

## Guidelines for Difficult Situations

---

### Learning To Manage Emotional Distress

The diagnosis of a serious illness or the recurrence of disease symptoms after a period of relative good health can affect the very core of our beings. They can affect:

- **Our self-esteem** – How we see ourselves
- **Our self-confidence** – What we feel we can do and achieve
- **Our sense of worth** – How we think others see us

Having a comfortable level of self-esteem, confidence and self-worth are all central to healthy emotional and psychological functioning in our day-to-day life.

Following a diagnosis of IBD, it's expected that you'd feel some degree of shock, anger, anxiety and depression. It's fairly certain that these are things you'd much rather not be feeling.

Allowing yourself to experience uncomfortable emotions is part of the road to feeling better. It's about acknowledging your feelings and recognising that you're entitled to have them. This is often referred to as a 'normalising' process. It takes away the responsibility or guilt you may be harbouring unnecessarily, for what may well be a legitimate experience.

Normalisation of the experience doesn't necessarily alleviate all the uncomfortable emotions but it does reduce the sense that you're fully responsible for your feelings, or that you could alter reality if only you tried harder. Try not to judge your feelings too harshly. They could be offering you important clues as to how you can come to terms with your experience of IBD and assist you in making decisions about your future. Be patient with yourself and with what you're feeling.

The next stage is to identify a problem-solving strategy that works for you.

Health professionals have developed a management strategy that is simple in design and based on four key ideas. It's easily remembered by the word it spells COPE.

**C** for Creativity

**O** for Optimism

**P** for Planning

**E** for Expert Information

The first step in the management strategy is to identify a central issue. Then refine the issue and simplify it so that you can understand it in its true essence. You may be experiencing many different problems that all seem to be inter-related. But try to choose one(s) that you can work on and which will make a significant and positive difference to your life.

### Managing Difficult Emotional Experiences

Despite all our positive efforts to manage the emotions of a diagnosis or ongoing illness, sometimes nothing seems to work. There might be times when you think that you're completely losing your mind. This is not the case and it could be that you're also experiencing depression or anxiety.

There's established medical evidence that a diagnosis of Crohn's disease or ulcerative colitis can result in a proportion of people developing either depression or anxiety. These are very real but treatable medical conditions that can and should be addressed.

Like IBD itself, depression and anxiety are not something within your control, and this is often difficult to understand at first. But effective treatments are available that will allow you to achieve emotional balance and gain a greater sense of control. This will be an important step in your overall recovery.

### Depression

It's only natural to feel down or distressed at times when living with IBD. You might have depression if, over a two-week period, you find that:

- you feel worthless or excessively guilty
- you feel sad, down or miserable most of the time

## Guidelines for Difficult Situations

---

- you've lost pleasure or interest in most of your normal activities.

You might feel these alongside these other symptoms:

- a loss or gain of weight or a decrease in appetite
- sleep disturbances
- slowing down, feeling restless, or feeling overwhelmed
- feeling tired or having no energy
- experiencing poor concentration or difficulties thinking
- having recurrent thoughts of death.

Discuss the symptoms with your doctor or clinical team as soon as possible. Your symptoms could be the result of your condition or the treatment you're receiving, or it may be that you're experiencing depression as well. Your clinical team will be able to work it out with you and then explore the best treatment options.

### Anxiety

Another common condition associated with IBD is anxiety. We all experience anxiety from time to time and it could be difficult to know what's normal and what's not, particularly if you have been unwell for some time. Also, the signs and symptoms of an anxiety disorder tend to develop gradually over time, which can add to the overall confusion.

You might have an anxiety disorder if, over a six-month period, on more days than not, you experience:

- feeling very worried
- finding it hard to stop worrying
- discovering that your anxiety is making it difficult for you to do everyday activities.

Discuss the symptoms with your doctor or clinical team. The anxiety you're feeling could be the result of your IBD or the treatment you're receiving, or it may be that you have an anxiety disorder. Your clinical team will be able to work it out with you and explore the best treatment options.

### Living With Someone Depressed With IBD

IBD undoubtedly affects the individual with the diagnosis. What's often not acknowledged is that IBD also affects family members, friends and associates to varying degrees. While they might not have the physical symptoms themselves, they can have a sustained emotional response to another person's illness.

Much of the information provided thus far in terms of individuals with IBD adjusting to the diagnosis and identifying strategies to manage their condition is just as relevant to those who are close to someone with the disease. Not having the diagnosis yourself doesn't mean that you're not affected, both in terms of what you see the person going through and what you experience in your own right.

If you are close to a person who has IBD, you will have to acknowledge your own experiences and recognise the importance of your role in terms of helping your friend, partner, or family member cope with the disease. You'll need to accept and appreciate that you're also vulnerable to difficult experiences and emotional distress. The COPE strategy outlined previously can also apply to you, and you are equally entitled to any available help.

### Living With A Child Depressed With IBD

It is not uncommon for children with IBD to have episodes of depression. Especially after a period of relative good health, a relapse can make them suddenly realise that their condition is not simply going to go away. Treatment with corticosteroids can also cause mood changes which exacerbate the problem. You can help the situation by reassuring your child that the setback is likely to be temporary and by making sure that your child receives prompt medical attention if necessary. Some children will benefit from counselling by a therapist familiar with IBD.

Experience has shown that depression is usually related to disease activity, treatment, or nutritional deficiencies. Once the symptoms lessen and the child feels well enough to resume normal activities, the depression usually disappears. Again,

## Guidelines for Difficult Situations

---

psychological therapy might be helpful for the child, parents, and the family as a whole.

### Helping Your Child Cope With IBD

No parent likes to see their child sick. It is completely normal to feel frustrated at times when you cannot simply make their pain and symptoms go away. The best way to help your child cope with IBD is by your own acceptance of their condition. You will need to come to terms with it realistically. IBD is not preventable or avoidable. It was not anything that you or your child did or did not do that brought about the onset of IBD, so there is nothing to be gained by blaming yourself or feeling guilty. Once you accept that your child has IBD, you can move on towards identifying ways in which you can provide the right kind of support and ensuring that your lives are as normal as possible.

Try to learn as much about the disease as you can. Ask questions of your child's clinical team, and encourage your child to do the same. CCA provides a wealth of information about IBD and can offer support to you and your child when needed. The Internet is also a valuable source of information about newer methods of IBD management and about where IBD research is heading. Some online resources are shown in Section 18 'Resources and services available for people with IBD.'

The presence of a chronic disease such as IBD within the family environment can have a huge impact on family dynamics:

- Parents will need to spend more time with a sick child than with other children. This can lead to feelings of resentment and jealousy, and cause constant friction between the children. If at all possible, try to avoid letting IBD become the focus of attention in your family life and make sure that your other children are receiving their fair share of your time, attention, and love.
- Some parents become overly protective of their child with IBD. A child's physical and emotional wellbeing, however, is best developed by encouraging him or her to participate in age-appropriate activities, just as you would do for your other children. And as soon as your child is old enough, it would be a good idea to foster independence by encouraging him or her to take responsibility for some aspects of the condition, such as taking medications or calling the IBD clinic when necessary. Many children thrive on responsibility and learn valuable life skills in the process. It is a difficult balancing act between helping children manage their condition while also fostering their development and independence. When symptoms are less severe or the disease is in remission, a conscious effort needs to be made to treat them like an average child of their age.
- If a child develops IBD at an age where the quest for independence is already a major issue (e.g., during adolescence), it can become a huge source of tension between parent and child. Parents might become alarmed when the child is in denial about the condition and refuses treatment, or is eating poorly and losing weight. This can lead to an ongoing battle of wills with seemingly no simple solution. These are all genuine concerns that need to be managed quickly and appropriately, usually with intervention by the child's clinical team. Psychological support for the child and/or family might also be appropriate in order for everyone to cope better with the challenges and to move forward.

Open two-way communication is the best means of identifying issues early and preventing them from escalating into major dramas. Children should be made to feel comfortable about voicing any fears or concerns they have about their disease and its treatment. Allowing pre-teens and adolescents the opportunity to take responsibility (within reason) for their own condition can give them a sense of control and help prevent tension from arising between parent and child. If non-resolvable issues remain despite you and your child doing the best you can, family therapy is a valuable option to consider. An expert in family dynamics can provide much-needed support to your entire family.

Above all, your knowledge about the disease and its symptoms, a calm and level-headed approach to dealing with them, together with your love and support, can have a reassuring effect on your child and on the rest of the family.

### Finding Support

If you have concerns about a health condition that you'd like to discuss with a qualified health professional, you're advised to:

- Contact your doctor
- In an emergency situation, call triple zero – 000
- Contact NURSE-ON-CALL ([www.health.vic.gov.au/nurseoncall/](http://www.health.vic.gov.au/nurseoncall/)) at 1300 60 60 24 for health advice from a registered nurse 24 hours a day, 7 days a week



## Guidelines for Difficult Situations

---

Organisations that can assist with mental health concerns are listed below

### Australian Psychological Society (APS)

APS is the premier professional organisation for psychologists in Australia, representing over 21,000 members. One of its services, the APS Find a Psychologist Service, is an online, telephone, and e-mail service for the general public, GPs, and other health professionals who are seeking the advice and assistance of a qualified APS Psychologist.

<https://www.psychology.org.au/FaP/>

### beyondblue

beyondblue is a national not-for-profit organisation that works to achieve an Australian community that understands depression and anxiety, empowering all Australians, at any life-stage, to seek help.

[www.beyondblue.org.au](http://www.beyondblue.org.au)

### Parentline

Parentline provides a statewide confidential telephone counselling service to parents and carers of children aged from birth to 18 years. Professional counsellors are able to explore a variety of issues that affect parenting and relationships.

T: 13 22 89 (8am to midnight 7 days a week)

[www.parentline.vic.gov.au](http://www.parentline.vic.gov.au)

### SANE Australia

SANE Australia is a national charity helping all Australians affected by mental illness lead a better life—through support, training, and education.

T: 1800 18 SANE (7263) (9 to 5 Monday to Friday)

[www.sane.org](http://www.sane.org)

### IBDclinic.org.au

IBDclinic.org.au is an online mental health service offering information, assessment, and online treatment programs ("eTherapy") for anxiety and/or depression for individuals with diagnosed with Inflammatory Bowel Disease (IBD). This website and its intervention programs are free and available to all individuals with IBD and also any health provider to use with their patients.

There are two 6-week IBD-focused psychological treatment programs. After an initial assessment, participants will have the option to undertake either a depression-focused treatment program or an anxiety-focused treatment program.

[www.ibdclinic.org.au/](http://www.ibdclinic.org.au/)