Inflammatory Bowel Disease: Beyond Nutrition and Medicine

Why is it important to tend to your mind?

Good health is not just about controlling the physical aspects of Inflammatory Bowel Disease (IBD). Receiving your diagnosis and living with IBD can be difficult, especially when it’s active. Having IBD can impact many areas of your life, including daily activities, social activity, body functions, health management, energy, pain, emotions, mental alertness, and sense of personal control.

You may have wondered how psychological and emotional factors might impact IBD. Knowing positive ways of coping, managing your stress, attending to your emotions, and staying connected to positive social supports are important. Together, these can increase your ability to heal, reduce the severity and number of IBD flare-ups, and lead to better overall well-being.

What about stress?

Stress is part of life. It does not cause IBD or automatically cause relapse, but stress may increase IBD activity. It may mean shorter healthy periods, delayed recovery, or more severe symptoms.

Stress can be thought of as a three-stage process involving: (1) an event, (2) your perceptions of it, and (3) your reaction to it. How your body reacts to stressful events depends on how you perceive and react to the event. Stresses are individual and so is their impact on your physical health. The more stressed you feel, the more likely it will affect your IBD symptoms.

IBD can increase your stress. For example, you may feel stress about body functions, physical pain, and changes in your privacy, boundaries, and physical abilities. Stress can also be about other things and those stresses can affect your condition as well.
How does my mood fit in?

Mood is an important factor in coping with IBD. From 25-50% of people with IBD may develop depression or anxiety (and these often occur together). Depression and anxiety are more likely at the time around initial diagnosis and when IBD is active. Some IBD treatments (e.g., steroids) make these symptoms more likely. If you experience depression-anxiety symptoms, you may experience more IBD problems. You may relapse quicker, have more symptoms during active IBD, and have a more difficult time achieving remission.

Common Symptoms Of Depression And Anxiety

- Low mood
- Loss of pleasure
- Loss of appetite or overeating
- Large weight gain or weight loss
- Low energy, feeling slowed down
- Low self-esteem
- Frequent thoughts of death/suicide
- Feeling hopeless, worthless, or guilty
- Poor sleep or oversleeping
- Difficulty concentrating or making decisions
- Feeling anxious or worried
- Feeling restless
- Being irritable

Some of these symptoms are also aspects of IBD. Treatment for mood difficulties can help you to control IBD symptoms. Talk to a physician or psychologist about your mood if you are having difficulties.

Why can’t I sleep?

You may be experiencing sleep problems (e.g., difficulty falling asleep, sleep interruptions, and feeling tired in the morning). Sleep can be disrupted for different reasons, such as need to use the bathroom, pain, body temperature problems (hot or cold), breathing problems, and nightmares.

Sleep problems can be present when IBD is active or inactive. Sleep affects physical, mental, and emotional well-being. Psychological therapies are effective in reducing or eliminating sleep problems. Specific medications may also be helpful.
Why can’t I keep up?

IBD can affect all areas of your life. You may have difficulties with working, attending school, and engaging in the social and leisure activities that you did before. It can be hard to adjust to these changes and this may lead to many emotions, such as guilt, grief, anger, loss, and hopelessness. These feelings are normal, but they are important to address if they become overwhelming. It can help to sort through your feelings and to learn about strategies for pacing and life-balance.

What other factors may be involved?

Other gastrointestinal disorders and early life events can influence IBD.

**IBS** – Stress affects IBS more than it affects IBD. If you have both IBD and IBS, it may be even more important to seek help with managing your stress, mood, and sleep difficulties.

**Early experiences** – Negative events and experiences as children can shape how the body and the mind develop. Early experiences with parents, such as drug/alcohol abuse, death, violence, neglect, mental illness, or divorce can increase your risk of health problems. These experiences increase risk of physical symptoms and emotional problems (e.g., depression, anxiety, and poor coping). Help dealing with these past experiences can reduce their impact on your future health.

Self-Assessment

- One way to assess if factors like IBS and childhood background impact IBD for you is to consider the following—How well do I feel when the IBD is in remission?
- When IBD is not active for a period of 6 months or more, you can experience same level of adjustment and quality of life as people without IBD. If you do not, then you may benefit from help

What’s my role?

You can help to reduce the impact IBD has on your physical, emotional, and mental health by improving your mood and coping abilities, following your medical treatment plan, and educating yourself about IBD.

**Coping** – There are different ways of coping that can lead to better and worse health outcomes. Good coping skills are important when IBD is active and inactive. Ask for help if you are not coping well or struggling when the IBD is in remission.
Ways Of Coping

Positive Coping

• Active thinking & doing:
  talking to others, pursuing physical
  fitness, planning enjoyable activities,
  problem-solving, allowing grief &
  mourning of losses
• Taking responsibility where you can
• Focusing on the things you can control
• Viewing “uncertainty” as reality or opportunity
• Following IBD healthcare advice

Negative Coping

• Avoiding & not wanting to think about it:
  withdrawing from people, eating too
  much or too little, staying in bed,
  “wishing” it were different
• Self-attack & self-blame
• Trying to control everything or feeling out of control
• Viewing “uncertainty” as negative, unending, and
  intolerable
• Disbelieving IBD healthcare advice

Treatment for IBD – Follow the advice of your healthcare team (e.g., your medical doctor, nurse, dietitian, and other professionals). Relapses are more likely when advice is not followed carefully. When you feel good and are symptom-free you might forget or be tempted to not take medications. Continued medication is necessary to prevent relapse. Medications also reduce risk of other problems (e.g., hospitalization, surgeries, future cancer).

Seek advice from your healthcare team if you are having difficulties following your treatment plan. It can be even harder to follow advice and keep up with your IBD care at times, especially when you:

• are newly diagnosed (first 1 to 2 years)
• are younger
• are very busy
• lack information or knowledge
• are in remission
• are prescribed many medications
• require meds frequently each day
• are concerned about side-effects
• are concerned about cost of meds
• experience severe or frequent flare-up
• experience severe pain or fatigue
• feel very low, down, sad, or anxious
• require surgery
• have accidents with bowel or stomas

Education – Seek information about IBD and treatments. Talk to your healthcare team and ask questions. Knowledge can increase your feelings of competence and control. It can also help decrease your distress. Pay attention to your body. Educate yourself about how your body is affected by IBD because IBD does not affect every person in the same way.
Why is support important?

You may feel insecure in your relationships. You may feel like withdrawing from family and friends for many reasons. For example, you may feel others do not understand, fear being judged by others, fear embarrassment about urgent bowel movements, or want to avoid well-intentioned—but not always useful—advice.

At different times you may benefit from more support. Social support from family and friends can help to improve your social and emotional well-being. IBD online chat rooms and self-help groups may also be helpful. It is important that your social support is positive for you. Ask for help if you are not able to identify positive social supports. With help you may be able to change your relationships with others to get the support you need from them.

How can psychology help?

The information in this pamphlet describes how the mind and body are connected with IBD. You can improve your adjustment and quality of life. Seek a therapist that you can be open with, who works with you in setting goals, and helps you feel supported.

Some Goals That May Help

- Learning relaxation strategies
- Addressing stress, depression, anxiety, and sleep difficulties
- Adopting positive coping and improving problem-solving skills
- Learning pain management skills
- Adopting necessary lifestyle changes
- Learning pacing and life-balance strategies
- Acceptance of IBD
- Enhancing social supports
- Addressing early experiences to reduce their impact on your future health

There are many qualified individuals who may be able to help you with these and other goals. You may access services within the health region, you may be covered through your work or school, or you may be able to receive community-based services that are free or income-based. Your treatment team can help find the right service for you.


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