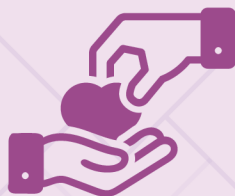




# IBD INDIA NEWSLETTER

created by patients for patients

Q1 2025



What is IBD?

Are there any  
resources available  
for IBD patients?

How do you  
treat IBD?

What causes IBD?

# DISCLAIMER

The contents of this newsletter are for educational purposes and do not qualify as medical advice.

Please consult with your doctor before acting on any information contained in this resource.

## DISCLOSURE

IBD India is solely responsible for the design, contents, publishing, and distribution of this educational resource.

This newsletter is supported by an educational grant from Pfizer India.

# From the Founders' Desk

Dear Friends,

It brings us immense pride and joy to introduce the inaugural edition of the IBD India Newsletter - a quarterly resource from IBD Patient Support Foundation (India) - for patients, created by a team of patients.

As two adults living with IBD and the founders of this organization, we have long envisioned a space where individuals across India living with Inflammatory Bowel Disease (IBD) can find the support they require, the information they need, and a sense of belonging and community. Today, with this newsletter, we are taking a step towards realizing that vision.

We started our journey in 2020 with a simple goal - to create a community for patients where they could feel “seen and heard”, and have easy access to reliable resources to understand and manage their disease well. Over the years, we have faced numerous challenges and undergone several learnings and transformations as we keep working towards achieving our goal. This newsletter is a product of those learnings.

Every three months, a new issue of this newsletter will bring forth to you the right information you need to understand IBD (vetted by experts), self-authored stories of grit, perseverance and strength of our community members, updates on activities undertaken by the Foundation, the latest developments in the management and treatment of IBD (nationally and globally), and other resources available to support you in your journey with IBD.

We are a young organization taking baby steps, but with your involvement and support, we are confident that we can make a lasting difference for those living with IBD in India. This newsletter has seen contributions from several community members and IBD experts. We are grateful to all of them.

Let us continue to raise awareness, support each other, and advocate for better healthcare solutions for all those affected by IBD in India. Together, lets [#makeIndiaIBDaware](#).

On behalf of our Foundation, we wish all readers a happy reading of this inaugural issue and wholeheartedly welcome your feedback to improve this resource.

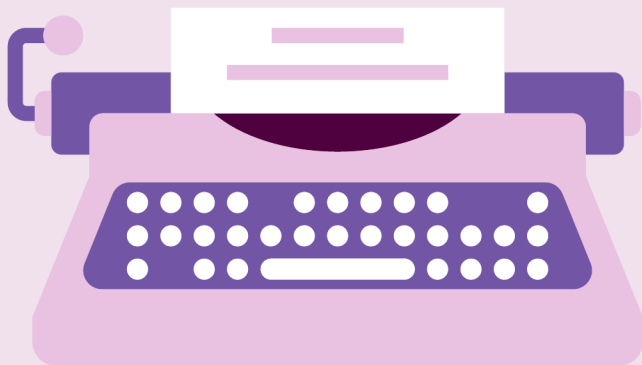
Warm regards,

Kumudini Ethiraj and Nikhil Jayswal

Founders, IBD Patient Support Foundation (India)



A CREATIVE OUTLET TO EXPRESS YOUR  
JOURNEY WITH IBD IN THE MOST  
UNCONVENTIONAL WAY POSSIBLE!



**WORD LIMIT: 500 WORDS**  
**DEADLINE: LAST DAY OF**  
**EACH MONTH**

THE TOP TWO ENTRIES WILL BE PUBLISHED  
IN OUR NEWSLETTER !

**CASH PRIZE WORTH 1200 INR**

Email Your Writeup : [reachibdindia@gmail.com](mailto:reachibdindia@gmail.com)



# Inflammation & Inflammatory Bowel Disease

## WHAT IS INFLAMMATION?



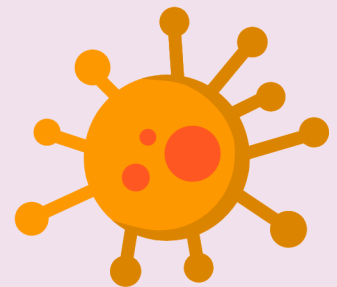
**Inflammation is our body's natural protective response to an injury or an infection.**

When tissues in our body are injured or infected with micro-organisms such as bacteria, viruses, parasites and fungi, the immune system of our body takes several steps to repair the injury or to prevent the infection from spreading to other healthy tissues in our body.

Fever is one such step. By raising our body's temperature, the immune system prevents the infection from spreading as micro-organisms cannot replicate very quickly at high temperatures.



Another step is to release various types of cells which destroy these micro-organisms and repair damaged cells of our body. Inflammation can cause pain, swelling and redness in the skin. Along with fever, these are signs that our immune system is working to heal us.



Inflammation may not feel good, but it is not always a bad sign. Once the injury is healed, or the infection is contained, inflammation dies down and we feel better again.



# INFLAMMATORY BOWEL DISEASE



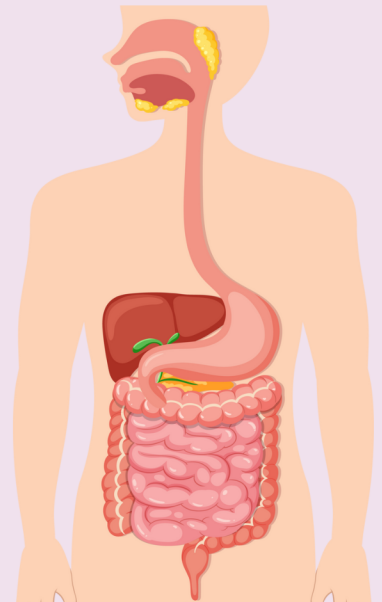
Inflammatory Bowel Disease (IBD) is a condition in which the body's immune system attacks healthy intestinal or bowel tissue and creates inflammation in the intestines. This inflammation is "chronic" – meaning it does not stop on its own. Chronic inflammation damages the cells in our intestine and leads to formation of "ulcers" or erosions in our intestines.

## Crohn's Disease and Ulcerative Colitis are two types of IBD.

**In Crohn's Disease, the ulcers may be formed in any part of the "digestive tract".**

Our digestive tract begins from the mouth and includes the food pipe also known as esophagus, stomach, small intestine, large intestine, the rectum and the anus.

**In Ulcerative Colitis, the ulcers are confined to the large intestine only.**



In Crohn's Disease, the ulcers are "deep" – affecting all the layers of the intestine, while in Ulcerative Colitis, the ulcers only affect the innermost layer of the large intestine. There are many more differences which affect how these diseases are treated.

Sometimes, doctors may have difficulty in correctly identifying the type of IBD.

## Crohn's Disease can also look like Intestinal Tuberculosis.

Since tuberculosis is still at large in India, patients can be misdiagnosed.

# WHAT CAUSES IBD?

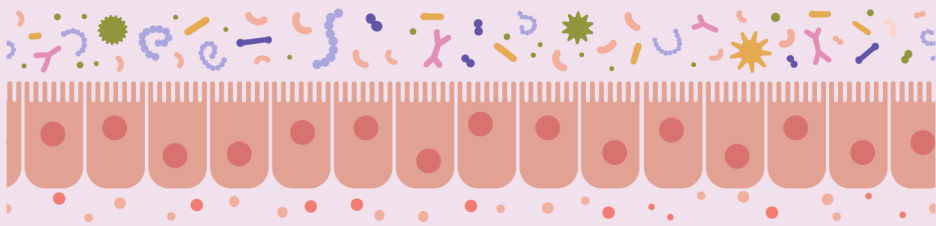
Unfortunately, we do not know what causes the immune system to start attacking healthy cells in our intestine, and why it is unable to stop, creating chronic inflammation. There is continuous research in this area.



What we have learnt is that it is a complex process involving genetics, environmental factors and an imbalance in the population of micro-organisms that live inside our intestines.



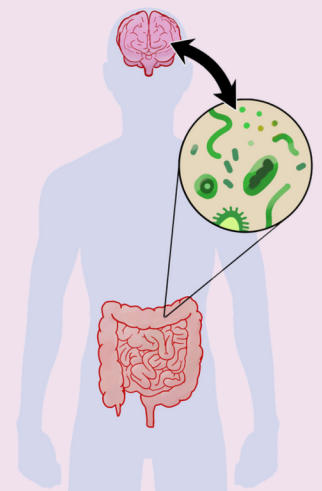
Yes! Our intestines are home to several micro-organisms. Many of them contribute to our good health.



**THERE IS NO SINGLE CAUSE OF IBD.**

The micro-organisms that live in our intestines are known as the "gut microbiome" or "gut microbiota". Our gut microbiome plays an important role in our health.

"Faecal Microbiota Transplantation" is a treatment to restore healthy gut microbiome and provide relief from symptoms of IBD.



**Scan the QR Code to watch a video on Faecal Microbiota Transplantation**

# WHAT ARE THE SYMPTOMS OF IBD?



There is a wide spectrum of symptoms of IBD. IBD is a disease, which varies greatly from person-to-person.



**Not all patients with IBD experience the same symptoms.**



Some common symptoms are fever, vomiting, weight loss, abdominal pain, frequent diarrhea (maybe bloody), pain during passing stools, “tenesmus” – the feeling of incomplete evacuation of bowels, fatigue, urgency and fecal incontinence.



Since many of these symptoms are present in many other diseases, diagnosing IBD is challenging. It requires a variety of tests and procedures such as blood tests, stool tests, colonoscopy, endoscopy, CT or MRI scans and microscopic examination of intestinal tissue.



**THERE IS NO SINGLE TEST FOR IBD.**



IBD can affect other organs also.

**They are called “extra-intestinal manifestations” of IBD.**



They can include inflammation of the eyes, joint pain, inflammation of skin, inflammation of liver, weakening of bones, etc.

# HOW DO WE CURE IBD?

Since we do not know the exact cause of IBD, unfortunately, we cannot cure it.

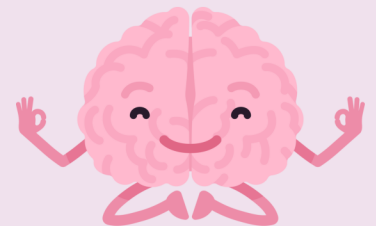
IBD is a “chronic” or lifelong disease.



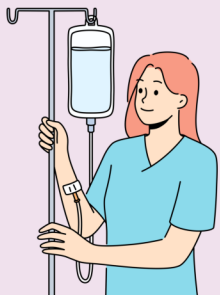
However, with medications, we can reduce the amount of inflammation and control the damage to our intestines and get relief from symptoms. With the right treatment, we can become symptom-free and achieve “remission”.



However, the right treatment needs to be supplemented by the right lifestyle, right diet, and good mental and emotional health.



It is important to remember that the right treatment and dietary restrictions will vary from person-to-person in IBD.



Once remission has been achieved, it is important to keep following up with the doctor to monitor disease activity and prevent “relapse” or “flare-ups” – a recurrence of disease symptoms.

Treatment of IBD is a constantly evolving process.

There is active research to understand how to use existing medications in the most efficient and beneficial manner. There are new drugs being developed. IBD is best treated by gastroenterologists who have a special interest in IBD.



**Your mental health is just as  
important as your physical health!**

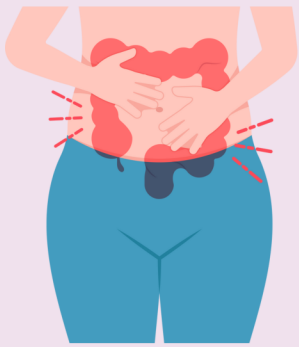
**Scan the QR code to access our  
free counseling services for IBD  
patients and caregivers.**





# Crohn's Disease and Ulcerative Colitis

Crohn's Disease (CD) and Ulcerative Colitis (UC) are the two commonly observed types of Inflammatory Bowel Disease (IBD).

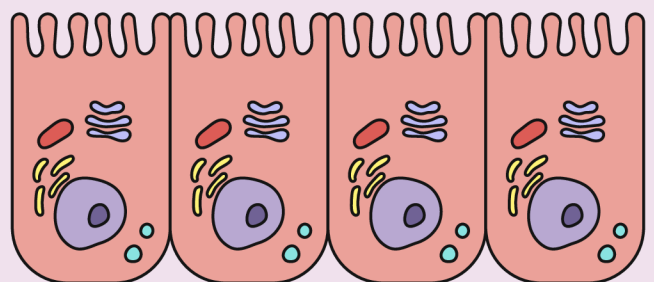


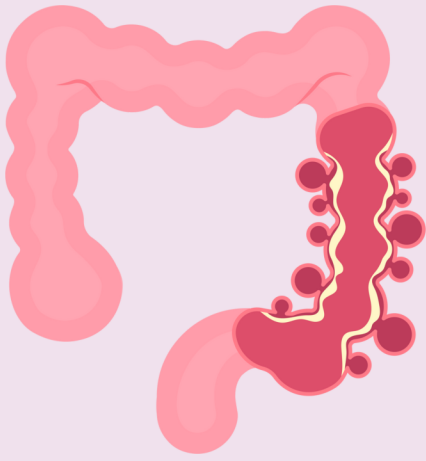
Both conditions are quite similar in many aspects. However, there are some important differences that patients must be aware of, to make informed choices about diet, lifestyle and treatment of their condition.

## Ulcers in Crohn's Disease and Ulcerative Colitis

**Our intestine has many layers. The innermost layer is called the "mucosa".**

This layer has cells that produce "mucus" – a slippery and sticky substance, which acts as a protective layer against harmful particles and micro-organisms. They get captured in the sticky mucus and are unable to enter the bloodstream and harm other organs in our body.





The ulcers in Ulcerative Colitis are usually continuous, leaving no healthy tissue, but limited to the innermost layer of the large intestine – the mucus layer. People living with Ulcerative Colitis experience significant amounts of blood and mucus in their stool.

The ulcers in Crohn's Disease can be present in any location in our digestive tract. The ulcers are present in small patches with areas of healthy tissue in between. The ulcers are "deep", meaning they penetrate the layers of our intestine. If left untreated, these ulcers can cause holes in our intestine which can be very dangerous for us.



Doctors consider these basic and other advanced differences to make a diagnosis of Crohn's Disease or Ulcerative Colitis and to prescribe appropriate treatment.

However, the differences are not always clear, leading to a diagnosis of "Indeterminate Colitis" or "IBD-Unclassified".

**In such cases, doctors must be given some time.**

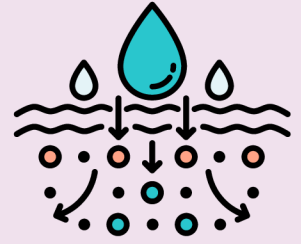
As time passes, the ulcers may change in response to treatment, or new symptoms may appear, which can help them make a better diagnosis, and treat you better.





# ULCERS AND DIET

The different areas of our intestine have different functions and are responsible for absorption of different nutrients. Hence, knowing which part of our intestine has ulcers can help us know what supplements or food items we may need to consume to make up for loss of absorption.



For example, if there are ulcers in the "ileum" – the last part of our small intestine – which is common in people with Crohn's Disease - it affects the absorption of Vitamin B12, which is a very important vitamin required to keep our nerves healthy.

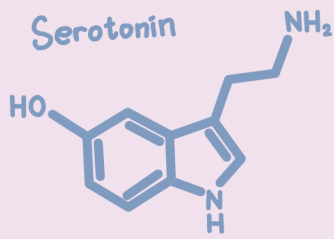
If we have ulcers in our ileum, we should take Vitamin B12 supplements and add food items rich in Vitamin B12 to our diet.

Similarly, since Ulcerative Colitis affects the large intestine, also known as "colon", which is responsible for absorption of water, patients with Ulcerative Colitis should drink more water to prevent themselves from being dehydrated.



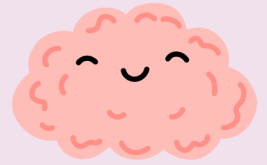
Scan the QR Code to watch a video on Nutrition in IBD





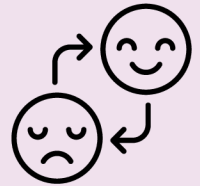
Our intestines are also responsible for producing a very important hormone called “serotonin”.

Serotonin has many important functions in our body, some of which are given below.



### Mood:

When we have normal levels of serotonin in our body, we feel emotionally calm, happy, and focused. When we have low levels of serotonin, we may feel depressed.



### Sleep:

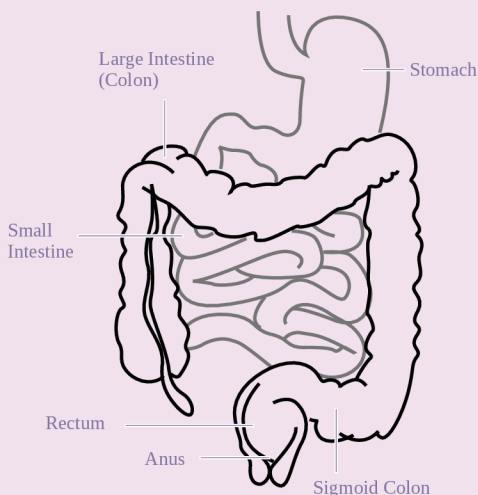
Serotonin is required to make “melatonin” - another hormone which regulates our “sleep cycle” - when we fall asleep and when we wake up. Serotonin also affects our quality of sleep.



### Digestion:

Serotonin affects the movement of our intestines, that helps to move the food through the “digestive tract”.

Hence, if our intestines are not healthy and we have ulcers in our intestines, we may not be able to produce enough serotonin that is required by our body, and it can affect our mood and sleep as well. Sometimes, doctors may give you medicines that help your body to maintain normal levels of serotonin. We should also eat foods that help our body to make serotonin.



mindful  
eating

STAY  
ACTIVE

Educating ourselves about basic biology of the intestine and the functions of different parts of our intestines, can help us to understand our symptoms, our treatment, and our dietary and lifestyle requirements.

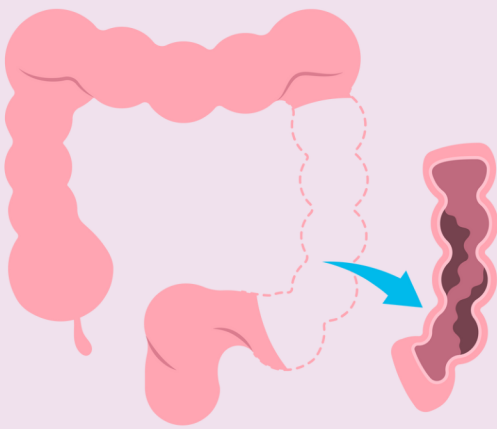
# SURGERY FOR IBD

Most of the medicines used for the treatment of Crohn's Disease and Ulcerative Colitis are the same. When medicines are not able to provide relief, surgery may be required.



**There are mainly two types of surgeries used to treat IBD.**

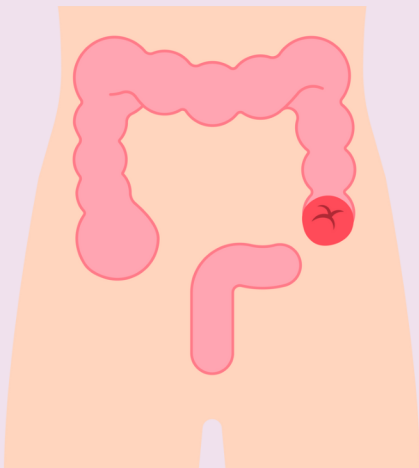
## Resection Surgery :



The diseased parts of the intestines are cut and removed, and the healthy parts of the intestines are joined together.

Patients may require resection surgery to get rid of ulcers that are not responding to medicines or to get relief from "stricture" – narrowing of the intestines, which prevents food from passing through the intestines.

## Ostomy Surgery :

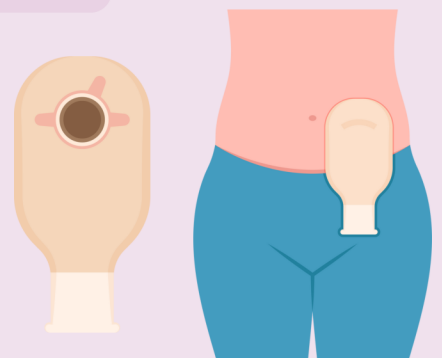


The healthy part of the intestines is cut from the diseased part. The diseased part may be then left inside the body to heal, or can be removed from the body permanently.

The end of the healthy part is then taken out of the body via a hole in the abdomen and sewn onto the skin.

**This is called an "ostomy" or a "stoma".**

The stoma or ostomy is covered by an "ostomy pouch" which collects the stool. The ostomy pouch must be emptied in the toilet multiple times a day and changed every few days.

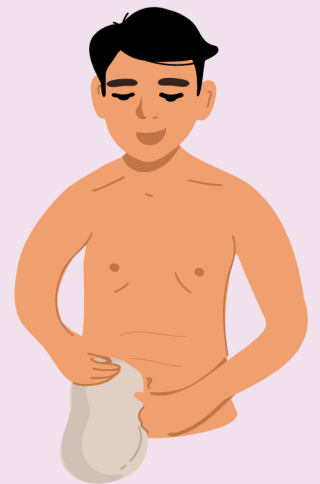


In Ulcerative Colitis, ostomy surgery can cure the disease for some (some, not all!) people. Additional surgery called “J-Pouch” surgery, can help to reverse the ostomy. In Crohn’s Disease, ostomy surgery will not cure the disease but can give your body a much needed break from the disease.



Scan the QR Code to learn more about “Ostomy”.

If your doctor recommends ostomy surgery, it’s natural to feel scared or disappointed. Speaking to other people with ostomies is helpful. Ostomy surgery has saved countless lives and many people with ostomies lead fulfilling lives, but adjusting to this change takes time.



It is extremely important to keep following up with your doctor to prevent a relapse and get maximum benefit from surgery.

**There can be symptoms of IBD even after resection, ostomy or j-pouch surgery.**

With newer medications, the number of people with IBD who have to get surgery is reducing.

Educating ourselves about our disease can help us to understand our disease better and take steps to increase the effectiveness of medical treatment. However, we do not need to know everything about our disease, and we should not be spending unnecessary time trying to learn everything about our disease.





# TRIAL VOLUNTEERS NEEDED!



TRY LOCALLY MADE OSTOMY  
SUPPORT UNDERWEAR  
FOR FREE AND GIVE US YOUR  
FEEDBACK!

SCAN THE QR CODES TO SEE THE  
PRODUCTS FOR TRIAL.



IF INTERESTED, WRITE TO US AT :  
[REACHIBDINDIA@GMAIL.COM](mailto:REACHIBDINDIA@GMAIL.COM)



The background of the entire image is a dense, repeating pattern of small, stylized purple flowers and thin, light-colored branches. The flowers are in various shades of purple, from light lavender to deep violet, and are scattered across a solid black background. The branches are thin and light-colored, creating a delicate, web-like structure that frames the text.

# WINNING STORIES FROM OUR WRITING CONTEST



# A MAGICAL BIRD WITH BROKEN WINGS - YET IT WILL FLY

WRITTEN BY KAYAL,  
LIVING WITH ULCERATIVE COLITIS





Life has never been only roses from the start. My heart always had desires to fly high in the skies and to live a loving, caring and happy life.

When a small little bird is born, food doesn't really matter, it just eats what it's fed with. Of course the mother knows what to feed! No restrictions, just eat and rest without any worry!

Little Bird was happy with friends and family and was starting to learn to fly with its dreams inside its heart. The beautiful feathers were just growing, giving the bird joy.

Then came a day of thorns. It hurt itself and blood was oozing. She was very afraid with so many fears inside her heart. The bird went to see the doctor. Doctor gave medicine and sent it back.

Within a week, the symptoms became worse. But there is one person who will never leave you. Guess who? The Mother Bird. So mom came down to take the little bird again to the clinic. Doctors said that a small part of the bird's wing was broken, but nobody can see it with normal eyes and no one can feel it except for the little one.

The little bird was in so much pain. The bird was put on mesalazine and within two days it got a severe infection. This time it was a critical situation. The bird was completely ill and almost lost all its feathers and even survival was a question.

In the hospital bed the bird became more and more weak physically, appearance changed and people started to ask too many questions to the bird's family. Some even said that the bird will not survive.

The bird never knew that the situation was so critical but the bird could feel from the eyes of her family that things were not right. The bird could only shed tears of pain on the hospital bed.

Then the specialist doctors said that the broken wings will heal but can break again anytime and will break again and again over her lifetime. Not knowing what to do, everyone went to the nest to have some rest and they were heartbroken and did not know what to do for their small little one's suffering.





Still with all the leftover strength the small little bird tried to walk with pain, so it can make itself feel better and make its family feel better. Bird knew it was very hard to fly while balancing the broken wing. There were times it could only walk. When it sat to take a rest or eat, it could see flocks flying high with all the happiness it had in its heart.

The bird was emotionally down and couldn't cope several times during this journey. Her family and friends were her strength.

Everytime she fell down, they gave their support. After a long time, the small bird realized there are more birds on Earth which can't even walk and had gratitude for how blessed she was that at least she was able to walk.

The bird walked, walked and walked for days, months and years. Tired, exhausted, it felt bad but still walked with a little smile on its face and pride in its heart on how far it had walked while hiding fear.

It tried different approaches to fly - improved its nutrition, tried to be calm, took numerous medicines. It was a very slow process of healing and the wing was still hurting and broken.

The little bird's wings were getting hurt every time the bird tried to fly. The bird never experienced the freedom of flying high with all its wings open in several years. But now it has experience of what to try and what not to.

There were times the bird had to give up but then God gave all his love to the bird to come against all the odds. The bird slowly started to fly! Sometimes it still breaks its wings but now it knows it can heal over time.

Though the bird can only fly for a certain period and with so many restrictions and still has a long way to go to achieve its dream, the achievement of even flying for some time was worth everything in the world for the bird.

The magical bird came this far and it will never give up on its broken wing. It is a warrior and with love and care, one day soon it will fly with the flocks happily and will achieve its dream.







# GRIEF WITH IBD



Grief is a term generally associated with the loss of a loved one. In this scenario the loved one is ME. Grief for me in this situation was losing the person I used to be before my Crohn's. I was always a happy and vibrant kid who would just never stop talking. Never one to make plans beforehand and was very flexible. I used to take life easy, and would never overthink any scenario.

Now I am a completely different person, to be precise, the exact opposite of who I was before. Always overthinking, moody, and could not function without a plan. It felt that instead of being a part of my life, Crohn's became my life. Activities that used to bring me happiness like dancing and reading, were no longer of interest to me. I used to love going out with family and friends, but the thought of going out scared me. I felt the safest inside my house, having minimum interaction with the outside world.

This "safety", however, did not bring me any happiness. I was constantly miserable even when I was not in a flare. My mood started reflecting on my behavior with others. I was constantly snapping at my family and getting angry for no reason. I became this person that I could not recognize. I remember distancing myself from my friends and internally blaming them for the distance.

After a struggle of three years, I reached a short-term remission in 2019. The timing could not have been any better, as I was relocating to a different city to pursue my Masters. For my masters thesis, I was researching grief and bereavement. That is when I had my Eureka moment! The themes that emerged from the research were isolation, anger, guilt, and loss of interest in activities that once used to bring them happiness.

During this research I realized, these were the similar emotions I had felt. Upon self-reflection, it made sense that in a way what I experienced was a type of grief. Grieving the girl that used to get happy at the smallest of things, the one who used to take life as a beautiful journey, and the girl who never used to get angry. I was using unhealthy coping strategies to make up for the grief I felt from losing the person I was before. Along with grieving the past, I was grieving the future.

All these questions of will I be able to work, find someone who accepts my condition, and a lot of other things. I remembered one of my research participants expressing how much she lost in the present day by worrying about her past and future, it was completely futile. This type of grief is something I am sure many individuals with a life-long illness might feel but would not have realized what it meant. At that particular moment, this quote from Harry Potter resonated with me.



*"Happiness can be found, even in the darkest of times, if one only remembers to turn on the light."*

I was so focused on hating my situation that I forgot to switch on the light in my life, to appreciate those that stuck by me. Crohn's may have played a part in this internalized grief of mine but it was me that refused to see the good things.

Yes, I am no longer the girl I used to be. However, my journey with Crohn's made me a much more resilient and empathetic individual. It instilled in me the sense of being non-judgemental and understanding others struggles. I started to appreciate my body for working its best to survive despite the condition. I was grateful for my family and friends that stuck by me despite my infuriating behavior. It was an eye-opening moment for me.

I made a promise to myself, to start doing the things that once brought me happiness no matter how small they are. We cannot change the past and nor can we predict the future. Why waste away our present amidst this?

It is very natural to grieve the things we lost due to our illness and what we think we might miss out in the future. At such times I stand in the balcony and remember to switch on the lights in my present life and find happiness in the smallest moments. When we have an illness that takes a huge toll on our body, we must make sure that on the days we do feel okay to make the most of it.

WRITTEN BY MAALVIKA,  
LIVING WITH CROHN'S DISEASE

The **MORE**  
you **REFLECT**  
the **MORE**  
you **LEARN**





WhatsApp Community



Youtube Channel



IBD India Website

## FINANCIAL AID



We provide a small amount of financial aid for medicines and diagnostic procedures.

Visit our website for details.

## 3-DAY FOOD JOURNAL

DATE:     /     /

MEAL	DAY 1 _ _ _ _ _	DAY 2 _ _ _ _ _	DAY 3 _ _ _ _ _
BREAKFAST (FIRST MEAL)			
SNACKS			
LUNCH (SECOND MEAL)			
SNACKS			
DINNER (THIRD MEAL)			
NOTES			

## 3-DAY FOOD JOURNAL

DATE:     /     /

MEAL	DAY 1 _ _ _ _ _	DAY 2 _ _ _ _ _	DAY 3 _ _ _ _ _
BREAKFAST (FIRST MEAL)			
SNACKS			
LUNCH (SECOND MEAL)			
SNACKS			
DINNER (THIRD MEAL)			
NOTES			

## NOTES



## NOTES

## NOTES



