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Foundation News

Many individuals with microscopic colitis have expressed interest in a support group. The Microscopic Colitis Foundation has initiated forming local support groups by offering a sign-up for those interested. Once enough interest in an area has been established, the foundation will move forward with establishing groups. Please spread the word! More information can be found here [Support Group](#)



**For your financial
contribution to the
Microscopic Colitis
Foundation**

Maintaining Remission After Weaning Off Budesonide

The process of weaning off budesonide is fraught with peril for microscopic colitis patients because experience shows that many patients are unable to maintain remission during or after the process. A relapse of symptoms can occur at any time up to about 8 weeks after the treatment is ended, if good practices are not followed to minimize the chances of suffering a relapse. When determining how to optimize the process of stepping down the treatment dosage as the end of the treatment regimen is approached, several issues must be considered.

One issue is the risk of the development of adrenal withdrawal symptoms if the dosage is tapered too quickly. This is a significant risk for most conventional corticosteroids. But clinical trials using

Entocort EC show that only approximately 9 to 21 % of budesonide is absorbed into the bloodstream. Therefore because of the relatively low percentage of active ingredient that's absorbed into the bloodstream when budesonide is used to treat the symptoms of microscopic colitis for short-term treatments of only a few months or less, the risk of adrenal withdrawal issues is only a fraction of the risk associated with most other corticosteroids. Because of that, in most cases the tapering period could probably be quite short without imposing a significant risk of adrenal withdrawal symptoms. But because some individuals are more sensitive to side effect risks of medications than others, an inappropriately short period of time in which the dose is stepped down (too quickly) might cause withdrawal symptoms in certain cases, so it seems prudent to err on the side of caution when ending the treatment.

Name: Microscopic Colitis Patient

Address: Anywhere in the world

Rx



*Take 3 capsules each morning
and see me in 6 months.*

Your Gastroenterologist

Most physicians typically initially prescribe budesonide for a relatively short treatment regimen (of only a few months), and with such a short treatment period, the dose tapering specified for the treatment is usually more than adequate to prevent any adrenal problems. For longer treatment programs, especially in cases where the treatment is continued for a year or more, the dose tapering becomes much more important because the risk of adrenal withdrawal symptoms becomes much more significant after longer treatment periods.

But beyond the need for tapered dosing when ending a corticosteroid treatment program in order to prevent or minimize the risk of possible adrenal issues, there are at least a couple of sound medical reasons why extending the dosage tapering even further tends to pay dividends in terms of maintaining remission. For one thing, most physicians significantly underestimate the amount of time required for the intestinal damage caused by the inflammation associated with MC to heal. Not only does relatively limited healing occur during a brief treatment of only a few months, but it is well documented that corticosteroids actually retard the healing process. This means that if budesonide is used to mask the symptoms of the disease, then in most cases it should be used for at least 6 months to a year, because that much time is typically required for an adequate level of healing needed to ensure that remission can be maintained after the treatment is ended.

And in addition, regardless of the length of the treatment, experience shows that ending a budesonide treatment too abruptly is commonly associated with a relapse of symptoms, for many microscopic colitis patients. Why does this happen? According to research published over 25 years ago (Goldsmith et al, 1990), corticosteroids are thought to suppress the inflammation associated with IBDs by reducing mast cell numbers in the mucosa of the intestines. But as a corticosteroid treatment is tapered and ended, mast cell numbers rebuild. While this observation does not appear to have been verified by published medical research, it seems apparent that the faster the treatment is tapered,

the faster the mast cell populations will be able to recover. And based on the behavior of mast cells during an allergic reaction, when mast cell numbers increase, they tend to overshoot normal densities and they become more active (more likely to release inflammatory agents). This happens rapidly during an acute allergic reaction. But when mast cell populations rebuild after ending a corticosteroid treatment, the extended period of time means that it's a chronic inflammatory event, rather than a brief, acute event. It's more like an allergic reaction in ultra-slow motion. The faster the taper, the faster mast cell populations will be able to increase, and the more likely they are to release larger amounts of proinflammatory agents. Thus the more likely they are to provoke an inflammatory state. If the inflammation modulators increase rapidly enough to exceed a certain threshold of inflammation (specific to the individual's immune system), then an adverse reaction can occur, leading to a relapse of symptoms.

It appears that currently the most common budesonide treatment program prescribed to treat microscopic colitis may be a 3-month period, consisting of 1 month at the full dose of 9 mg per day, followed by a month of 6 mg per day, and ending after 1 month of 3 mg per day. Some gastroenterologists prescribe an even shorter treatment regimen, and/or they prescribe a lower beginning dosage (such as 6 mg per day). But aside from being too short to be effective in most cases, such treatment programs have another fault. Prescribed treatments tend to follow a one-size-fits-all format, but most IBD patients do not respond to budesonide treatments uniformly. Patients tend to have varying response rates to medications, especially corticosteroids, and one-size-fits-all treatment programs leave a lot to be desired. For one thing, it's well known that after an initial treatment with a corticosteroid, patients tend to have a progressively lowered response rate (efficacy rate) with subsequent treatments. In other words, subsequent treatments become less and less effective for that patient.

Most MC patients see significant improvement within a couple of weeks after starting a budesonide treatment, especially if they have made diet changes to avoid their main food sensitivities. Some require a month or 2 to reach a similar stage of progress, while a few may see significant improvement within 2 or 3 days. So it makes sense (and yields better results) to adapt the treatment to the patient, rather than to force the patient to follow a rigid treatment program that may lead to adverse results in some cases.

So rather than to lower the dose at some arbitrary time during the treatment (such as after 1 month), many patients find it much more practical to step down the dosage at the first signs of constipation. This allows for the differences in response rates among various patients, and it minimizes the risk of reducing the dose too soon, or failing to reduce the dose in time to prevent serious constipation issues.

Remember that the goal of weaning off budesonide is not just to be able to stop taking the medication. The most important goal is to remain in remission as the medication is phased out. It helps to listen to your body, and if your body tells you that it's time to reduce the dose, then it's probably time to reduce the dose. Likewise, if your body tells you that it's not ready for a reduced dose, it might be prudent to continue with the current dose for a week or so longer, before reducing it. Hopefully your GI specialist will understand this and support your needs.

1. Corticosteroid treatment reduces mast cell numbers in inflammatory bowel disease.

Using Steroids Increases the Risk of Developing Diabetes



Like other IBD patients, many MC patients use a corticosteroid to help mask the symptoms of the disease. Researchers at Columbia University in New York did a search of the data available in electronic health records and discovered that among IBD patients, 20 % of those who used this class of drugs developed steroid-induced diabetes. Among IBD patients who did not use these drugs, less than 6 % developed diabetes. In other words, those who used steroids were 7.42 times as likely to develop diabetes as those who did not use the drugs. And steroid users were 2.25 times as likely to develop the condition known as prediabetes as those who did not take drugs in this class.

It's also worth noting that increasing age and parenteral nutrition (intravenous feeding) increased the risk of developing diabetes. And in males, parenteral nutrition increased the risk of developing prediabetes. Therefore, for patients using corticosteroid medications to treat MC, it seems prudent to keep an eye on blood glucose levels. For most patients, monitoring blood glucose levels can be useful for making treatment changes before diabetes actually develops. And for patients who already have diabetes, being aware of the additional blood glucose risks imposed by steroids can be helpful for preventing unexpected blood sugar control issues.

[Haribhakti, S. \(2015, December 11\).](#) Patients

It's Not Just Us - Everyone Wants Safer Food



There's a movement among food processors and manufacturers toward food products and labels that contain fewer chemical additives and more transparency. And it continues to gain momentum. Apparently microscopic colitis patients are not the only people clamoring for safer, simpler food, with labels that can be easily understood without the need for a degree in food chemistry. The industry is definitely listening, and they are responding to consumer concerns at an astonishingly fast pace. Food industry news releases from one food manufacturer after another, announcing sweeping changes in the formulations of some or all of their products seem to be all the rage these days. In fact, companies seem to be falling all over themselves as they attempt to announce changes ahead of the competition. And while it's not unusual for food manufacturers to change formulations of their products, prior to the recent trend it was almost unheard of for products to be reformulated with fewer ingredients.

What's behind the movement? Companies don't spend the money required to make such changes unless they have a good reason. And the reason appears to be demand. More people are becoming more health conscious, and they are choosing food products with less

Who Receive Steroids for IBD At Heightened Risk for Diabetes.
GI Surgery.

What To Eat For Breakfast: Keep It Simple!



Breakfast is one of the most frequent conundrums when dealing with a flare. While many of the typical breakfast choices are high in fiber or gluten that can worsen a flare, a well-planned out fulfilling first meal of the day can still be enjoyed. An excellent choice for a gut-healing breakfast is a simple soup. Follow the guidelines below for a nutritious and healing soup.

- Use homemade bone broth. Bone broth provides nutrients not found in commercial stock.
- Stick to well-cooked mushy vegetables that do not cause a reaction, such as carrots, squash, zucchini and turnips.
- Add a well-cooked protein such as turkey, lamb or game meats (like bison).
- Do not add spices, as they can increase inflammation. Salt is okay.
- Minimize grains. Most individuals do not react to white rice like Jasmine or Basmati rice. Test your reaction prior to adding a small amount to your soup or try a gluten-free noodle option.

With attentive planning, breakfast can be a satisfying and healing meal. For more detailed information, visit the [Support Forum](#) for a Stage One Suggested Eating Plan under Guidelines For Recovery.

Dealing With MC When

processing and fewer chemical additives. And this isn't lost on the industry. Unnecessary ingredients such as preservatives, dyes, and various chemical ingredients with names that no one can pronounce are being phased out of processed foods at an unprecedented rate. Chemical ingredients that were added over the decades without any questions, are now being questioned.

In 1958, the Food Additives Amendment became law. The intent was to require manufacturers of new food ingredients to verify their safety. Any food additive shown to cause cancer in either humans or animals was prohibited from approval by FDA regulations. And the FDA published in the Federal Register the first list of substances generally recognized as safe (GRAS).

But the FDA established an option whereby manufacturers could "self-affirm" the safety of substances used as food additives to get them added to the GRAS list. This pretty much set up an arrangement whereby the fox was guarding the hen house, for all practical purposes. Basically, all a manufacturer had to do was to certify that they had done all the necessary research, including assembling a panel of experts to review any safety concerns, and be prepared to defend the ingredient's GRAS status if necessary. Manufacturers didn't actually have to provide any proof of anything - they just had to certify that they decided that the product was safe, and be willing to defend that position.

So naturally the GRAS list eventually got to be quite long, all without any need for testing by the FDA to prove that the substances were actually safe. One or two were contested by data from independent testing labs, and withdrawn over the years (such as saccharin, when it was shown to cause cancer in animals), but then saccharin was allowed to be relisted. As would be expected with "self-affirmation", a lot of substances were listed that probably shouldn't have been allowed. In other words, as is so often the

Tragedy Strikes



As many know, stress can trigger a flare-up. It's particularly difficult to deal with and control microscopic colitis during times of trauma and tragedy. However, the following tips can help to get you through a time of difficulty.

- **Continue Taking Any Medications on a Schedule.** It's important to consistently take medication at the same time each day. Although you may be flaring, the medication can help to prevent symptoms from worsening further.
- **Nap or Rest.** Even if you are unable to take a nap during the day due to work or having children, try to rest for any amount of time. At work, you can lie down in your car during a lunch break. At home with children, try laying in bed for quiet reading time. Do not focus on forcing yourself to sleep. Simply allow your body to relax.
- **Reach Out to Others.** Do not try to take on the burden of "doing it all". Ask help from loved ones to cook dinner or do the dishes.
- **Say No.** Politely but firmly decline any requests from others to take on more work such as a bake sale for your church or knitting blankets for a charity. The extra work will only cause further stress.
- **Keep your mind busy.** Doing low-level activities like reading, journaling or crossword puzzles can help to reduce stress and in return ease flare symptoms.
- **Make Simple Basic Meals.** Go back to safe, comforting and nutritious foods during a flare like a basic broth or soup.

case when the FDA is in charge, no one was looking out for the best interests of consumers. After all, assuming that cancer is the only disease that food additives can cause is naive at best. It's doubtful whether any of the currently-listed FDA GRAS substances will be delisted, but it's becoming increasingly clear that far fewer of them will be used in most food products in the foreseeable future.

Does all of this sound like déjà vu? It should, to microscopic colitis patients at least, because MC patients are typically forced to learn that if they don't take charge of their own health, they may not have any health left to take charge of, in the long run. And now the general public is beginning to recognize that they are in the same boat. And they are convincing food manufacturers to provide them with safer, more nutritious food.

There are other food trends that have evolved during the past few decades, such as the rise in organically-produced food, and the creation of genetically modified (GM) foods. Both continue to increase, but consumer opinions about them differ widely. A recent survey showed that while 55 % of Americans say that organically grown produce is better for health than produce grown by conventional methods, 41 % feel that there is no difference, and 3 % believe that conventionally grown produce is superior.

The survey showed that 39 % of Americans feel that GM foods are detrimental for health. But 48 % say that there's no difference between GM foods and conventional foods, and 10 % feel that GM foods are superior for health. The survey also showed that about 3 % of Americans follow a strict vegan or vegetarian diet, while another 6 % say they follow a mostly vegan or vegetarian diet.

Interestingly, the survey included a little insight into the way that diet restrictions are perceived in social settings. 31 % of Americans say that it bothers them (to some degree) when a guest requests

Eating poorly will only exacerbate a flare-up.

- **Seek Support.** Whether it be from a family member, friend, therapist or an online support group, take time to talk with others about your feelings and struggles. Feeling supported can really make a difference during difficult times.

Did you know?

Donations to the Microscopic Colitis Foundation can be made through Amazon Smile and PayPal Giving.

Amazon Smile provides a wonderful way for individuals to support his or her charity. Every time you shop with Amazon through Amazon Smile, a portion of your purchase will be donated to your charity of choice, at no cost to you.

#StartWithaSmile at smile.amazon.com for your holiday gifts and Amazon donates to the Microscopic Colitis Foundation.

PayPal Giving is a service provided through PayPal. A donation made through PayPal Giving will go 100% to the non-profit. PayPal Giving can be accessed [here](#).

special menu accommodations. And on the other hand, 37 % feel that hosts should always ask guests ahead of time if they have any food restrictions.

So after several decades of unhealthy trends in food manufacturing, where manufacturers seemed to pride themselves in seeing who could produce products with the longest and most confusing ingredient lists, the tide has turned. Ingredient lists are now deflating, and presumably this trend will result in better, safer food, for generations to come.

A survey of 1,700 registered dietitians (RDs) from across the U. S. collected their opinions on consumer trends in food and eating for next year. According to the survey results, 49 % of RDs believe that instead of dieting, consumers will be more likely to use mindful eating as a means to improve their health. And 59 % believe that consumers will choose more whole foods and foods that have had less processing. So this suggests that the trends in food manufacturing appear to be on target and will probably continue for the foreseeable future.

If you want to read more:

[Fresh, Healthy Food Is Not a Trend.](#) It's a Movement

[The New Food Fights:](#) U.S. Public Divides Over Food Science

[Nutrition Experts Reveal Diets Are Out & Mindful Eating Is In](#)

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