

Communicating your IBD

Communicating with family

You may need to discuss:

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

By talking to them about the challenges you are facing, your family will begin to understand why some days are better for you than others. This will allow them to more easily adapt to your needs, in order to give you the best support that they can. Talking to your family is important for another reason. If you have no significant partner, a close friend or someone else to talk to, the danger might be that you start to bottle things up, running the risk of becoming isolated within your own family.

As in all families, there are good times and there are bad times; however, these will happen whether you have IBD or not. Over time your family will become used to you and your symptoms. Time brings normality. Just as your partner is with you for the long term in supporting you, so is your family. But remember, your relationship is not simply with this thing we call 'a family'! Your family is a group of individuals that might be made up of mother, father, brother, sister, grandfather, grandmother, aunts, uncles, cousins, nephews, nieces, and so on. Your relationship with each of them as individuals will need to be considered, as well as their relationships with each other.

Emotional support

Make sure your family know about your IBD, and how you feel on a day to day basis. Silence can sometimes be deafening if they do not know what is wrong with you! Are you just having a bad day, or is it something more significant, something more worrying? Is it something they need to help you with (getting you to the doctor for example) as opposed to letting you get on with it, and deal with it in your own way?

What to say to different family members?

Through communicating about your IBD, you and your family can learn to share the same vocabulary – which will help you share the same normality. So, think about the different members of your family and how you need to speak to them.

For example, your mother/father will have a different relationship with you than your brothers and sisters. How you tell your mother about how you need to plan for possible faecal incontinence on a family trip will be different to how you talk to your brother, or your grandmother. Or how you tell your teenage sister that you are too tired to listen to her latest boyfriend issues (without her then thinking badly of you) is a problem anyone with a teenage sibling has, let alone someone with IBD!

Understanding the differences between your parents and your siblings, while also seeing the commonalities, and modifying your communications with them, is important in managing this. For example what you might tell your older brother about any issues IBD brings you when going on a date will be different to what you might tell an older sister (and will differ from what you tell your mother).

However, the common theme is that you are a family, and while some family members may be a strong support to you, others may try to shield you (dads with their little girls for example) while some may want to distance themselves from you as a result of their fear, ignorance or immaturity. It is important that you try to communicate to your family not only as a group, but also as individuals – some families find they become closer as a result.

What if you are newly diagnosed?

If you are newly diagnosed, or if your illness has entered a new stage, things may seem unfamiliar and difficult/frightening while you (and your family) adapt to the new situation. Over time, however, the new circumstances will come to be seen as 'normal'. You and your family may learn to treat the challenges your disease gives you with a degree of indifference or even disdain.

It is important to remember to keep control of your response to your symptoms; your symptoms should not control your behaviour. This is important for others as well as yourself – remember that your family members care about you, so they will worry about you if they are unsure about how you feel, what you think, how you are managing.

Family activities

Normal family activities may be affected by your IBD, and family plans may need to change, depending on how you feel at the time. While you can still do activities, sometimes, just because you are having a rough time, there may be disruption to normal family life. However, you must communicate that not everything the family does together depends on you being well – if you can't join in, it doesn't matter; you shouldn't feel like you are letting anyone down. If you had a broken leg you wouldn't expect to go swimming, or play football – your IBD is the same in that, at times, it will limit what you are able to do.

You must also make sure that you do not feel you are a burden to your family; neither are you stopping them/inhibiting them for doing things. Your communications with them, and them with you, must reflect this important fact. So, make sure that everyone realises that your symptoms should not be a burden to them at particular times, or stop them doing things.