Microscopic Colitis Foundation

Newsletter Archive

Wayne's Blog

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Don't Give Up before Trying All the Options for Controlling the Toughest MC Cases

by Wayne Persky

Budesonide Option

When first diagnosed, most microscopic colitis (MC) patients first try the treatment prescribed by their gastroenterologist, which is typically a three month treatment using a tapered dose of budesonide. Some are lucky, and this treatment resolves their symptoms.

Unfortunately, published medical research shows that approximately 80% of patients who respond to budesonide, relapse soon after the treatment is ended. And additional published research shows that each time a budesonide treatment is stopped and restarted, it becomes less effective. These days, if after one or more treatment regimens with budesonide, remission cannot be maintained, many gastroenterologists will recommend using a biological. But many patients are reluctant to use biologicals (for good reason), and more than a few would rather not use budesonide, either, because of the side effects, or because they are dissatisfied with the way it does not completely resolve their symptoms.

> **Most patients using budesonide relapse after treatment ends.**

> **Biologicals are problematic.**

Diet Option

Posts shared by members of our discussion and support forum over the years verify that the vast majority of us are able to modify our diet to successfully prevent symptoms, and keep our disease under control over the long term (with or without medications). For patients who don't respond to medical treatments, dietary control is the only option (unless they would rather just learn to live with the symptoms).

But What if Our Symptoms Don't Fade Away?

The medical approach treats the symptoms and not the cause. The prescribed treatments involve attempting to suppress the inflammation that causes and perpetuates MC. Anti-inflammatory medications, such as budesonide, do not prevent the inflammation from being regenerated, they only attempt to suppress inflammation after it is generated. By contrast, proper diet changes eliminate the problem that causes the inflammation in the first place, so that inflammation is no longer generated.

If we've been attempting to control the disease using diet, and we're unable to notice any improvement in symptoms after at least 6 to 8 weeks, it may be time to take a hard look at our treatment program to make sure it is as meticulous as we believe it to be.

In many situations such as this, a food or beverage has been given a free pass, and inappropriately assumed to be safe, simply because we've used it all our lives without any problems, so we have no reason to suspect it. In other cases, one or more items in our diet are cross contaminated, and although in many cases, the cross-contamination level might be low (possibly even below the 20 ppm limit for gluten-free labeling used in the US), it's sufficient to perpetuate a reaction, because we ingest the item (or items) regularly, or we eat large amounts of possibly risky foods, or our immune system is hypersensitive because our inflammation level is so high. Or maybe the problem lies in toothpaste, or a cosmetic product, or something else.

“ “

Look for other possible foods that you may react to.

Check for cross-contamination.

Avoid Being Deficient in Vitamin D or Magnesium.

Research shows that about 75% of the people in the world have vitamin D levels that are inadequate to protect against disease, and that implies that most people have vitamin D levels that are inadequate to allow normal healing (Reddy, and Edwards, 2019).[1] Statistics regarding worldwide magnesium deficiency are even worse, with some authorities claiming that 90% of the population is magnesium deficient. (DiNicolantonio, O'Keefe, and Wilson, 2018; Froelich, 2020, February 1)[2,3]

Anyone who has compromised kidney function (low eGFR results) should check with their doctor before changing their magnesium dose, because excess magnesium in the bloodstream has to be eliminated by the kidneys, and compromised kidney function can lead to excessive blood levels of magnesium that can cause cardiovascular issues. Those of us who have normal kidney function don't have to be concerned about this issue.

Stress Trumps Everything

Chronic stress can trigger a flare.

And always remember, chronic stress, and sometimes even higher levels of acute stress, although short-lived, can be be sufficient to trigger, or maintain a reaction. It's well known that stress can lead to both physiological and psychological inflammation (Carnegie Mellon University, 2012, April 2; Cohen, Janicki-Deverts, Doyle, and Turner, 2012) .[4,5]

Published research proves that the existence of prior stressful events increases the risk of flares and the severity of flares, after IBD develops (Bednarikova, et al., 2021).[6] The cited research presumably excluded MC patients (as usual), but there's no reason why the research findings should not apply to MC patients, as well as other IBD patients. For example, according to the findings of this research study, living through a disaster, witnessing a serious accident, having a family member sent to prison, financial problems, or serious illness can create problems for IBD patients later in life. Even childhood life stressors such as physical abuse and neglect can increase the risk of IBD flares later in life.

MC and PTSD both cause stress.

Both syndromes impose strong feelings of isolation, helplessness, and loss of control. Because of the

chronic stress imposed by PTSD, it may be impossible to control the symptoms of MC (because stress perpetuates inflammation) until any PTSD issues are addressed and at least mitigated sufficiently so that chronic stress levels are more reasonable. Fortunately, professional help is much more readily available these days than it has been in the past, and the information source cited here is only one of many (Trauma Recovery, n.d.).[7]

> **Traumatic childhood events and PTSD can trigger flares.**

> **Seek professional help to address serious stressors.**

Consider Bile Acid Malabsorption (BAM)

BAM is relatively common.

If nothing suspicious can be tracked down, after carefully considering everything that goes into our mouth, or on our skin, and we don't currently have any major stress issues, it may be time to consider another possibility, namely, bile acid malabsorption (BAM). Published research shows that in a trial involving 27 collagenous colitis patients who were refractive to conventional treatment, 78% of them achieved prompt remission after they were treated with a bile acid sequestrant (Ung, Gillberg, Kilander, and Abrahamsson, 2000).[8]

Wait to treat until gluten free for 8 weeks.

The reason we don't recommend attempting to treat BAM initially (for MC patients), as some gastroenterologists attempt to do, is because unless gluten has been avoided for six or eight weeks, in order to allow the antigliadin antibody level to decline to levels below the threshold at which a reaction is triggered, treating BAM prematurely, in most cases, will not be successful, because the immune system will be dominated by the antigliadin antibodies, so that it continues to react against them. But after 6 to 8 weeks of faithfully following a gluten-free diet, gluten should no longer be dominating the immune system, so if no improvements in diarrhea symptoms are noted, then there is a very good chance that treating BAM will bring remission (assuming that BAM is the issue preventing remission).

Until now, doctors have had no medical diagnostic test capable of detecting diarrhea due to bile acid malabsorption. Now, however, researchers at the University of Copenhagen, in Denmark, have reported a blood test that will detect BAM (Lewinska, et al., 2023).[9] They refer to the issue as bile acid diarrhea (BAD), but it's the same problem that we refer to as BAM. Hopefully, this result can be used to develop a test in the future.

Treating BAM is not always easy.

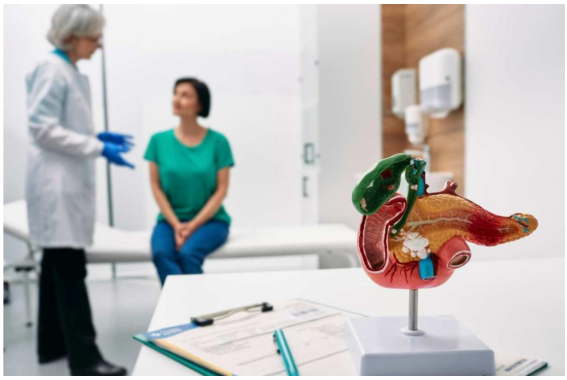
Although BAM sometimes responds to the labeled dose recommended on the bile acid sequestrant that our doctor prescribes, in many cases (probably most cases) the ideal dose will have to be determined

experimentally, by trial and error. Too much will cause cramps and constipation, and too little, will not resolve the diarrhea. It takes approximately two weeks for the effects of an adjusted dose of bile acid sequestrant to completely stabilize, but estimates of how well the dose is going to work can usually be seen sooner than that. An ineffective, or partially effective dose is usually too small, and by continuing to experiment with the dose, we can eventually find a dose that controls our diarrhea to our satisfaction.

> **BAM is common, and can be treated.**

> **Proper dose of bile acid sequestrant is crucial.**

Specific brand may be important



For the worst cases of BAM, a specific brand may be required. Many of the members of our discussion and support forum who need to use a bile acid sequestrant, seem to have the best results using a cholestyramine product that was originally sold under the brand name Sandoz, and is now branded Epic. Apparently, Epic was manufacturing these products for Sandoz, prior to the name change. For anyone who might need to seek out these particular products, they are:

42806-266-95 Orange 60 USP packets
42806-267-97 Orange Can
42806-270-95 Light Orange 60 USP packets
42806-271–97 Light Orange Can

Other BAM Considerations

Common Issues

Typically, those who are unable to successfully find a dose of cholestyramine that will resolve BAM, either haven't waited long enough for their antigliadin antibody level to decline sufficiently before attempting to treat BAM, or the dose of bile acid sequestrant they are using is insufficient. As many as eight packets, or the equivalent dose, may be required in severe cases.

Use of a bile acid sequestrant carries a relatively low risk of any adverse outcomes. When bile acid sequestrants are prescribed in order to lower cholesterol levels, they are recommended to be taken with meals. However, when using bile acid sequestrants to treat BAM, that rule should be ignored.

Nutrient malabsorption is already a problem with either active MC, or diarrhea caused by BAM, and bile acid sequestrants will only further reduce the absorption of nutrients. So, we definitely don't want to take bile acid sequestrants with meals (unless we're also trying to treat high cholesterol levels). Since bile acid

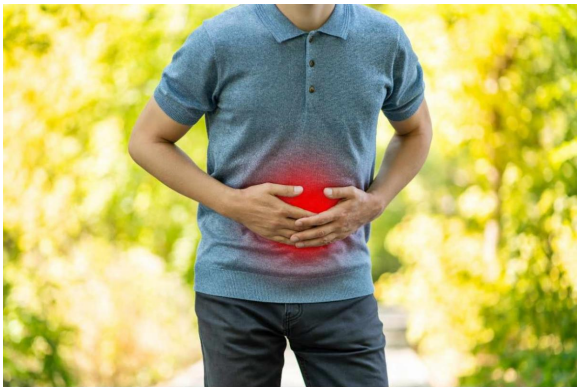
bile acid sequestrants with meals (unless we're also trying to treat high cholesterol levels). Since bile acid sequestrants also tend to significantly reduce the effectiveness of certain medications, and they tend to prevent the normal absorption of folic acid, and fat-soluble vitamins, such as A, D, E, and K, we need to be careful about the timing of when we take a bile acid sequestrant.

In order to minimize the risk of losing nutrients or deactivating medications, bile acid sequestrants should either be taken at least 4 to 6 hours before eating or taking any medications or supplements; or at least an hour or two after eating, or taking medications or supplements. If it becomes necessary to bend those rules a little, that shouldn't cause any major problems, we just won't get optimal results.

> **Correct dosage is important.**

> **Correct timing before or after meals is important.**

What if treating BAM still doesn't bring remission?



Although we may be faced with less desirable options, we still have an ace-in-the-hole that can usually be used to bring remission in even the most persistent cases. Since it's impossible to verify that in refractive cases, every option described above has not been meticulously applied, and something has been overlooked, we can't assume that these failures to reach remission are due to human error. And we're well aware that there are exceptions to every rule. Therefore, we certainly can't rule out the possibility that although the vast majority of us are able to successfully use diet changes to control our MC, there may be a very small percentage of MC patients for whom diet changes alone, will not bring remission.

Low dose budesonide can be safely used to maintain remission.

In cases where every attempt to reach remission has failed, if budesonide can be used to bring remission (while maintaining a safe diet), but remission cannot be maintained when the budesonide treatment is completely stopped, it may be necessary to use a low maintenance dose of budesonide (in combination with a safe diet), in order to maintain control of the disease over the long term. In such situations, some of our discussion forum members have been able to successfully use a dose somewhere between one 3 mg capsule per day, and one 3 mg capsule every sixth or seventh day. Published medical research proves that long-term use of budesonide at these low dosages will not lead to any significant adverse effects, in most cases.

MC is often a tough disease to deal with.

Controlling the disease with dietary management requires significant lifestyle changes. But virtually all of us can find our solution, as long as we don't give up before we find it. The key to controlling MC, even in the toughest cases, is dedication and persistence. In our journey to remission, if the treatment program we've chosen isn't working, after allowing adequate time for it to work, then it's time to try something else. We have to follow a quote from Winston Churchill — *"If you are going through hell, keep going."*

MC is sometimes described as a lonely disease, and in the most difficult cases, we are the only ones capable of coaxing the disease into remission. We have to listen to our body, and follow the cues that it offers. Our doctors, and other MC patients may be able to help, but ultimately, we are the only ones who can take control of our situation, bring our disease to remission, and keep it there.

Listen to your body.

Dedication and persistence are key.

References

1. Reddy, P., and Edwards, L. R. (2019). Magnesium Supplementation in Vitamin D Deficiency. American Journal of Therapeutics, 26(1), e124-e132. Retrieved from https://pubmed.ncbi.nlm.nih.gov/28471760/
2. DiNicolantonio, J. J., O'Keefe, J. H., and Wilson, W. (2018). Subclinical magnesium deficiency: a principal driver of cardiovascular disease and a public health crisis. Open Heart, 5(1), e000668. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5786912/
3. Froelich, M. (2020, February 1). 10 Signs You Are Deficient in Magnesium (And What To Do About It). Longmont Leader, Retrieved from https://www.longmontleader.com/local-news/10-signs-you-are-deficient-in-magnesium-and-what-to-do-about-it-2386610
4. Carnegie Mellon University. (2012, April 2). How stress influences disease: Study reveals inflammation as the culprit. ScienceDaily, Retrieved from https://www.sciencedaily.com/releases/2012/04/120402162546.htm
5. Cohen, S., Janicki-Deverts, D., Doyle, W. J., and Turner, R. B. (2012). Chronic stress, glucocorticoid receptor resistance, inflammation, and disease risk. Proceedings of the National Academy Of Sciences of the United States of America (PNAS), 109(16), pp 5995–5999. Retrieved from https://www.pnas.org/doi/full/10.1073/pnas.1118355109
6. Bednarikova, H., Kascakova, N., Furstova, J., Zelinkova, Z., Falt, P., Hasto, J., and Tavel, P. (2021). Life Stressors in Patients with Inflammatory Bowel Disease: Comparison with a Population-Based Healthy Control Group in the Czech Republic. International Journal of Environmental Research and Public Health, 18(6), 3237. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8003904/
7. Trauma Recovery. (n.d.). Phases of trauma recovery. Manitoba Trauma Information and Education Centre, Retrieved from https://trauma-informed.ca/recovery/phases-of-trauma-recovery/
8. Ung, K.-A., Gillberg, R., Kilander, A., and Abrahamsson, H. (2000). Role of bile acids and bile acid binding agents in patients with collagenous colitis. Gut, 46(2), pp 170–175. Retrieved from https://gut.bmj.com/content/46/2/170.full
9. Lewinska, M., Kårhus, M. L., Ellegaard, A-M. G., Romero-Gómez, M., Macias, R. I. R., Anderson, J. B., . . . Knop, F. K. (2023). Serum lipidome unravels a diagnostic potential in bile acid diarrhoea. Gut, Published Online First. Retrieved from https://gut.bmj.com/content/early/2023/04/18/gutjnl-2022-329213

You may have noticed that our Discussion Forum has been down since Christmas. Because of the holidays, there has been a delay in fixing it. It should be up and available again soon.

Check Out Wayne's Newest Blogs

Is a Parasite Carried by Cats a Serious Health Risk for Humans, Especially Older People?

Selecting Safe Foods for an MC Diet is Difficult. Why are USDA Scientists Trying to Convince Americans to Eat More risky foods?

Look for a Survey in January

The purpose of this survey is to gather information about the various types of treatments used for microscopic colitis, evaluate their effectiveness, and understand patient satisfaction with the treatments. We will communicate the results in a later newsletter.

Let us know what you like and don't like about the new design.

Contact Us: wayne.persky@gmail.com