

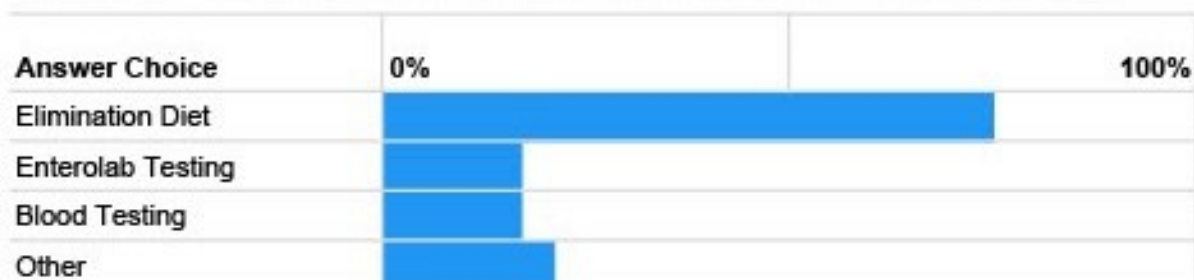


Survey Results: Part 2 Looking at Diet and the Journey to Remission by Wayne Persky and Rosalyn Upson

The previous newsletter looked at how various medications performed in treating microscopic colitis. Now we look at the other available tool, diet. We know from the experiences of many MC patients, that our diet is critically important for most of us. Many of us have discovered that the onset of MC can bring with it sensitivities to a number of food groups. And in addition, some foods are just too irritating or gas producing when we are reacting. One of the purposes of the survey was to see just how prevalent sensitivities are to the most commonly reported foods, and just how successful people are in improving symptoms using diet. We also wanted to see where people were at in their journey toward control of, and hopefully remission from, MC.

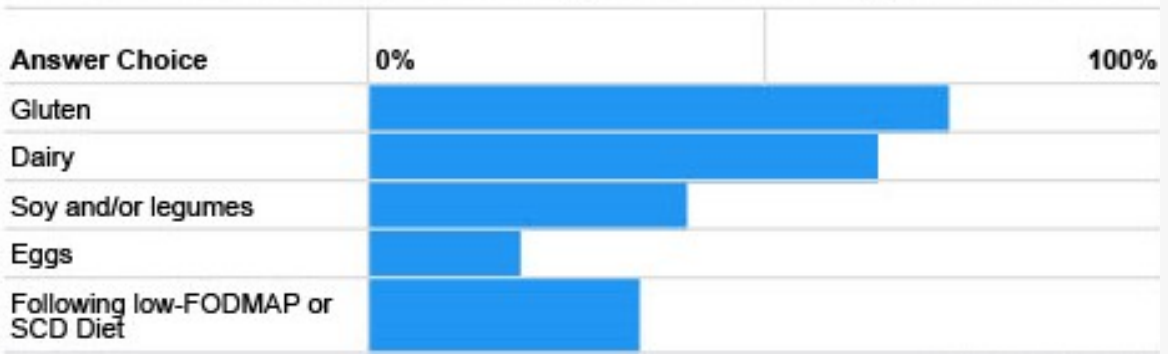
Of all who responded, 76% are using diet to help control their symptoms. Let's take a closer look at what the survey revealed.

20. How have you explored which foods to eliminate. Check all that apply.



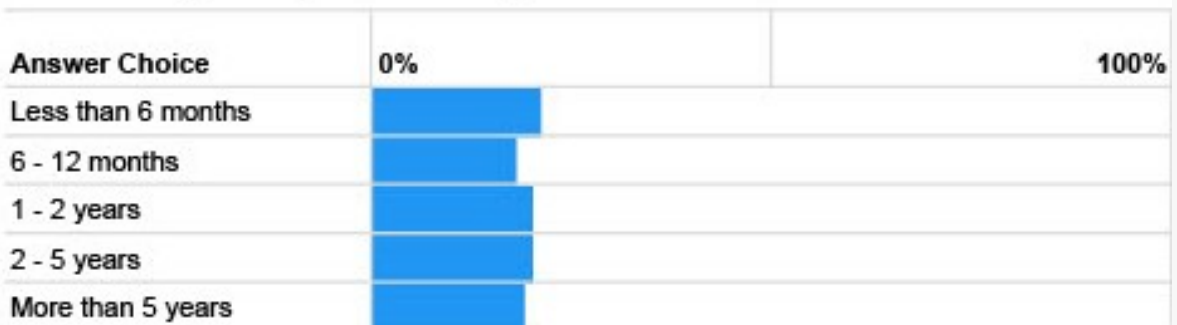
Using an elimination diet was the most popular, with 75% using it to try and identify problematic foods. Enterolab testing and various types of blood testing were next. Other types of testing weren't identified.

21. Which of the following foods have you eliminated from your diet. Check all



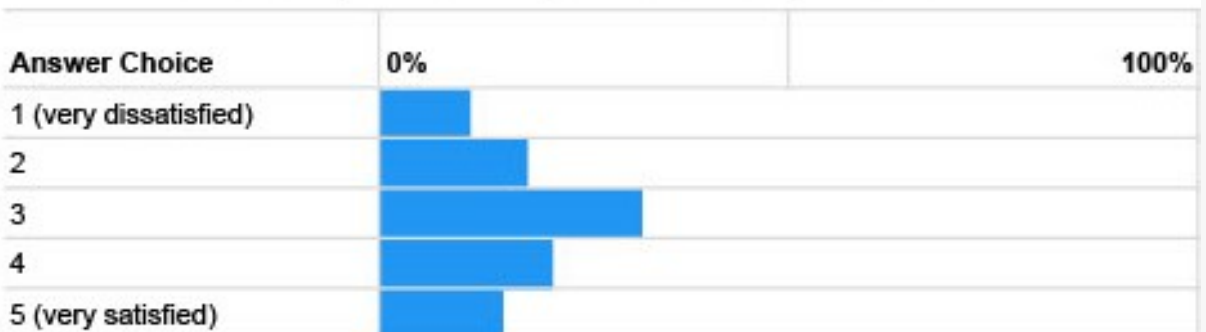
You can see what classes of foods were most commonly eliminated. This reflects what we have observed over the years, but now we have some real numbers. Around 73% have eliminated gluten, with the other major allergens following at significant, but lesser numbers. And 34% are following the low-FODMAP or SCD diet, reflecting their popularity.

22. How long have you been using an elimination diet?



There are many people who have used diet to control their symptoms for years, speaking to its importance.

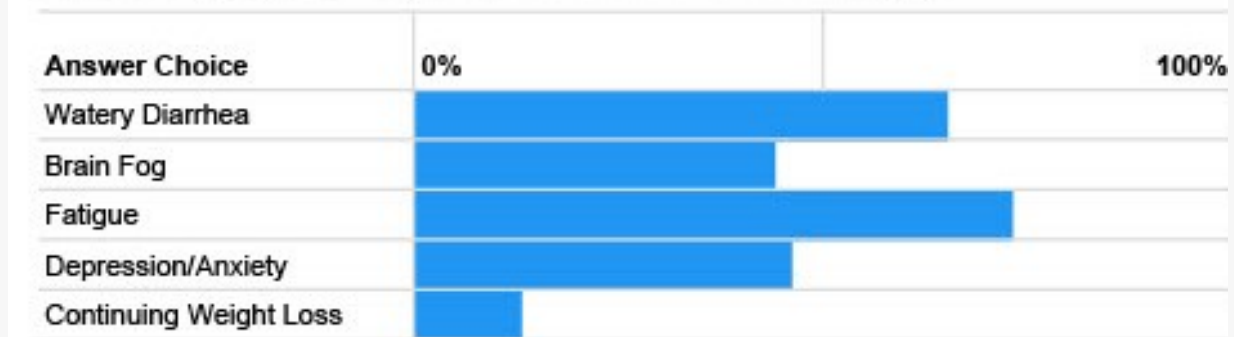
23. How satisfied are you with using diet to control your MC?



About 36% are very, or highly satisfied with using diet to control their symptoms. But that leaves around 30% who are struggling, and not very satisfied, with another 34% in the middle.

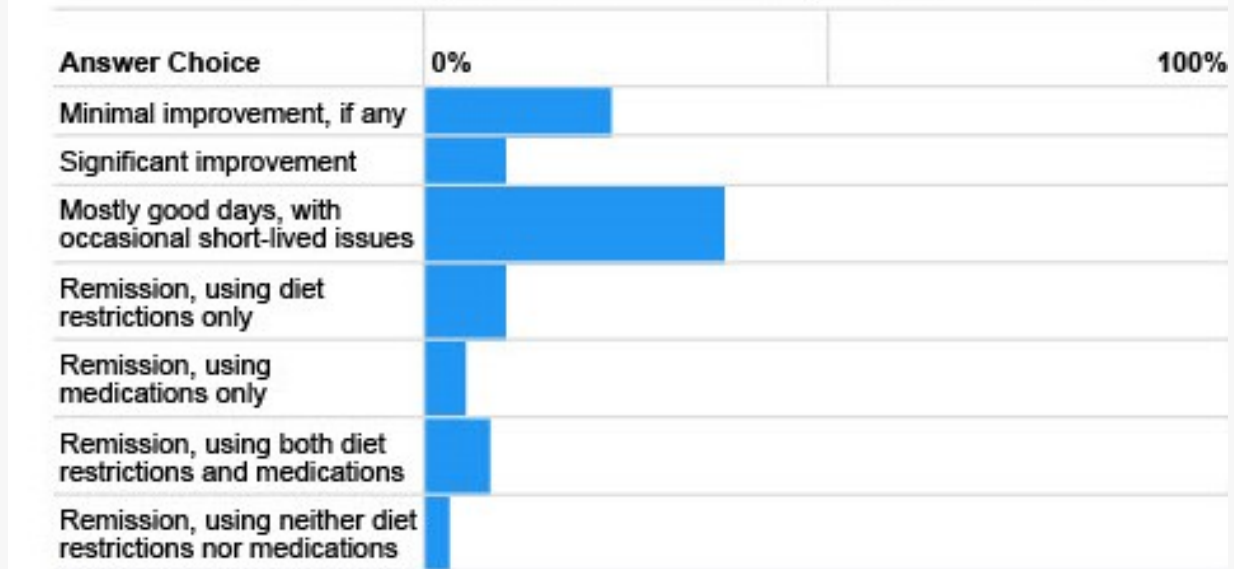
Now let's take a look at where we are at in our journey toward healing.

24. What symptoms do you still have? Check all that apply.



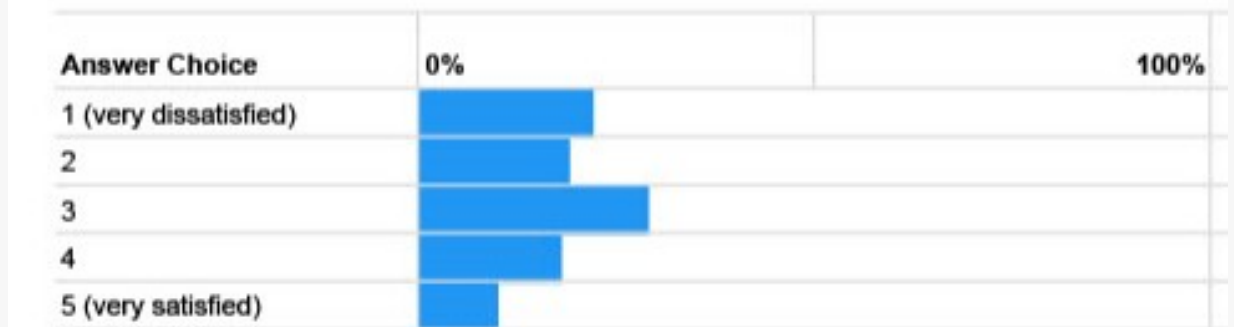
A lot of us still have on-going symptoms. It takes a lot longer than we hope to heal.

25. Which of the following answers best describes your current MC situation?



This survey questions provides a snapshot of where we are at in the journey toward recovery. The goal for all of us is remission, and 26% of the respondents are in that category. But unfortunately about 23% have not seen much progress. The rest have seen some improvement, but are still have a ways to go.

18. How satisfied are you with your overall medical treatment for MC?



This final question asks about your satisfaction with your medical treatment. Many of us have had issues with our doctors, but others have been quite satisfied.

20. How have you explored which foods to eliminate.

Not surprisingly, 75% of survey respondents used an elimination diet to determine their food sensitivities. Although using an elimination diet (and a food/reaction journal in some cases) may require more diligence and self-control than any of the other options, in the final analysis, it's the least expensive option, it's more reliable than using blood testing, and it helps us to learn how to use diet changes to control our disease.

Ordering tests to determine food sensitivities may save time, and remove doubts, but of course they're more expensive than using an elimination diet, and many of the tests offered by various labs have not been found to be consistently accurate. False positive results cause us to avoid foods unnecessarily, and false negative results can prevent us from ever reaching remission. To date, the most accurate and reliable tests, are the stool tests offered by Enterolab. Blood tests typically offer too many false positive results, and the occasional false negative results can have disastrous effects on our recovery (or lack of recovery).

21. Which of the following foods have you eliminated from your diet.

The survey results showed that 73% of respondents are avoiding gluten, with fewer numbers avoiding dairy, soy, and eggs, respectively. And that is the order in which we've found that most of us show sensitivities to these foods, although based on the food sensitivities of the members of the MC discussion and support forum, we typically show higher rates of reaction than the avoidance rates indicated by the survey (roughly 20 to 30% higher for gluten and dairy, and 50 to 80% higher for soy and chicken eggs, compared with the survey results).

Although there might be other explanations, these higher rates (higher actual sensitivity rates of discussion and support forum members, when compared with the avoidance rates indicated by survey question number 24, may explain why so many survey respondents are not yet in remission. One other reason, for example would be related to the fact that the intestines heal more slowly than most organs in the body, suggesting that most of us require more time to suppress inflammation and initiate good healing, than we anticipate. In other words, simply stated, most of us need more healing time in order to reach remission, than we realize.

Interestingly, 34% of respondents are following a low FODMAP diet, or the SCD diet. While these diets certainly work for a few MC patients, both diets allow certain foods that many of us cannot tolerate, therefore the diets have to be modified somewhat in order to be safe for most MC patients.

22. How long have you been using an elimination diet?

The fact that many survey respondents have been using an elimination diet for more than five years is a good indication of how well it works for many of us. And this survey question showed that MC patients in all stages of recovery responded to the survey.

23. How satisfied are you with using diet to control your MC?

Survey responses to this question showed that 36% of respondents are either very, or highly satisfied with their diet results, while 30% were either struggling, or disappointed with their results. 34% of responses were somewhere in the middle.

24. What symptoms do you still have?

We've learned by the shared experiences of the members of our discussion and support forum that symptoms such as brain fog, fatigue, and to some extent, depression and anxiety, can take up to two years or more to fade away after reaching remission, so it's not surprising that these symptoms were commonly reported by survey respondents. On the other hand, symptoms such as watery diarrhea, and continuing weight loss, are signs of continuing chronic inflammation, and active MC.

Because inflammation control, and the onset of healing, typically takes longer than most of us expect, a significant number of these responses were probably made by respondents who simply need more healing time in order to reach remission. But in the cases where these symptoms are still being experienced after following an elimination diet for a year or more, diet cross-contamination with traces of gluten, casein, soy, egg albumin, or one of their derivatives, is a distinct possibility.

Published research shows that 50% of meals certified as gluten-free by restaurants, for example, are cross contaminated, especially later in the day, as counters used for meal preparations

become more likely to be contaminated after extensive use. Labels on commercially processed foods are sometimes changed without notice, and occasionally they fail to list an allergen.

And in households where family members continue to eat foods containing gluten or other food sensitivities, cross-contamination can easily occur on counters, cooking utensils, or by other means, such as toaster ovens, or barbecue grills. Gluten and soy, especially, are ubiquitous, so we have to constantly be on guard for possible sources of contamination.

25. Which of the following answers best describes your current MC situation?

The responses to the survey question show that 26% of respondents are in remission, and 23% have seen very little (if any) progress. The other 51% have seen some improvement, but have not yet been able to reach remission. Again, maybe more time is needed, or cross-contamination may be an issue.

18. How satisfied are you with your overall medical condition for MC?

The responses to this question show that significantly more survey respondents have been dissatisfied with their medical treatment than those who have been satisfied. A common complaint (although this wasn't mentioned in survey responses) is that gastroenterologists typically fail to adequately discuss details of the disease with their patients. And the fact that published research shows that at least 80% of MC patients who respond to the most popular treatment (budesonide) relapse after the treatment is ended, doesn't help the popularity of medical treatment for MC.

Future Survey Possibilities

This initial survey has provided a lot of useful information. However, the questions were rather broad, and didn't get into as much detail as we might like. We are considering periodic follow-up surveys, and would like your input. We want to be selective, cover topics of the greatest interest, and not be too frequent. You can provide input on possible topics you would like covered, or any other suggestions for the surveys, by replying to this newsletter. We will collect your comments, and use them to help provide direction.

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