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## After We Reach Remission, What's Next?

How do we get back into circulation, and learn to live within the limits imposed by our new norm? Once we regain the confidence we need to leave the house without worry, and we begin to think about traveling again. We're eager to get started, but not quite sure how to go about it. We would like to begin socializing with friends again, but we realize taking that step is fraught with peril, because almost all social gatherings involve food.

### Learning to live within our new limits

The first thing we need to recognize and accept, if we haven't already done so, is that our lives have been permanently changed, now that we have microscopic colitis (MC). Certain things that we've done all our lives will continue to be a part of our new life. But much of what seemed normal before, will require special attention and a few concessions, if we intend to continue doing them. We'll be able to get back to socializing with friends, traveling, and the other pursuits that we've been missing since our diagnosis, but there'll be a new set of rules defining how we can go about them, in order to prevent a relapse of symptoms.

### Socializing

Most of us are eager to get back into circulation with our friends and various social events, and this desire ranks high on our priority list. The most important limitation for this activity will be the way that we approach the food selections that social gatherings



virtually always involve. Obviously, we can't just eat what everyone else is eating, because that will usually guarantee a reaction. When we're at a public place, we have to be very careful about what we eat and drink. We don't want to be conspicuous, but on the other hand,

we don't want to be sick, either. After all, if we're going to be sick for a week or more after going to an event, is it really in our best interest to go?

If we're at a wedding reception, for example, and we're just standing around empty-handed, hoping that no one will notice that we're not eating or drinking anything, some helpful soul at every event will inevitably spot us and suggest that we try this, or that. And after we carefully explain why we can't eat any of the food there because of our food sensitivities, they'll always suggest, "Well, a little bit surely won't hurt you. Just try a little."

The problem is, a little bit surely will hurt us. It would probably cause us to suffer through at least several days of misery. So please don't fall for that line. To avoid looking conspicuous, we can carry a glass that contains a safe drink, or even water, and take a sip now and then, as we mingle with our friends, and we'll be less likely to draw attention. If someone asks why we're not eating, we can tell them that we had a big meal before we left home, and we'd be uncomfortable if we tried to eat more. And that should be the truth, because eating before we leave home should prevent us from feeling hungry while we're at an event.

Drinks that we know from past history are safe for us should be a safe choice in that situation, as long as they don't contain any additional additives. But foods must be selected very carefully, whenever we're eating anything away from home. Think of it this way — whenever we're eating food that we have not prepared ourselves, we have moved out of our safety zone into an area that may, or may not, contain numerous booby traps.



### **Eating away from home**

Communicating our wishes and needs to waiters at restaurants, and also friends and relatives, may benefit from our giving a little thought to their situation. Most people have heard of celiac disease, so they may be at least somewhat familiar with gluten sensitivity issues. And lactose intolerance is so common that

most people at least believe that they understand dairy intolerance. The main problem is that they almost always misinterpret dairy intolerance as lactose intolerance, because they know that lactose intolerance is common among the general population. Most likely, they have never heard of casein intolerance.

Because of that, they mistakenly assume that foods like butter and yogurt are safe choices for people who are dairy intolerant. Of course, that's not correct for our situation, since both those foods are loaded with casein, and casein intolerance is a much more important food sensitivity than lactose for MC patients. True, we're intolerant to lactose, when our intestines are inflamed, but lactose does not cause the production of antibodies, as casein does. We merely can't digest lactose completely, so opportunistic gut bacteria tend to utilize it as a prebiotic, and this results in gas, bloating, cramps, and diarrhea as they proceed to break it down.

This type of diarrhea is usually short-term, however, and it should end after the intestinal contents are emptied. Casein, on the other

hand, causes the production of antibodies, and these antibodies result in the type of inflammation (lymphocytic infiltration) that causes the longer-term, persistent, and often watery, diarrhea that's normally associated with MC.

Soy sensitivity can be even more difficult to communicate, because it's not as well-known among the general population, even though it can be a major problem for us. And because soy is often hidden in many foods, even if someone knows and understands what it is, they may overlook it due to labeling issues.

For us, legumes can be a problem. Most of us who are sensitive to soy are also sensitive to most legumes. But this issue will fly under the radar for most people, making soy contamination of our foods a major risk whenever we eat away from home.

FDA labeling laws do not apply to restaurant foods.

All this confusion appears to be caused by poorly thought-out FDA policies. Many of us assume that the foods on restaurant menus are under the same FDA requirements as retail packaged food, but this simply is not true. And worse yet, the FDA has never bothered to clarify this issue for consumers. Instead, they sort of metaphorically sweep it under the rug hoping that no one will notice.

Please be aware that although the FDA requires labeling on all retail foods that reveals the presence of any of the officially specified allergens, this is not a requirement for restaurant foods. That sort of leaves everyone in the dark, regarding restaurant food. True, many restaurants do attempt to post any allergen risks that might be in their food, but that's not actually an official requirement — compliance is strictly voluntarily.<sup>1</sup>

**Upscale restaurants are the safest places for us to eat, if we eat out.**

Upscale restaurants are generally the safest restaurant choices, for anyone who needs to order food that specifically avoids certain ingredients. Their chefs almost always understand that foods ordered with gluten free, soy free, or dairy free restrictions have to



be absolutely free of those ingredients, and they understand how to actually fulfill that request. Consequently, meals at upscale restaurants are generally safe for most of us, as long as we order carefully.

**By comparison, fast food restaurants are generally not nearly so safe for us.**

Published research shows that at least a third of their meals claimed to be gluten-free, are not.<sup>2</sup> Breakfast is usually the safest meal (at 27% contaminated, according to the study), but meals served later in the day are more likely to be cross contaminated with gluten. Often this happens simply because contaminants tend to accumulate on countertops with repeated use by numerous employees, and those countertops are not properly cleaned before our food is prepared there. And obviously, a 27% contamination rate makes eating breakfast at most of those restaurants unacceptable, unless we crave to get sick from at least 1/4 of our meals.

And if those foods are commonly cross contaminated with gluten, it's a safe bet that they're also cross contaminated with other off-limit ingredients, as well. The study showed that over half of all pastas and pizzas analyzed were cross contaminated with gluten. Obviously, meeting with friends at a pizza place is typically a very poor choice for an MC patient. Whenever possible, suggest meeting at a restaurant that you know offers some safe options for you, when arranging to meet with friends at a restaurant. If you're aware of more than one restaurant that offers safe options, then suggest those restaurants as options, also.

Bear in mind that the statistics from this study are averages, and don't necessarily apply to individual restaurants, or specific restaurant chains. Some restaurants provide much better training for their employees than others, and in some instances, the foods offered by certain restaurants or restaurant chains are inherently more likely to remain free of contaminants because of the way they're stored, handled, and served.

An approximate estimate of the level of risk of cross-contamination at any restaurant can probably be obtained by looking at their menu. If the menu predominantly contains foods that are naturally rich in gluten, such as pasta or pizza, it's probably safe to assume that the risk of cross-contamination at that restaurant is relatively high.

On the other hand, if we look at the menu from a dedicated gluten-free restaurant, and see that there are no items on the list that contain gluten, obviously, the risk of cross-contamination there would be extremely low. Most restaurants will fall somewhere between those two extremes, but we should be able to get a rough estimate of the risk, by simply looking at the items on the menu.

**We can always take safe food with us, when we leave home.**

If our friends insist on meeting at a pizza place, for example, taking our own food from home will allow us to stay safe while still being able to socialize. A few of our friends might consider that behavior to be odd, but if they're really friends, they'll understand and be supportive. And taking food from home may be our best option for various other social events whenever we're not sure whether the food available there will be absolutely safe for us.

## Travel



Finding suitable restaurants when traveling is much simpler today than in the past, thanks to numerous smart phone apps that are updated regularly. Certain popular restaurant chains cater to the needs of people who have food sensitivities, and they can be easily located with those apps. Most of the big, well-known organic grocery store chains include gluten-free and vegan options in their deli sections. All in all, allergen free foods are much easier to find these days than at any time in the past.

That said, if we want to minimize our chances of getting sick and having to deal with the nightmare of searching for a bathroom in a hurry while traveling in a strange city, the safest strategy is to take our food with us when we leave home. That totally eliminates all of the restaurant risk and all of the associated worry.

### **Traveling by car**

When traveling by car, taking along a good ice chest or portable refrigerator in which to keep foods can eliminate the problem of trying to find safe snacks or meals while traveling, or even at our destination. Some people even carry a small portable freezer along on the trip, to allow an even greater variety of foods that can be taken from home. Of course, those of us who have an RV available, or can rent one for the trip, will already have a refrigerator and freezer available.

If we're visiting with friends, and we're not sure they understand how to keep food truly safe from cross-contamination (most people don't), we can offer to do the cooking ourselves while we're there. If our host accepts our offer, then we can be sure our food will be safe, assuming that we start with safe, basic ingredients.

### **Cruises**

Cruise line restaurants have an excellent safety record. Their chefs are very knowledgeable, and well-qualified to accommodate almost anyone's needs. After booking our cruise, we can request any special meal requirements at least a couple of weeks before the cruise. Then, every meal we're served while on board during the cruise will adhere carefully to those restrictions.

If we need a snack during the day, there will almost always be conveniently located areas on the ship that include safe snacks, properly labeled for anyone with diet restrictions. If the ship docks at various ports of call and allows passengers to disembark so that they can explore places of interest, we can even ask the chef to prepare a safe brownbag meal that we can take with us, to eat while we're out exploring.

### **Traveling by air.**

Traveling by air, unfortunately, is much more complicated, especially for people who have food sensitivities. We can still call ahead before the trip to order gluten-free foods. But when mealtime comes around, we will almost surely be disappointed with the foods that we're served, unless we happen to be a vegan or vegetarian. Meals will mostly consist of assorted fruit, maybe a stick or two of celery, and possibly other items that contain very little nutrition. And while airlines can provide gluten-free meals, they're usually not set up to allow for other food sensitivities.

Therefore, if we intend to eat a safe, nutritious meal during a flight, we'll need to take our food with us. For short trips, we can simply avoid eating on the plane, and eat before we leave home. But for longer trips, we'll want to take some food with us. And of course, if we do that, whatever we take with us will have to pass a security

inspection at the airport. Before attempting to carry our own food on a flight, it may behoove us to ask an experienced airline traveler who has food sensitivities for guidelines on how to select foods and how to pack them. This will save us a lot of time and trouble at the airport. A letter from our doctor may help.

The laws regarding the carrying of liquids are rigid. Rather than to list all those details here for planning purposes, there are some good guidelines for air travel at the link below:

<https://www.perskyfarms.com/phpBB/viewtopic.php?f=62&t=11853>

### **Accommodations at our destination**

If we're staying at a hotel or motel, we should try to get a room with a kitchen or kitchenette. Doing so will allow us to eat many of our meals in our room, and save us the trouble of having to locate a safe restaurant. If the room only contains a kitchenette, be aware that there will probably only be a microwave, so we'll probably want to fully cook our meals before we leave home, so that all we have to do is rewarm them before eating.

These days, it's possible to rent an apartment, condominium, or house during our trip, and that will allow us to gain access to a kitchen. There are numerous smart phone apps to facilitate searches for places to stay.

### **What should we do if we have a relapse of symptoms?**

If we know, or suspect we know what caused the reaction to begin, we need to make sure we avoid that food, or medication, or supplement, or whatever, in the future, or a short-term reaction may turn into a long-term flare. If we don't know what initiated the reaction, then it may be necessary to go back to the simple, bland, elimination diet that we used to achieve remission initially. Even if we do know what initiated the reaction, if avoiding that food doesn't stop the reaction within a day, then dropping back to a simple elimination diet may be the quickest, surest way to stop the reaction and get back to remission.

Flares that occur after remission is achieved can sometimes be very difficult to break. And the longer they persist, the more difficult they become to resolve. If we needed help from budesonide in order to reach remission initially, then we may need help from budesonide again if the diet changes don't bring remission within a reasonable amount of time. If we do decide to begin taking budesonide, then it will provide the quickest, surest results if we start with a full dose.

### **We can be sure that one thing will never change.**

And that's the fact that life is constantly changing. As our environment changes, and other aspects of the world around us continue to evolve, they may affect our health. And surely, aging will affect our health. Consequently, we may occasionally find it necessary to modify our diet.

Experience has shown that some of us may occasionally develop an additional sensitivity to food, medication, supplement or something else in our environment. If the problem persists after careful exploring, ordering a test kit from EnteroLab might help.

## **Dealing with the emotional challenges caused by MC**

Although this issue is the last one to be discussed in this article, it

definitely is not the least important issue associated with MC. Coming to terms with the necessary changes can be difficult and involve the emotions of anger, a feeling of unfairness, sadness, or depression.



MC alters not only our genes and our physical integrity, but it also makes emotional changes to our psyche. Sometimes these changes are slight, and sometimes they may seem extreme, but there will be changes.

We spend most of our time dealing with the physical side of

MC. But what about those emotional changes? Some of the changes may affect some of us to a much greater extent than the physical issues caused by MC. For most of us, this is especially true after we've reached remission, and we've settled into a routine that reflects our new norm.

Most of us feel sadness over the personal freedoms and options that we have lost due to MC. Occasionally those emotions may build up to the point where they interfere with our daily lives to the extent that we find it necessary to seek a way to deal with the feelings of depression and loneliness.

And as a corollary to that, we feel more empathy toward others who have had a similar experience — in other words, other MC patients. Because we feel so isolated from the general population, we find that we have an almost primal urge to bond with other MC patients. And whenever we can actually do so, it typically leaves us with a very refreshed, uplifted, and renewed feeling.

### **Humans are social creatures.**

In general, we feel very comfortable and relaxed when we're around other MC patients. We're in our comfort zone, because they're just like us, so we know they understand us. By contrast, whenever we're around other people in the general population, we feel very uncomfortable (although we may not always realize it at the time), because we're well aware that they don't understand us.

Why is that so important? It's important because it's not just a small peccadillo — it's a critical issue that we associate with the general population. Because humans evolved as social creatures, we're only truly comfortable when we're around others who are just like us.

The good news is that many more people, in addition to those with celiac and MC, are becoming aware of the impact of food sensitivities, especially gluten, on health. This is responsible for the increasing number of grocery items available and the increasing awareness of these issues by restaurants and the general public. This will make dealing with the social aspects easier as time goes on.

### **References:**

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**"Oh, it's alright. You couldn't know that I'm honey-intolerant."**