

Communicating your IBD

What is a support network?

A support network is a matrix, an interconnection of people centred on you, who are there to support you through life's up and downs. This is something everyone needs – not just someone with IBD. We all have people who are there for us, and who we are there for when they need support. However, as a person with IBD, because of the challenges IBD presents you with, it is important that you identify and build a strong support network, so that you do not need to face these challenges alone.

Top tips

- Your support network doesn't have to just include your partner, or your family. Friends, and/or your employer, can also be hugely supportive.
- Your local and national IBD organisations can help you.
- There is useful information at the EFCCA [European Support Groups link](#), and the EFCCA link, at the top of each LIFE and IBD web page.
- Look out for any public information meetings, or support group meetings. If you feel comfortable in attending, encourage your friend/partner to accompany you and learn more about IBD and talk to other members.
- Your support network will be unique to you, but it is very likely that the core to it will be
 - A family member
 - Your spouse or partner
 - A close friend
 - Your physician/nurse
- You need someone who you can emotionally open up to, someone who you do not need to cover up with, someone with whom you can 'just let it all go'.
- Your support network will act as a 'buffer' against stress, helping you feel that others are there and care for you, and so help you through difficult times.
- Communication with your support network is essential, otherwise you will feel isolated. Your communication with different members of your support group will depend upon the variables in the Communication Pyramid (trust, disclosure, vocabulary, and personal judgement/choices).
- Most importantly, this network stops your IBD from isolating you, reminding you that you are not alone.

Personal boundaries

We all differ in our level of personal boundaries. Some people like to share everything with the world; others are more private and only like to share things with those closest to them. People are different – so you will need to work within your own personal boundaries when you communicate about your IBD, but you will also need to consider the personal boundaries of your audience.

- IBD is associated with physical, sexual, emotional and personal issues, disclosure of which is associated with varying degrees of intimacy, trust, and confidence in the person to whom these details are being disclosed.
- There are degrees of disclosure regarding things which are private/personal which need to be evaluated before any discussion.
- Therefore, because these boundaries are 'personal' this module cannot give you specific advice on which words to say – just a framework to work in.

SO

- Be comfortable with your approach.
- How much, or how little you want to say about your IBD, is up to you.
- The conversations and comfort levels will be different in different situations (e.g. employer versus healthcare professional).
- However, it is better to have someone (doctor, nurse) who you can open up with unreservedly.
- Your personal boundaries will reflect your personality – some people are open, some are private – neither is better than the other.

BUT REMEMBER

- There can be issues when the person with IBD bottles up their problems.
- IBD can sometimes be physically isolating (with topics which can be thought of as socially taboo).
- Everyone needs support.
- All the research suggests that individuals with support networks do better than those without.
- So you do need to try and build up such resources, and have other people to rely on.
- Again, this is an individual choice: some people need lots of people in their support network, some only need a few close friends.

The 'Ideal' Supporter

It might help to have a picture an 'Ideal' Supporter, someone who unequivocally, intuitively and naturally just does the right thing for you.

While nobody is perfect, having an image of what you would (ideally) envisage as the best possible support for you might help you in your communications with different people. This ideal is something you can aim for when you talk to others.

In fact, the different types of 'ideal' supporting behaviours are likely to spread across a number of your contacts in your network, not concentrated into one person. In addition, while these ideals are a 'nice-to-have', you cannot demand them, nor can you expect them. Most of the people you know will not offer you all of these, but unless you have this picture of what you would like from them, how can you influence them to give you such support?

However, that's really what your communication is about – aiming to gain the best level of support you can from your family, friends, teachers/tutors, healthcare practitioner.

This might be difficult to imagine, so here are some thoughts about what an Ideal Supporter might behave like. Some of these behaviours might work for you, others may not – but working through this process might help you see in your mind what you actually want from your supporters.

You are my supporter – this is how you can help me. This is what I need from you. This is how you should act, what you need to know. I value your support it helps to make me feel better.

- The Ideal Supporter
- Does not make me feel isolated because I have IBD
- Does not make me feel 'poor me'
- Gives me understanding, not sympathy
- Knows they cannot 'mend' me
- Knows they cannot catch IBD (or my symptoms)
- Asks questions
- Allows me to be well, when I am well
- Allows me to be ill, when I am ill
- Laughs about my illness and cries about my illness – but always with me
- Lets me go out; lets me stay in; respects my decision to go out/to stay in
- Respects my control over my medicine
- Lets me have ownership of my health
- Does not judge me by my symptoms (or IBD)
- Realises I am not defined by IBD
- Realises I am who I am; I am not my illness
- Realises that this is my life – I am normal, allow me to live a normal life
- Helps me work out the best way for me.