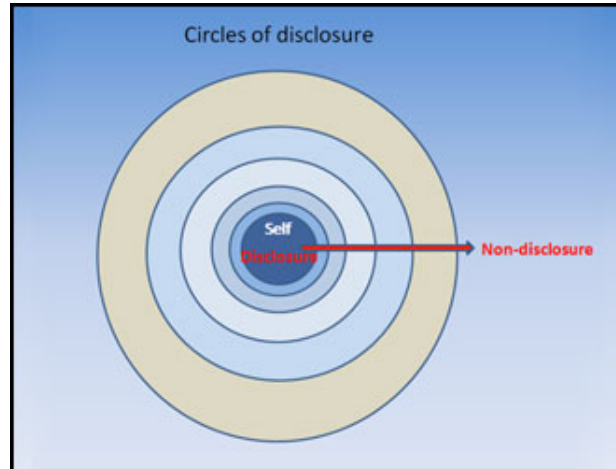
- Think about your partner, friends, colleagues, employer, etc.
- If you tell them something, do you trust them?
- What do you want to say to them?
- Imagine wanting to tell them something – a close, intimate piece of information? Could you? Place them on the rainbow above, depending on how much trust you have in them with that piece of information?



- Now think about another piece of information, maybe not so private? Where would they sit on the trust line now?
- How much do you trust them today? How open do you feel? Was it the same as last year? How will it be in 6 months time?

Disclosure

All this really means is that (for example) you may want to share things with your friends which you may not want to share in the same way with your family. Similarly telling your tutor, or your employer, about an aspect of your illness may be different to how you tell your partner, or your doctor.



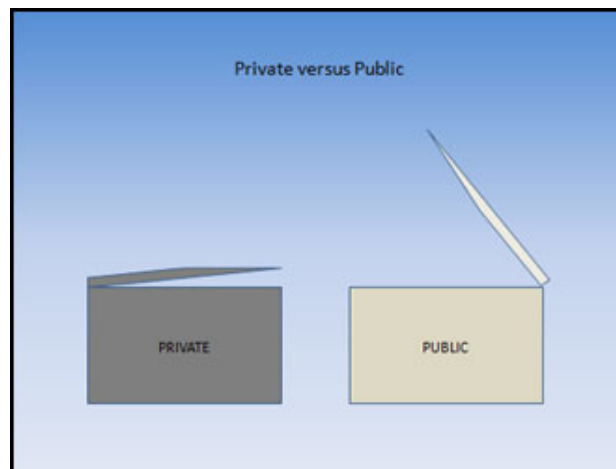
- Think about your partner, friends, colleagues, employer, tutor, etc.
- What do you want to say to them? How much of yourself are you sharing with them by telling them this information?
- Think about your IBD in general. Place one of your contacts on the chart above, their position being dependent on how much disclosure you feel happy sharing with them about your IBD.
- What about incontinence? Where do they sit on the chart now?
- Would they sit in the same place if you were discussing fatigue?
- How comfortable are you with them today? How open do you feel? Was it the same as last year? How will it be in 6 months time?
- What about another contact; do they sit differently on the chart?

Information visualisation

This is a similar exercise to the disclosure one, but is about topics, rather than contacts. There are things we like to keep private, while there are things which we don't mind people knowing about.

These topics will be very personal to us, and so what we want to keep secret, and what we want to share with others, will depend on our personality. Some people are just more private than others.

It is not wrong to be private, just as it is not wrong to tell people things. It's who you are. What you think you should keep private about your IBD, and what you are happy to talk about, will depend on you, the person you are talking to, and the topic.



- Have a think about a certain topic – for example, fatigue. How private or public is that for you? So, put it in one of the boxes.
- What about incontinence? Put it in a box.
- Think of other topics around your IBD. Where would you put them?
- Now, look into the box. Would any of the topics move across the boxes if you were talking to your healthcare practitioner? What about your mother or father?

All this really means is that nothing is fixed. Topics which can be private, embarrassing and upsetting at one stage of your disease can become easier to talk about and less distressing at a different stage, or with different people.

Vocabulary matrix visualization

[Click here](#) to view and print a larger version of this table

- When you talk to people about your illness, what words do you use?
- Look at the vocabulary matrix. What words would you use for the different people you are talking to?
- Click on the [Glossary](#); see what other words you could add to the left hand column, and what words you would use to talk to you partner, your mother/father, or your employer (for example).
- Many people get embarrassed over 'toilet' words (faeces, poo, stool, etc). Be aware that most people have a set vocabulary that they have used since childhood, and which will be defined by their age, social background, education and personal comfort-zone.

Vocabulary matrix						
Word	Partner	Family	Teacher	Employer	Friend	Physician
flare						
diarrhoea						
colon						
endoscopy						
faeces						
incontinence						
wind						
mood						
fatigue						

All this means is that your vocabulary will change depending on who you talk to. You need to be comfortable with the words you use, but the words you choose must not make the person you are talking to uncomfortable – otherwise you will not communicate effectively!