

Communicating your IBD

Communicating with spouse/ partner

You may need to discuss:

- **your emotional relationship;**
- **your physical relationship;**
- **sexual issues;**
- **intimacy issues;**
- **financial issues.**

Top tips

- All couples can experience difficulties in communication at various times – this is normal.
- IBD does not separate you from life's normal problems – it is part of your normal life, and the challenges associated with it.
- Accept that you and your partner will have a number of issues which you need to discuss; acknowledge them, but treat them for what they are – things to manage, not to define you, or to rule your relationship.
- Remember, you are a partnership first and foremost; IBD may add a level of complication to your life, but so do many things! Treat the IBD for what it is – something you can both manage, together.

Emotional support

Your spouse or partner, by definition, will share your life, and therefore your IBD with you. Of all the communication groups, your partner will have the most cherished relationship with you. However, communication with your partner presents a unique set of challenges due to the complex, intimate nature of your relationship, never mind the added complication of you trying to communicate your personal perspective on your IBD to them.

They will need to know in more detail all the intimacies of having IBD (e.g. what they should expect from IBD; what the symptoms are; what can happen with a flare; what the side effects of therapy might be) especially in the early days when you are coming to terms with your disease, and until the appropriate therapeutic regimen is identified.

This is because, as your partner, they will be significantly involved in your life. They will be on life's journey with you. They will need to understand that the disease will present you, and them, with ups and downs. For example, you may need to share with your partner details about what fistulising disease is (and what it means) which you would not (necessarily) tell your mother, a friend, or indeed a 'future partner' at the start of your relationship.

It may help your partner to understand the disease if they accompany you to see your consultant or physician, and/or if they also meet others with IBD, and their families. The ups and down of the disease will add a layer of complexity to your relationship. You should both accept that the disease will put strains on your relationship; it will at times impact strongly upon your life, your partner's life, and your lives together.

Managing fears and anxieties

There will be natural anxieties (fear of going out; embarrassment if an accident happens) – but don't let this isolate you both. Discuss options, and communicate your fears and anxieties, so you both have a plan to deal with specific issues. Consider encouraging your partner/spouse to learn about IBD – perhaps visit this website, or use other written materials (which they can assimilate in their own time and at their own speed). Alternatively, perhaps encouraging them to speak openly about their fears might help them realise the importance of providing you with the appropriate level of support (both practical and emotional) especially during a flare.

Let's think about fears and anxieties from your partner's perspective for a moment...

...they may want to protect you; mend or fix the illness for you; make it 'go away'. Be the one you depend on; manage your life so you are not in danger, in harm, in pain. You may want to become dependent upon them, and so 'hide' from the problems your disease brings. They may feel scared for you (and themselves), and so hide their feelings, or envisage the worst possible scenario in any given situation. On the other hand, your partner may want to deal with your condition by ignoring it – i.e. not wanting to know anything about the disease, and just wanting you to handle it alone. This is sometimes how people deal with illnesses, and is perhaps based on their own experience of managing poor health. Alternatively, you may want to protect them by not being open, or apologising for being ill, or feeling it is your fault you have brought this on you both, or feeling guilty. These feelings can make you feel even more alone.

Try to listen to your partner's fears, and remember that other people with IBD, and their partners, also experience these problems. Sometimes, in people with newly diagnosed IBD, there is a feeling of euphoria for the partner, as the symptoms at long last have a label – now he/she can start getting better. But, when the person with IBD doesn't improve as quickly as is 'expected', or the partner realises that there is not a cure – just a continuous management of the disease – other emotions can arise: blame, frustration, anger, guilt and helplessness. In general then, a balance has to be struck between the partner wanting to overprotect/ indulge/ protect you and not giving enough support/understanding/consideration. Any communication you have with them has to tackle this.

Difficult topics

Your illness may or may not affect your role in your relationship. Who (now) is the main breadwinner? Who contributes what to the household? Who is dependent upon whom? Are you a mother, a father, a husband, a wife, a patient, or someone who is also dependent upon your partner? You may find it hard to initiate certain necessary conversations about your IBD. How do you tell your partner some of the more difficult aspects? The sooner you are able to have the confidence to do this, the easier it is, because you have not had the opportunity for certain negative behaviours to have become engrained (fixed). Importantly, don't allow a distance in communication to build up with you and your partner – that will lead to a feeling of, or living in, isolation.

While a number of these issues and topics also apply to communicating with other groups of people, the unique point about communicating with your partner is important to the level of intimacy involved, both sexual and non-sexual. It is something which you (as a partnership) will need to assess for yourselves.

Be as honest as you can, as soon as you can. Be aware that it might be difficult if your partner does not find out about details of your illness from you, but via another route. If they do, how will this affect the trust and openness between you? How will they feel if they perceive you don't trust them, or are not able to confide in them?

So, what do you say? This is very personal; you will have to make the judgement yourself. But, some practical advice: initially, it might be best to keep it factual, for example: "This is what my disease is..."; "these are my symptoms..."; "this is what happens when I have a flare..."; "this is what I have to do if I have a stoma..."; "this is what I need to think about if I travel...".

Let's look at some specific areas:

Toilet habits: some people do not mind going to the toilet (both urinating and/or defecating) in front of their partner. However, for other people, it is a private matter, and even having a conversation 'through the toilet door' is a big taboo! So, if you need to share the practicalities of your toilet mechanics, which your IBD necessitates, with your partner, you will need to judge on a personal level what you actually want to share, depending not only on what you need to tell them, but also on your partner's comfort zone.

Sexual relations: IBD can act as a wedge between partners, when it is difficult for your partner to accept that, on occasion, your symptoms may make you feel you don't want to engage in a physical sexual relationship. It is not a rejection of them – you are unwell. The classic phrase "not tonight darling, I have a headache" may sound silly; but the concept captured by the phrase is not – i.e. that

you have symptoms which make you feel less than approachable. Tell them (gently) that sexual relationships may be difficult at times, especially if IBD affects intimate areas of your body. It does not mean you don't love them, or that you don't want to be intimate with them, just that it might not be appropriate at that moment in time.

Financial matters: there will also be possible effects of IBD on your job, or on your partner's job, and this may impact on your income (e.g. you may want to change your job to suit your situation). You may be concerned about getting a mortgage, or keeping up the repayments on a mortgage you already have. Financial worries can add another level of strain to relationships, not just to those living with IBD. Again, the specifics of any communication have to be identified by you, but don't allow any such concerns to isolate you. You may need to seek advice from banks, financial advisors and social security departments – but agree on any such approach with your partner.