

5

Colitis Topics

EVERYONE

Should Know About

Flares

Stress

Prednisone

Probiotics

Relationships



iHaveUC

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5 Colitis Topics Everyone Should Know About was compiled and written by Adam Scheuer. The data within the different sections was gathered from online surveys conducted through the iHaveUC website over the past two years.

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Welcome



My name is Adam Scheuer. I have Ulcerative Colitis(UC), which I'm sure you've already guessed. I speak with UC patients daily from around the world, and it's my ultimate goal that this ebook helps to answer a ton of your UC questions. If you find yourself nodding your head, or even saying a few times "HOLY CRAP - that sounds like me", that's also what this ebook is meant to do.

Not too many people talk about UC, but thankfully, there is a great group of THOUSANDS OF PEOPLE who have participated in some extremely valuable surveys over the past few years.

The information included in this ebook is meant for all the people of the world who are struggling with UC as well as the family members and friends who know or live with a UC'er right now.

HOW THE INFORMATION WAS COLLECTED

All of the survey data was collected from anonymous UC patients who live all over the world. Open ended questions (with sometimes lengthy and detailed responses) as well as close ended questions make up the bulk of the survey data. Most of the surveys consisted of between 4-8 questions and each survey is based on a specific theme.

Since the iHaveUC.com website was started, there has always been a strong desire for people to know more about ulcerative colitis. The reality is that there is an increasingly growing amount of information over the Internet, however, it is often hard to read and digest, and often it is backed by groups with special interests who some might label "drug companies". Maybe you have even felt lost in the information superhighway. Don't worry, you're not alone. I was sitting at the computer for quite some time in my early UC days doing the same thing, the same goes for my wife and family. I even would get emails and messages from relatives about all sorts of UC news from time to time, and heck, that still happens.

But at the end of the day, I can't think of a better way for someone new to UC or even a veteran UC patient to learn about common colitis questions than by going straight to the source. Asking actual UC patients for their previous and current experiences is what the surveys have been able to finally do.

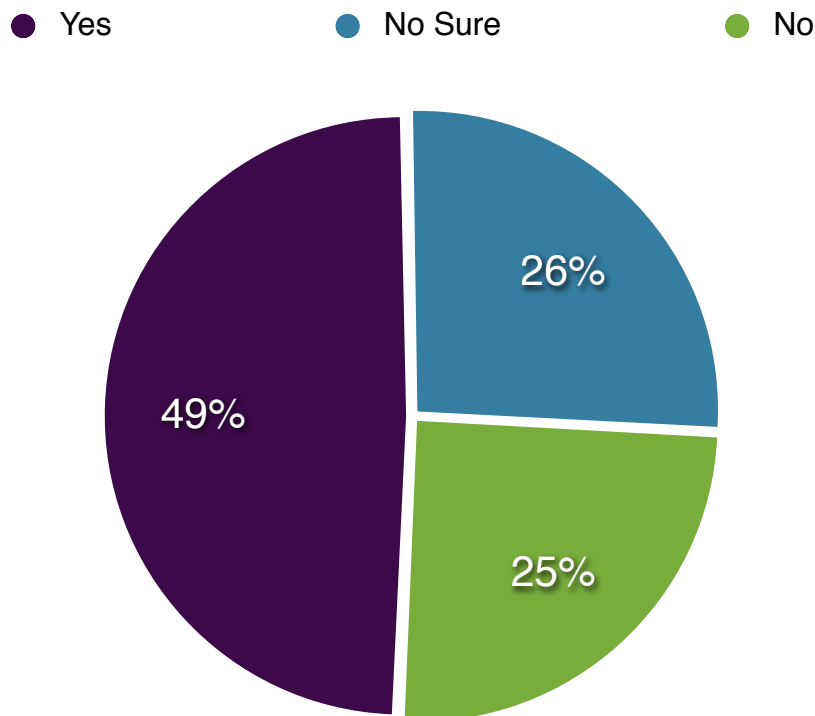
If you are a believer in the idea that hundreds of brains are smarter than just one, I'm glad you've taken the time to learn more about UC.

Topic 1: Triggering, Entering and Coping with Colitis Flares

data collected September 2012. 157 People participated

Question 1:

Do you ever have false starts? (you think you're starting a flare but you're really not)

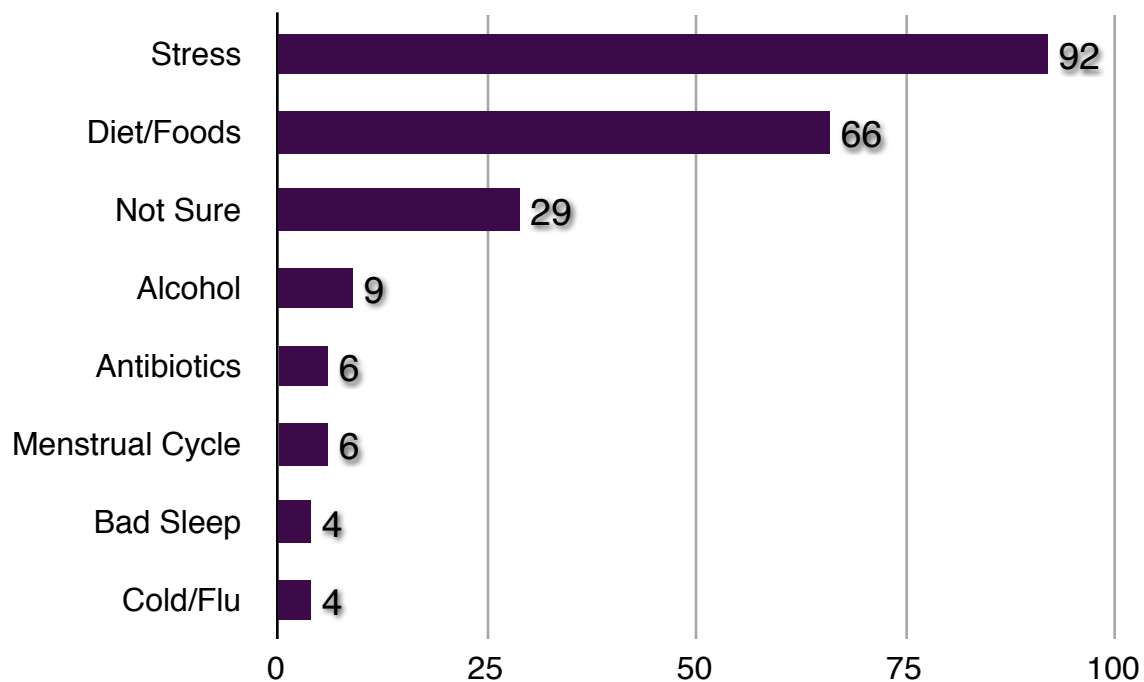


Question 2:

What do you think TRIGGERS your UC flares?

Is it always the same thing, or do different things trigger your colitis flares?

■ The most common responses (one person may have mentioned multiple answers)



Below is a small sample of some of the full responses from survey participants:

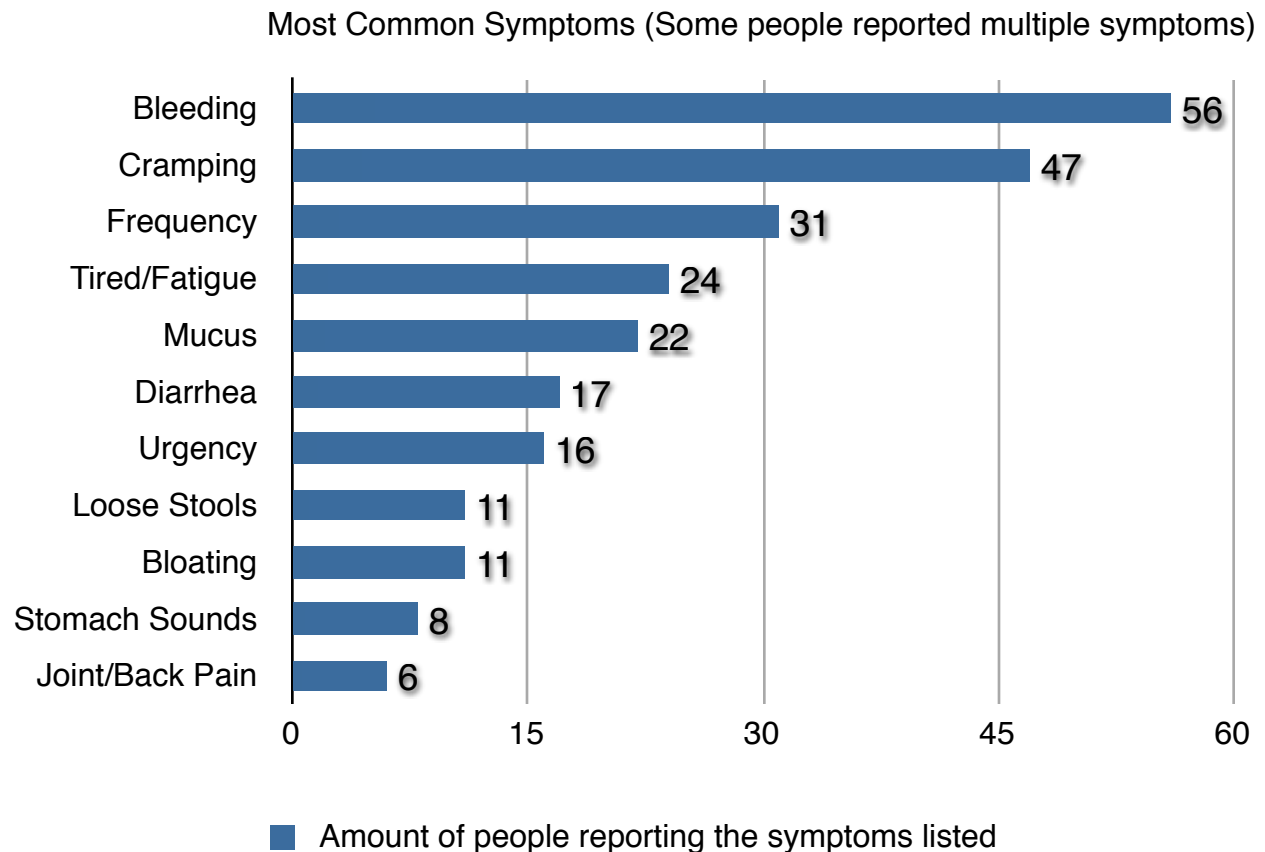
(the full survey can be viewed online: [Colitis Flare Full Survey Results Page](#))

- It is always the food and stress for me.
- I always worry when school holidays come up, if i'm gonna get anything it's when my body thinks it can relax, it's not even that I have kids at school anymore, I work in a school! The last two flares have been over christmas and easter holidays and my very first flare was during the summer holidays.
Perhaps I should change my job!

- Although my doctor always disagrees, my flares always coincide with a meal i clearly should not have eaten. Previous culprits include full on Xmas dinner and take away indian curry from a street stall.
- I was diagnosed 1 year ago and certain foods will set it off.
Milk products, caffeine, wheat products (which are no longer in my diet) were the worst. It also seems that raw fruits and vegetables will aggravate it.
- Even if I take my medications and respect my diet now and the symptoms of flares do show up. But I can not tolerate at all coca cola or coffee. And if I feel well with my medications and try to reduce the dose of Salofalk for example blood in the stool appears:(
- Getting slack with medications always triggers a flare. If I am compliant, no flares. I suspect that Ensure and Boost make the bleeding worse. I also suspect that even though I am on a gluten-free diet, that the g-free grains aren't helping end the flare. There is more blood when I eat pasta, rice, etc than if I just eat meat, veggies and fruit.
- Wheat always triggers me, and so does severe stress. Depending on how well I am, I could be triggered by a cold or a period.
- Stress, alcohol. Only flared once due to a combination of these two.
- Different things at different times, but the main culprits are: antibiotics, stress, other illnesses, lack of sleep, and of course GOK (God Only Knows).
- Refined food like cake; sugar; fried food.I try to avoid these.
Anxiety is also a trigger.
- It could be the weather, that slice of pizza, stress. I'm not sure. It seems to come out of nowhere each time. Blindsided!
- I have had UC for just over 10 years and with my experience in the last few years I always thought it was triggered by my diet. I don't believe that is strictly related to my diet anymore. I think stress also plays a part in it as well. I think diet has a lot to do with my flares, about 80% and leave the remaining 20% to stress and other things. I stay on diet of lean meats, veggies, some fruit and beans. I can have too much fruit and veggies which cause irritations to my colitis, but not flareups. I avoid as much as possible the things that I have learned that irritate my colitis like sugar (cereal, cakes, cookies..), dairy, wheat and a good beer. At times it is hard to down my favorite sweets or beer and if I have a small serving or one beer I am usually good. If I get a little crazy it brings on irritation and sometimes flare ups if I continue the bad eating habits over a few weeks. I have been in a flare up for about 2 or 3 months now and my diet didn't change much outside of eating more fruits and veggies over a period of a few weeks. Now I have cut back the intake of those and am still struggling to get back on track.
- When I was in elementary school, my mom thought the flares were seasonally related; when I was in my teens, the flares seemed to be more around exam time and beginning of school. Through my adult years, flares have been related to stress but if I had to connect them once more, I would say they are usually seasonal...spring and fall.

Question 3:

How do you know you have entered a UC Flare? What starts to happen to your mind and/or body?



Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online: [Colitis Flare Full Survey Results Page](#))

- Massive ejection of everything in my bowels. Just the hugest amount. At first I feel proud but then I realize what is about to happen. What follows is typical UC symptoms - blood, mucous, fever, loss of energy etc...
- I have real bad gas and feel as if I need to go all day and the next day I am usually in a flair.
- I start noticing some of the symptoms such as loss of appetite, frequent restroom visits, abdominal pain, fatigue, nausea, etc.

- I feel very tired and out of sorts. Just not myself. Then the gas and urgency start.
- The flare starts with a large amount of mucus, then lots of blood, diarrhea and cramping. What goes thru my mind at the time is this f--kin sucks.
- Feel anxious about trying to stop flare from getting worse, frequent trips to the bathroom, discomfort, blood or mucus in stools
- Begins with mucus and soft poop - basically, normal/hard poop ceases - then cramping and urges to go with no results. Tired after flare for a week or so. Mind wonders how bad this flare will be. Must take all precautions to keep it from getting bad. I wonder WHY IS THIS HAPPENING AGAIN?! What causes this? With all our medical science and technology, SOMEONE needs to find the cause!
- I have had urgency to go to the toilet (possible 16 urgent trips to the bathroom per day) blood and mucus and diarrhea. I'm drained and in a foul mood with the situation of feeling like a prisoner in my own home. When having to go out, all I can think of when in that state is - where is the nearest toilet to where I am going, will I be able to make it on time, breaking out in a sweat and my blood pressure raising when I realize I'm needing the bathroom and businesses allowing only staff to use their toilet facilities, its an awful situation to be in.
- Increase in gas and bloating, Left sided abdominal pain followed by blood in stool
- A real flare is for me when I see blood/ an when my belly is very big (then I know my bowels are inflamed). I have little diarrhea even when i'm not in flare, so i don't consider it as a clue
- I slowly start into some of the original symptoms I had prior to being diagnosed - it starts with gas, then abdominal cramping, then diarrhea. I usually don't know it's a flare (and not just the flu or upset stomach) until all of this has been going on for more than a week. On one or two flares I've started bleeding again.
- I start to feel like I have the flu and more frequent BM's. I get a low grade fever and have severe bubble-gut.
- I feel pain in my lower stomach, this ranges from so intense that i have to sit down so just annoying and small. i always get canker sores, i feel very tired, my stools are loose and happen more often.
- Becoming sicker from day to day. So, first of there are some blood and/or mucus in the white-friend or on the paper. Then I'm going to have dizziness, then friends tell me that I'm looking bad(for the last few flares they accustomed and don't tell anything))) also i'm usually get worse with sleeping.(especially till on the drugs)
- It usually starts with urgency, loose stools, and sometimes blood. A bad flare will also include crazy fatigue, chills, and cold sweats.
- It starts with gurgling stomach sounds, liquid stool, painful bowel movements, passing blood and mucous, appearing in that order. Then urgency, gas, fatigue, emotional lability etc hits after a few days of pain.

Question 4:

How do you cope with and how have you brought yourself out of an Ulcerative Colitis flare?

Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online: [Colitis Flare Full Survey Results Page](#))

- Managing food. Like completely stopped eating outside. And taking as much rest as possible. Like going early to bed and getting up little late. Then mild exercise.
- I cope by sleeping, increasing liquids including liquid foods, seeing the doc and staying positive!
- I try to give myself more time for myself to relax. I will review my diet and come up with my own plan to get rid of the symptoms. I will do whatever i need to do to avoid going on steroids
- Change my diet, see my acupuncturist, and if that doesn't work I see my GI doc and start some form of steroids
- Strict eating habits, yoga, meditation, Greens+ supplement
- bland diet
bump up all medications in my arsenal
hydrate with water
rest- especially when my body demands that i rest
- Chicken soup,carrots, meats
- Watch what I eat and try to keep stress level down.
- Prednisone, the evil yet wonderful medicine. I am now eating very carefully and exercising less. Have cut gluten and sugar out of my diet. Also careful with Lactaid and caffeine. I was already eating a very healthy diet, so not having to change much, but I miss bread!
- Slowing down
taking copious amounts of doctor prescribed medications
and the most important one Tumeric capsules
this has had a huge impact on clearing up my colitis recent flare up (which lasted 1.5 years)
- I try not to get my self so worked up, I relax a lot more now.
- I just mainly let it run it's course, which of course drains me and I have had to leave work before. The best thing is for me to just lay down, relax and do absolutely nothing (except go to the bathroom of course) I continue my medication, and use suppositories. I have no insurance so I am very limited on what I can do.

RECAP



I hope you can see how there are quite a few ideas that different UC'ers of the world have to get out of flares. There's also quite a few common thoughts and feelings behind what has landed some people in these flare ups. Stress is often one of the questions that many people wonder about. Can it really be a major factor? Does it play a significant role in UC flare ups? Those are all great questions. We're going to get into a whole survey about stress in just a little bit so there's much more about that FOR SURE!

Hopefully you now have a great feel from the responses listed above, but please remember they are just a random sample of a few answers from the complete survey data. If you'd like to read all of the participant's responses to this entire survey, you can do that at this link: [Triggering and Coping with UC Flares Survey Results ONLINE](#).

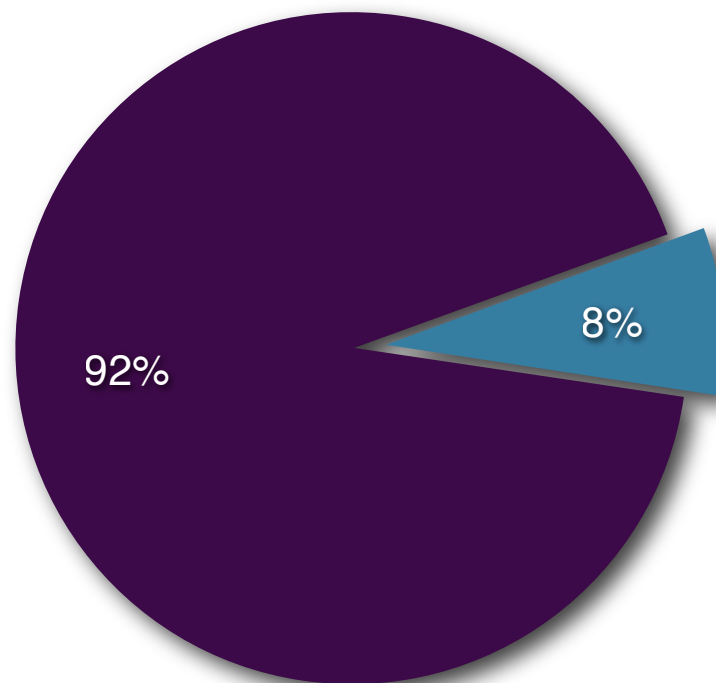
Topic 2: Colitis and Stress

data collected August 2012, 151 people participated

Question 1:

Do you believe that stress affects your ulcerative colitis?

● Yes ● No Sure ● No (Zero "No" Answers)



Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online here: [Colitis Stress Survey Full Results](#))

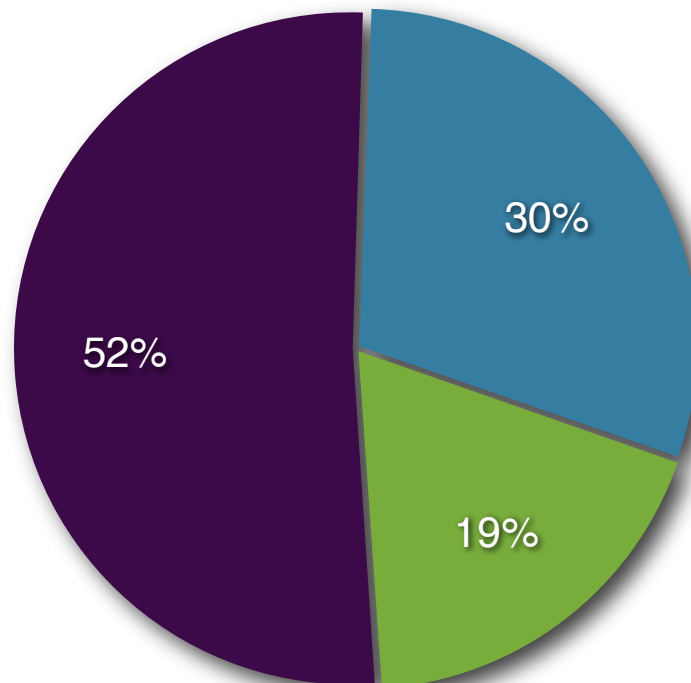
- My first flare was at a very dark time in my life. Other flares rates to major life stressors

- I have been through a marriage break-up. In the most stressful parts my UC was worse, when things settled, so did the UC. Earlier before I was diagnosed, I had been through a very stressful time with a miscarriage and family illness and deaths. There definitely seemed to be a correlation.
- I just notice that when I'm anxious or worried, I don't necessarily run to the toilet but I feel like I could, I get the sensations of wanting to go for a bowel movement, for example if a loved one isn't feeling well, straight away I get all knotted inside & often will pass wind.
- Stress used to literally take over, now all I have to do is take a step back and let it walk by. No use worrying really, things could get better the next day.
- Stress was the main reason for my last flare up. It also causes my pulse to race which I can feel pounding in my gut. There is a vicious cycle in that stress makes the UC worse and then that makes life more difficult which is more stressful!
- I can trace every flare to a period of either intense physical or intense mental/emotional stress, or a combo of both.
- Stress triggers bad eating habits which seems to trigger my episodes. Its a circular effect. Also, I used to exercise rigidly. That seems to trigger it too now.
- I was a graduate student when I was diagnosed, the week of my thesis defense I thought I was going to have to schedule breaks into the defense!
During stressful times my symptoms (usually just cramps) come back even when I'm in remission, if I'm not, then heaven help us.
- When I went into my biggest flare ever I was dealing with breakup from my fiancé, moving back home and a ton of other stress like work, I'm a teacher.
- It can become a cycle...I get stressed out, then I worry about my health, then I don't sleep as well, and the stress creates a domino effect health-wise. For me, a lot of stress management is how much control I have of the source of your stress.
- Absolutely! Without fail, if I'm having a particularly stressful day, I feel it in my stomach (and colon). I also feel its more difficult for my body to heal when I'm stressed.
- Including seasonal stress - like exam time in the spring and start of school time in the fall; holiday time; etc.
- Graduate school stress and depression, I believe, contributed greatly to my most recent flare.
- Well, I do find that when I get worked up, either angry or emotional as such, that tension seems to worsen, joints flare up and muscles tighten. These are symptoms of the UC, but I have found that just maybe it could be related.

Question 2:

Do you think you handle stress well when it presents itself in your life?

- Sometimes
- No, I have a hard time with stressful situations
- Most of the Time



Question 3:

What's an example of a stressful situation you've recently faced, AND HOW did you get past it?

Below is a small sample of some of the full responses from survey participants:

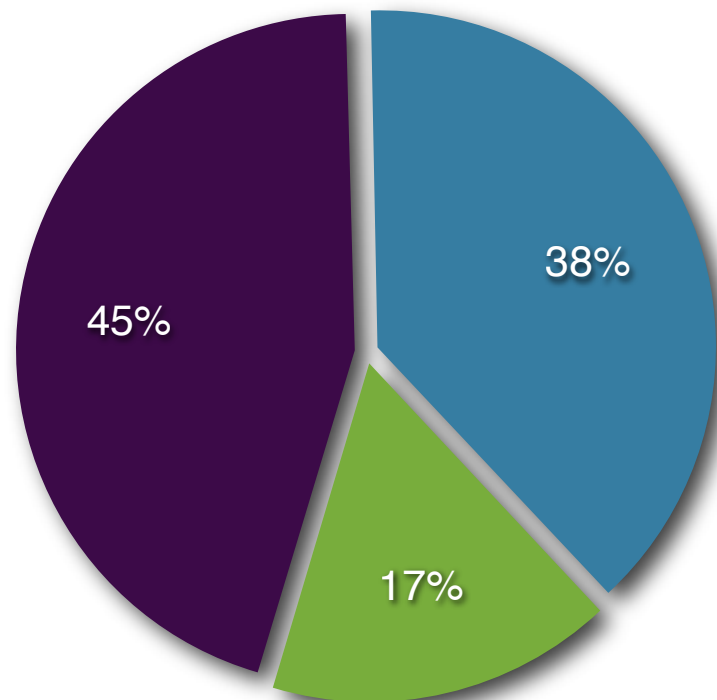
(the full survey can be viewed online here: [Colitis Stress Survey Full Results](#))

- Dealing with people at work. I got around it by taking anti-anxiety pills.
- I practice mindfulness on a daily basis. This helps me manage every day stress as well as more significant stress.
- I found trying to complete my Masters whilst working full time very stressful. I took a year off to focus on my health and now I completing it, however purchased leave so that I can take 1 day off a week to focus on study, it also helps me do the things I need to for my health like appointments etc.
- Selling our condo and buying a house required my family (including my two young daughters) to move in with my in- laws for 3 long weeks. Very stressful situation. I took a lot of long walks, quiet time alone (reading books, listening to music), and vented to my poor husband as needed.
- Moving to another state with 2 small kids. I got past it by staying present and trying to listen to my body. Also started a yoga practice.
- Just everyday stresses with my partners grandmother being sick, and worrying about general things like uni and feeling crappy. I got past these by just trying not to worry and taking some 'me' time, such as watching a movie
- I had a very stressful situation at work where I was asked to lie to customers and it put me in an unethical and non-compliant situation. Of course because I wouldn't do what the manager asked me, the situation became extremely stressful and I became very ill. I lost bowel control at work and was so sick I went on disability. I am still struggling and trying to get myself healthy. I try to get rest, do yoga and I am going to therapy.
- Hubby's job has us moving. Third move in three years. I meditate to get past it, and it works.
- I had a lot of bereavements, a relationship end, new emotional job, recent diagnosis etc. In the end I saw a counsellor to help me get through it and I now feel my thinking has changed and I have new coping strategies.

Question 4:

Are your doctor's appointments/doctor visits stressful for you?

● Sometimes Yes, Sometimes No, just depends ● No ● Yes



Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online here: [Colitis Stress Survey Full Results](#))

- It depends on how I'm feeling at the time. I was with my GI monday and I was feeling stressful as I was in a flair and felt yuck! I also feel that I want to get on top of my UC and can feel that the more I talk to my GI the more I'm taking up his time. I do know that he is there for me and is concerned about my condition. He does come from a more academic perspective. I can sometimes walk away feeling like I have more I wanted to know.
- Most doctors do not listen. Just want you to follow the cookie cutter protocol.

- Sometimes I feel stressed about possible outcomes prior to visits but I have an excellent specialist who is the most cheerful man of earth! He is very good at explaining things clearly, giving a realistic view and making me feel I am being treated as an individual and not a number,
- When I have been feeling awful I tend to get upset when im at the doctors, when Im feeling good Im all smiles haha.
- My consultant is friendly, listens to me, is calm, reasonable and I'm very lucky.
- They used to be. I would cry and get overwhelmed in my appointments but then when I started getting into natural medicine and acupuncture I've had an easier time with my doctors because I've realized that I can control how I feel and I need to take measures to eliminate stress and help myself feel better by looking at lifestyle changes. And I feel lucky enough to have found great support including acupuncturists, natropathic doctors who help with nutrition and other lifestyle issues.
- I get anxiety before most appointments. Sometimes I feel as though I have to plan my whole life around visits to the doctor.
- Being 23 and just having to deal with being sick and going to the doctor is stressful in itself. The bill comes and that is stressful too! However, when I have been doing well for several months (like now) and I just have to go for a refill, it doesn't seem so bad.
- Depends who I'm seeing, the GI nurse is sympathetic however the consultant stresses me because I find it embarrassing talking about all my problems, especially as he doesn't understand the impact for a young female adult and I don't agree with everything he says. It would be nice he understood the psychological aspects as well and could recommend a workshop on how to control stress etc.
- Since I switched to a natural doctor that gives me hope and inspiration when I see him, I have been less worried to see a Dr.
- My new doctor feels some of the anxiety that goes along with uc is mental, I just don't think someone who hasn't lived daily with hemorrhoids for over 2 years can fully understand the mental exhaustion UC can create, so I sometimes leave thinking its all in my head but I know it's not
- I love my doctor he is really good. The only constraint is time factor, I am a professor and research, teaching, committee work, speaking appointments etc. demand a lot of time.
- Sometimes they are just routine and sometimes I worry about the results, particularly if I haven't been feeling great and have had a UC flare up, I find it quite distressing. Its never pleasant hearing that the medication you are on is not working and you need to change it: or the medication you are on is working for the UC but causing other problems.

Question 5:

Are there any particular UC symptoms that you think are "more" related to stress compared to others?

- Frequency and urgency increase when I am stressed.
- Usually if I'm stressed, i get a lot of 'movement' and noise coming from my sigmoid/colon
- Diarrhea
- Blood. I always start having blood when I am stressed
- Cramping
- Bowel urgency and the inability to find a vacant public restroom at the critical time.
- No, all of them appear.
- Nausea, upset stomach, loose bowel movements
- This last year I have started to get really bad joint pain. For a 33 year old woman I feel like I am 200 years old and can barely get out of bed. And well, explosive diarrhea when bad elements combine - for example: not eating properly+having coffee or too much coffee +stressing and making my whole body tense+not exercising+not resting enough = all equals bad news. It's as though my nerves are in my large colon.
The joint pain is still new and I don't know yet much about it...
- No, I think they all go hand-in-hand.
- Burning sensation in my colon and bouts of diarrhea
- Diarrhea is 80% of the time related to my stress levels
- For me, I'd say the stomach pain/lack of appetite is related to stress.
- Lower back pain, increased bowel movements.
- I've noticed that when I'm particularly stressed, I can feel a flare coming on through the "colitis flu"-the aches, chills, and fevers that usually go away after a day in bed.
- Fatigue and cramping
- The cramping and pain - especially right after the bathroom
- Looseness and frequency of stools

Question 6:

Helpful thoughts on how you manage stress in your life:

Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online here: [Colitis Stress Survey Full Results](#))

- Take time for yourself, your no good to anyway if your not healthy.
- I believe that I need to get back into yoga and meditation.
Also a good old laugh can help.
Last Sunday I felt yuck, we were suppose to go to friends and yes I could have stayed in bed that would have been nice as I am a busy person. However I decided to go and just enjoy my friends and families company. My friends know that I have UC. It was good it just made me not focus on myself and we had a good afternoon. I just ate bland food and sipped on soda & lime.
- 1) Mindfulness - learn it, love it, live it!
2) Stop watching the news. I also avoid conversations with others about politics or other "heated" topics.
3) Be honest with yourself about what you can handle and how much time you have to do things others want you to do.
4) Get at least 7 hours of sleep every night and one nap a week.
- I think that a meaningful yoga practice will help with stress
- Don't feel bad for setting aside time all for yourself, if you need to get out of the house, just do it! don't feel guilty for feeling like you need a day off for watching a movie or sleeping in!
- Hot baths. Cuddles from OH and from my kids. Long walks. Apart from that I'd say I just 'don't' manage stress because it's not in my nature. Oh dear.
- Meditation has done wonders for me. Cleared up my symptoms.
- Make time for yourself, time to relax, time to do hobbies. Also don't take on everyones worries or least be able to support people then separate your mind from it. Most of all don't keep everything to yourself if you need to talk do it and if you feel you have none see a counsellor or ring a helpline.
- Take life with a grain of salt. Look at the big picture and realize everyone has something they have to deal with and this is just a short time and you can get through whatever is stressing you out, just like you have overcame things in the past.

RECAP



Stress. It always finds ways to creep into our lives, and that can make life miserable. However, there are ways to mitigate potentially stressful times without having your life turned upside down. I'm a firm believer that stress plays a significant role in our body's immune system response. As the world famous developmental molecular biologist Dr. John Medina points out in his book titled *[Brain Rules](#)*, the adrenaline and cortisol release that takes place when our bodies is stressed allowed our species to adapt and break away from life-threatening situations. (If we still had to face an angry lion on the plains of Africa, we'd all be happy as hell that our bodies pumped us full of adrenaline.) However, constant stress is something we should all try to avoid. Realizing what parts of life can be controlled and what other parts of daily life are out of our control is another method that I use to limit stress. And that simple thought process has been very helpful to thousands of others.

No matter who you are, you probably have a stressful life. And there is no reason to avoid that reality. Taking a few minutes to write down what stresses you have in your life, and then deciding what you can help to control is a simple activity that may also help you get past active colitis symptoms. It only takes a minute to pull out a piece of paper and brainstorm on the stress you face. And it has worked wonders for me. It may for you as well.

To read the full responses to Stress Survey, you can visit the [Stress Survey Online - here](#).

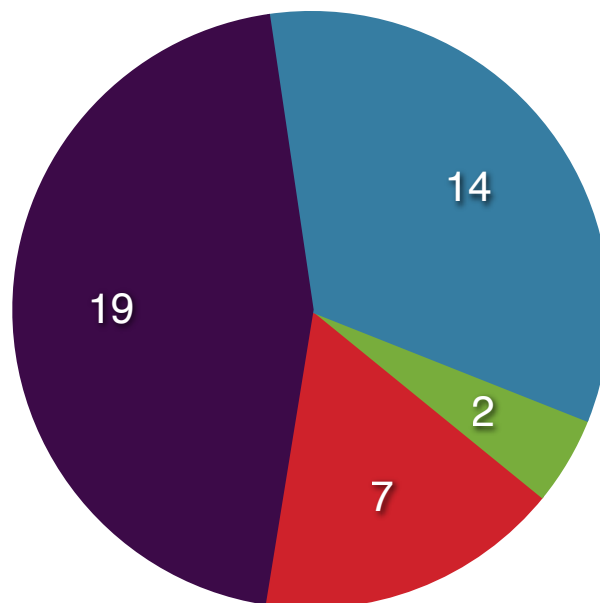
Topic 3: Prednisone/ Prednisolone

data collected September 2011, 42 people participated

Question 1:

Since You Were Diagnosed, what percentage of the time have you been taking Prednisone/Prednisolone?

The numbers in the graph below represent people who have been diagnosed with UC.



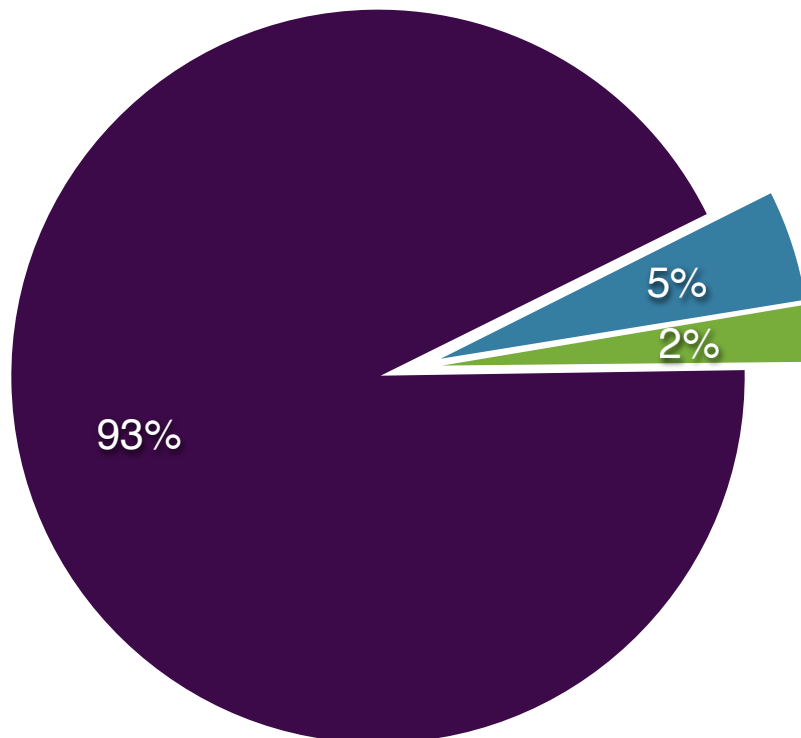
● 5-25% of time ● 25-50% of time ● 50-75% of time ● 75-100% of time

Question 2:

Did you Experience any Side Effects from the Prednisone/Prednisolone?

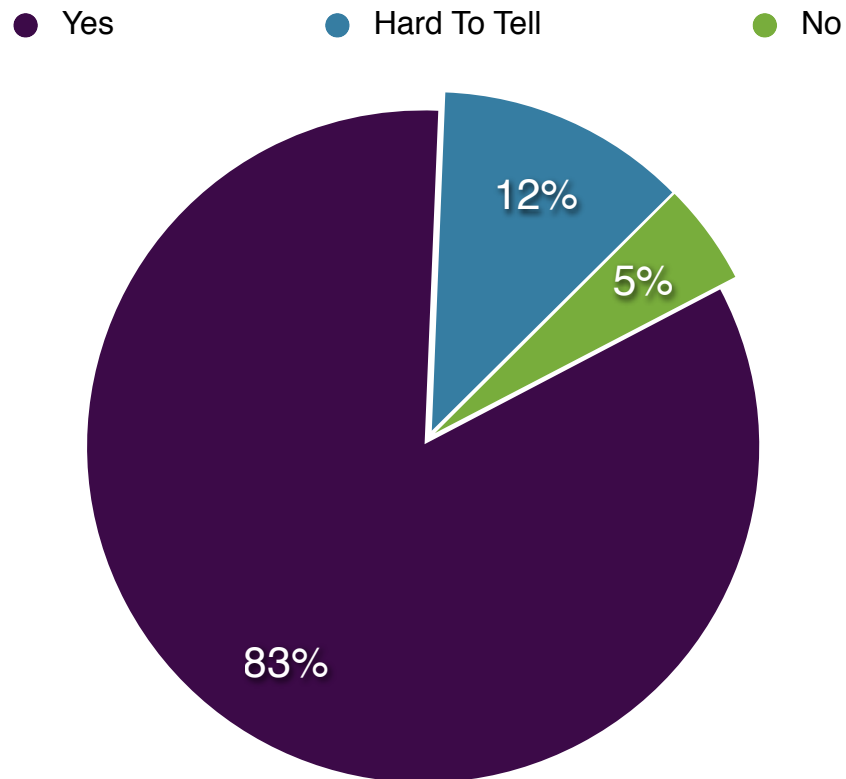
● Yes ● No ● Not Sure

The numbers within the graph represent UC patient's responses



Question 3:

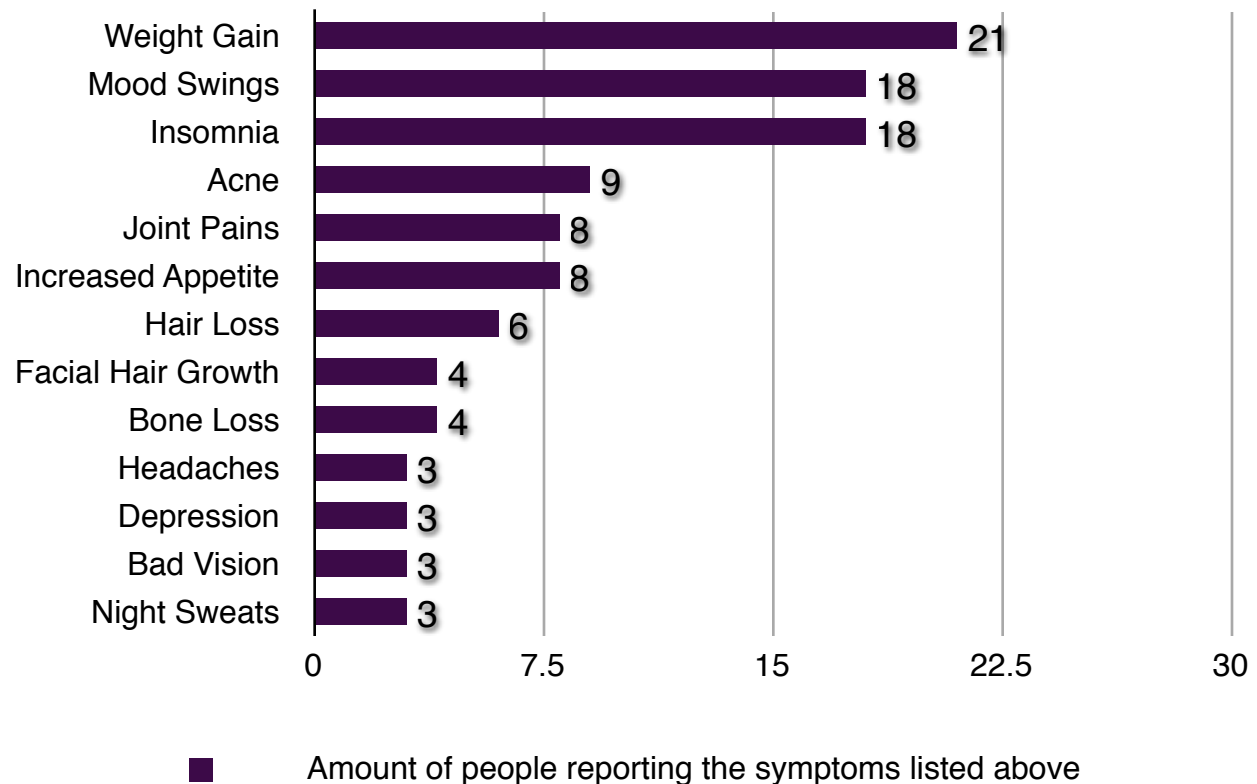
Did you Get "MOONFACE" the puffy head/face side effect from the Prednisone/Prednisolone?



Question 4:

If you experienced Side Effects from the Prednisone/ Prednisolone, what were they?

(People may have reported more than one side effect)



Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online here: [Prednisone/Prednisolone Survey Results Online](#))

- I had moon face, weight gain, emotional swings, night sweats and sleep problems.
- I feel like my vision is off. and of course my glucose is elevated
- I had roid rage, was very angry and moody. I imagined things and got paranoid.
- Moodiness (anxiety, anger, hyper) acne, weight gain/munchies, Lack of sleep AND too much sleep, bad dreams
- Joint pain, insomnia, irritability, hair loss

- Weight gain, 20 pounds in a month. Mood swings, pretty much turned a mellow guy into an asshole. High blood pressure.
- Extremely hungry and facial hair growth (not fun for a female)
- Anger, Sweating, Headaches, Blurry vision, Moon face
- Puffy face, insomnia, hyped, mood swings, increased appetite, blood sugar fluctuations, ie low blood sugar, hypoglycemia, changes in white blood cell count and glucose, sodium, fatigue, joint pains --- these are all pronounced at higher dose
- Facial hair got darker and thicker, acne, weight gain
- Bounding heart rate, irritability, mood swings, increased appetite, weight gain, insomnia
- Bra lard, bingo wings, love handles for weight gain and turning into a pepperoni pizza (moon face and spots)... Well, a hyperactive pizza more-like.
- Hungry all the time but other than that, I felt great - arthritis joint pain went away. However, I did also experience bone loss.
- Makes me crazy! Don't even feel like myself. Jittery, can't sleep, mood swings, muscle aches, joint aches, MAJOR acne, hair growth, blurred vision
- Bad sleep patterns, bad skin, weight gain, mood swings, shakiness, muscle weakness, moon belly, weak ribs, feelings of personality change, lack of patience, need I say more!!!
- Some damage to bone structure (weakening).

Question 5:

If you experienced Side Effects from the Prednisone/ Prednisolone, did they go away?

Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online here: [Prednisone/Prednisolone Survey Results Online](#))

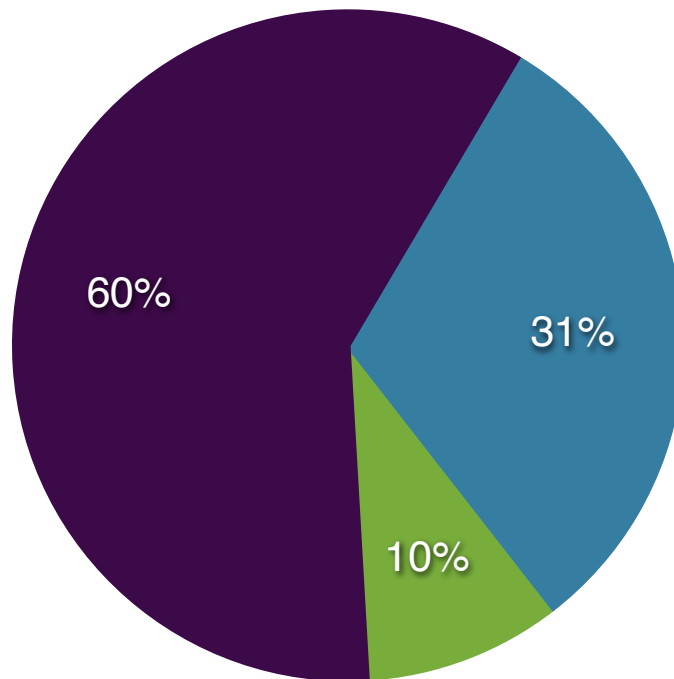
- Mostly everything went away, it took a long time to loose the "I want to eat feeling". I do still have to deal with the new hair growth.
- Yes, eventually.
- Yes because I am no longer on the drug.

- Yes
- As I weaned the dose down, the affects lessened. Once off it, they eventually went away completely.
- Yes, they did go away
- After some time yes.
- The side-effects lessened with decrease in dosage from the high dose, but they didn't go away entirely.
- Bones still crack, hips hurt, joint pain, others went away
- All but the facial hair
- They have slowly gone away
- All went away except I seem to have a permanent increase in acne and my skin texture is weird.
- Yes they went away when I got off it
- Yes, but it has been hard to lose the belly fat
- After the prednisone the side affects went a way but some still "haunt me" for example I gained 50 pounds and am still trying to lose it. I went from underweight to over weight and am now at the top of normal.
- All of my side effects went away after 2-3 months of being off of prednisone

Question 6:

Was the Prednisone/Prednisolone Effective in Treating Your UC?

● Yes ● Kinda, but not completely ● No

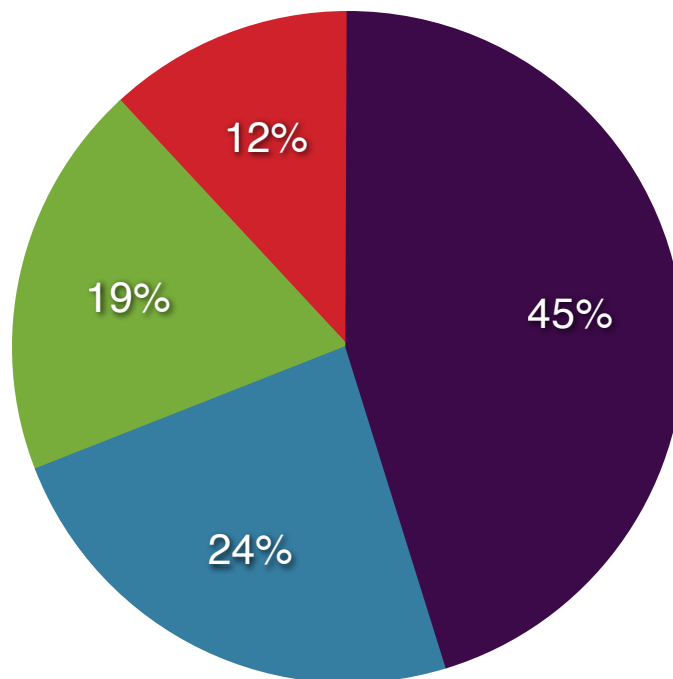


Question 7:

**If your doctor recommended Prednisone/
Prednisolone to you again, would you take it?**

- Depends on the situation, if I'm really sick with UC symptoms...maybe
- I would I guess, but I'd be scared as hell of side effects
- Heck No!
- Yes for sure

The percentage of people's answers are represented below:



Question 8:

Any Advice you can offer to others with UC who are taking or need to take Prednisone/Prednisolone?

Below is a small sample of some of the full responses from survey participants:

(the full survey can be viewed online here: [Prednisone/Prednisolone Survey Results Online](#))

- Be prepared... have a buddy who knows the symptoms and is willing to help you through them. Make sure you really like your doctor because one doctor might tell you, you NEED the prednisone. Where another might help you find the right plan to come off of it because of all the side effects that you'll get.
- Weigh out your options before taking a medication like prednisone. It is a serious drug that causes a lot of nasty, nasty side effects and you are going to have to determine if it is right for you.
- There are absolutely side effects associated with steroids. But I would rather have a moon face than spend my day passing mucus and blood. Vanity needs to take a back seat to health. Prednisone is an amazing drug for fast relief. It is something our bodies produce on their own anyway. Sometimes we just need a bit more help.
- I think everyone's experiences differ slightly with this medication. Not everyone has a bad reaction. I did, and a 10 year old friend of mine had similar side effects. It is not normal for a happy child like him to suddenly have such dark and irrational thoughts.
My advice would be to avoid it, but then, I haven't tried any other medications and they may also have bad side affects.
On the other hand... Prednisolone definitely helped me into remission!
- Try to get off the medication as fast as possible, I thought it was a miracle drug at first. I could work long hours, eat pretty much anything and have the occasional beer. Then came the weight gain, mood swings and food cravings. Coming off prednisone was hands down one of the hardest most painful things I have done in my life.
- It worked when other medications didn't so even though the side effects are nasty it was better than bloody diarrhea all day long
- Only take it if you absolutely need to, shocked when my doc told me people always ask for it must be the energy boost. And if your taking it use a calcium supplement.
- Hang in there. It's a horrible drug but it is a miracle drug too. Get as much support from loved ones when things are really getting to you. It's how I got through it .
- Be patient and follow Drs orders.

RECAP



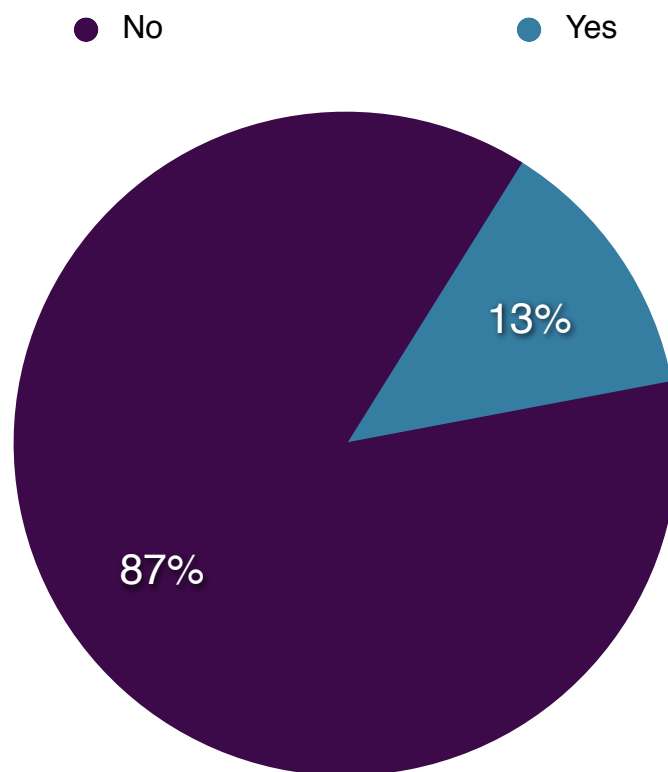
As you can see from much of the responses above, almost everyone has very strong feelings towards this medication. It is a very powerful medication, and like all other medications, it is one which you should be consulting with a physician or medical professional about before, during and after using. I myself have used prednisone/prednisolone steroids several times in my tenure as a colitis patient, and let me tell you, it's always a great big huge relief when I was finally off them. The full list of responses to this survey can be found online. Here's that link if you are interested in reading more: [Prednisone Survey Page](#).

Topic 4: Probiotics

Data was collected in February of 2012, 129 UC patients participated in this survey

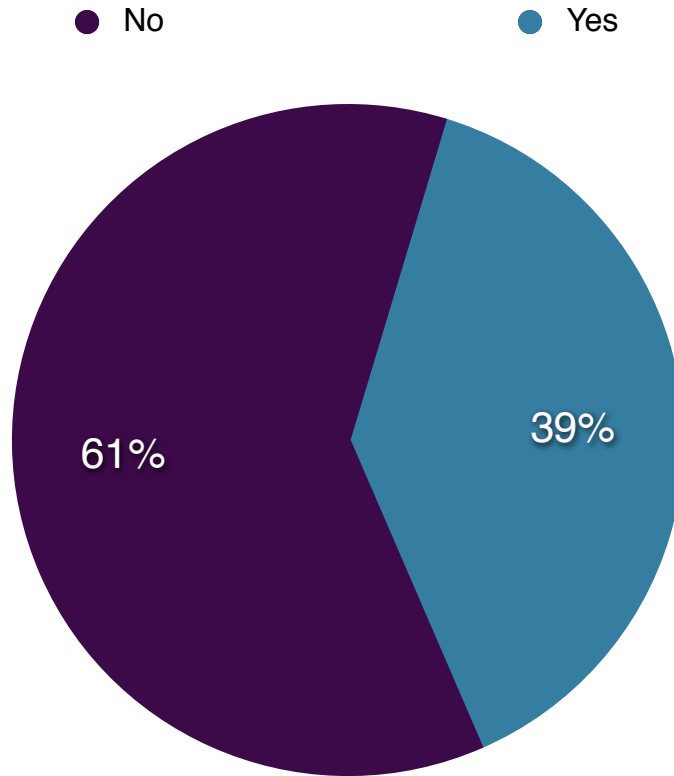
Question 1:

Did you take probiotics *before* you were diagnosed with UC?



Question 2:

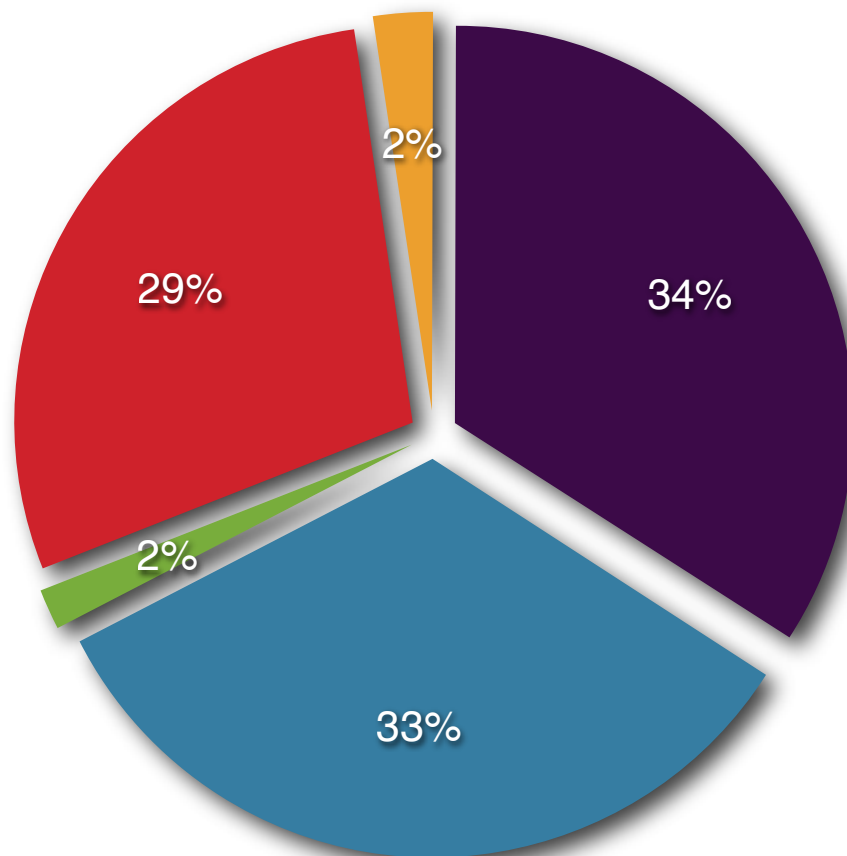
Did your doctor recommend for you to take probiotics?



Question 3:

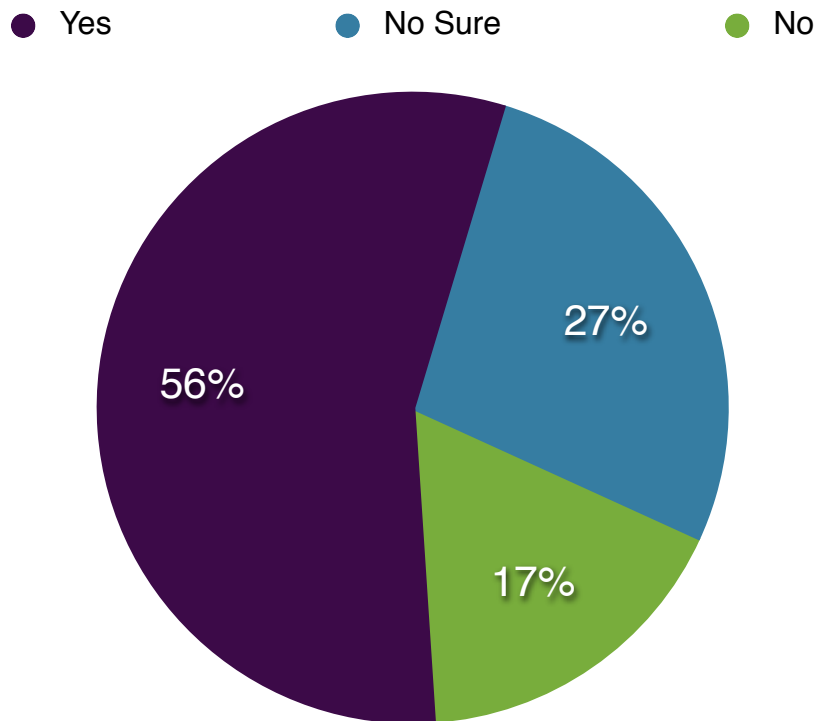
Overall, Did/do Probiotics help with treating your UC symptoms?

- Not Sure if they were positive or negative
- YES - They helped more than I expected
- NO - They made me worse
- Yes - They helped a little bit
- No - they did not help me



Question 4:

Do you plan on using probiotics forever?



RECAP



Probiotics and whether UC patients should be using them or not has always been a very popular topic on the iHaveUC.com website for a very long time.

Not a week goes by where I hear from several UC'ers or their family members who are telling me how happy they are to have found probiotics.

I definitely don't anticipate that changing anytime soon. With such a high percentage of UC'ers reporting positive benefits from probiotic use along with other UC'ers believing their UC is in remission due to probiotics, it is a hard aspect of the disease to avoid.

Gastroenterologist offices around the world are even feeling the effects of probiotics. More and more of the doctors offices I've communicated with are beginning to tell me how there are marketing representatives from a few different probiotic companies reaching out to the gastro doctor community. So, as a little tip, you might want to ask your GI doctor if he/she has any free samples of probiotics lying around. You might be surprised if you are handed a sample to try by your doctor.

The link below is linked to the iHaveUC.com affiliate account with Amazon.com which almost always has the lowest prices for these types of products.

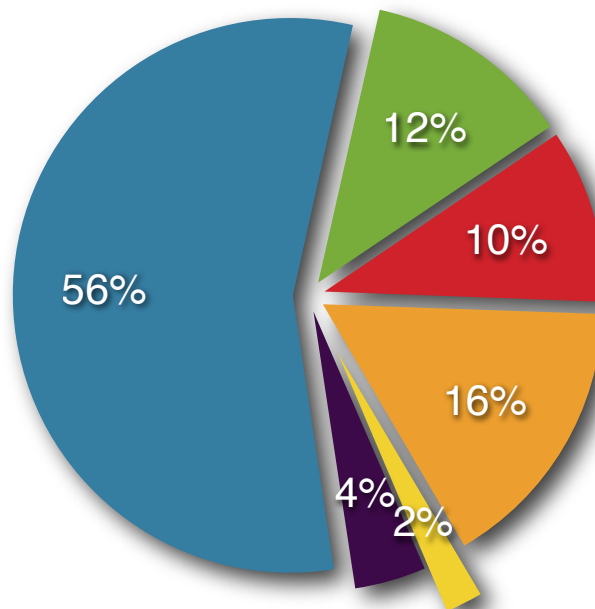
website link: [Full List of Probiotics on Amazon.com with Customer Reviews](#)

Topic 5: Relationships and UC

Data was collected October, 2011, **50 people participated in the results**

Question 1:

How many relationships have you been in since being diagnosed?

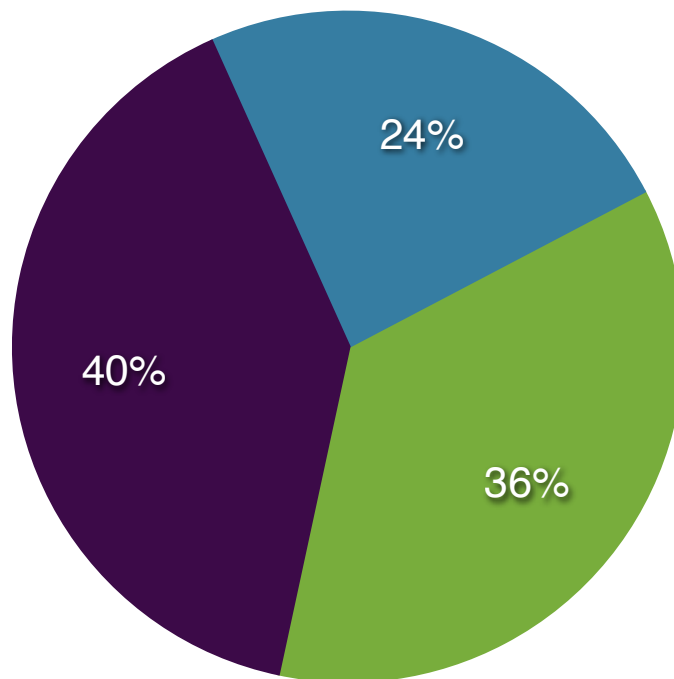


● 0 Relationships ● 1 ● 2 ● 3-4 ● 5-10 ● 10+

Question 2:

Were you in a relationship when you were diagnosed with Ulcerative Colitis?

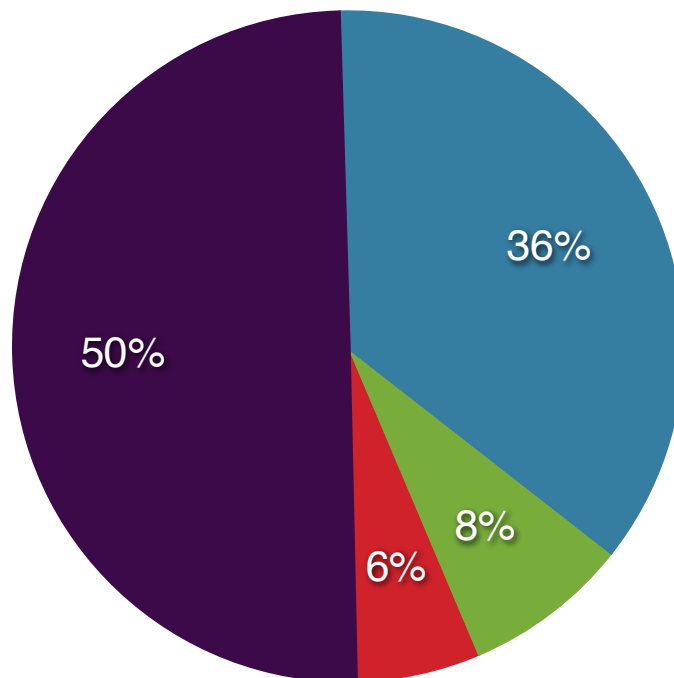
- Yes, and I am still in that same relationship
- Yes I was, but I am NOW finished with that relationship
- No



Question 3:

In your most recent/current relationship, how open/honest were you with your partner about your symptoms?

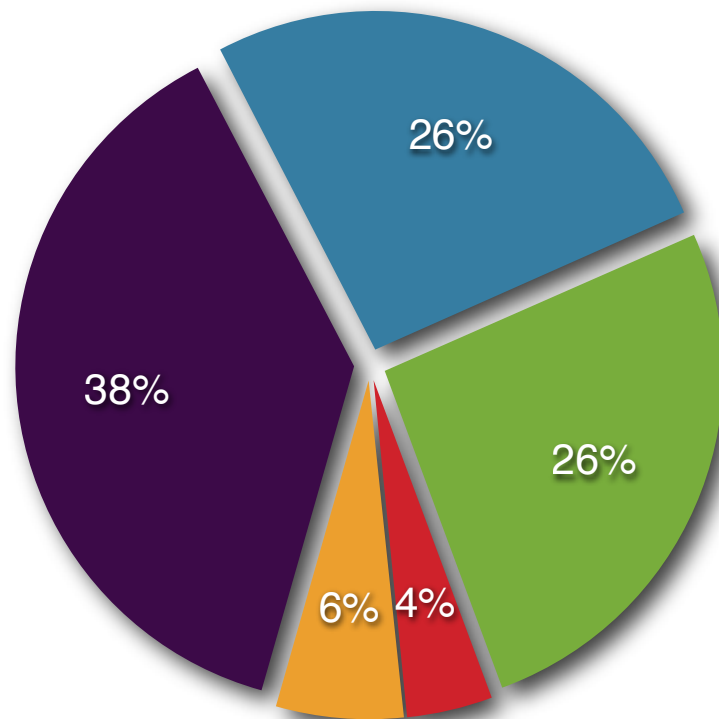
- Almost completely, but I would still hide a few things sometimes
- 100% open book, I would leave the bathroom door open all the time
- I really only would say that I have a sensitive stomach, and just need the bathroom
- None of the above



Question 4:

**How much of an effect did your Colitis Diagnosis/
Symptoms alter your Intimate Moments?**

- A Little bit less intimacy
- Much less Intimacy
- No change in "Sex Life" moments with my partner
- Call me crazy, but this part of the relationship increased in volume
- none of the above



Question 5:

What has been the hardest part of living with colitis and trying to maintain a relationship?

Question 6:

Have you ever felt like you have failed your partner because because of your colitis? If yes, Why & How?

Question 7:

What suggestions would you give to other UC'ers who are in or trying to start a relationship?

Question 8:

Is there anything else you would like to add about Ulcerative Colitis and Relationships from your perspective?

The answers to the 4 questions above can be found in their entirety on the full survey results page: <http://www.ihaveuc.com/relationships-and-ulcerative-colitis-50-person-survey/>

RECAP:



Relationships are important. They most definitely are. And, for many people who are living with ulcerative colitis, communicating with your significant other(s) is often an on-going process. As you can see from the survey results, there is a wide range once again in how people have decided to handle this aspect of life. Like many parts of this disease, UC patients don't always agree on everything, and that is perfectly fine.

For me, I have benefitted and learned from living two totally separate lives. One when I was a pre-diagnosed UC person hiding all the symptoms from my wife. And the complete opposite was true once I finally had my diagnosis. I think its safe to say that there were times during my severe UC days when my wife (and other family members) might have been amazed at how many details about my UC I was constantly sharing. For me, it was a relief to share the breaking news from the bathroom.

Every UC patient is no-doubt entitled to handle this in his/her own way, and I applaud anybody who decides to talk openly about UC symptoms to those you are in a relationship with. I truly think it helps out the overall healing process by communicating to others the details of what is happening when you are not feeling your best.

Conclusion:



I hope you learned a ton of things about ulcerative colitis. That is exactly what this free ebook was designed to do. Some of these topics are very personal, and others are simply not talked about very often. So, feel free to print this book out, and leave it sitting around your bathroom if you like, or heck, share it with your co-workers or friends.

Ulcerative Colitis is a difficult disease to come to terms with. There were many times where I would lie in bed asking myself so many questions. But those days have passed. And I hope that those days have passed or will very soon for you as well.

Just because this introductory ebook is finished, does not mean you won't hear from me again. There are quite a few messages I want to make sure you read, and I'm sure there will be lots of news in the coming weeks and months on the www.iHaveUC.com website that you are welcomed to catch up on.

I post stories from other UC'ers almost daily, and because you are now part of the website's newsletter, you will have the opportunity to participate in future survey's when they are announced.

If you have some specific questions, whether they are about strange side effects, or medications, or anything else related to UC, I'd encourage you to use the search functionality from the website. There are now tens of thousands of comments from other people and over one-thousand personal stories I've posted over the years. And all this information is for people like you to take advantage of.

If you want to learn more about my complete story of life before, during, and after my diagnosis, what I eat, what I don't eat, and how I became medication free, you can order my complete [Colitis Package eBooks](#) (*Feeling Crappy to Feeling Happy & Cooking for Ulcerative Colitis*) which are also available on the site.

Final Thought:

If you, or someone you know is in the middle of a never-ending flare up right now, I can assure you of one thing - it will end. Flares do not go on forever, and it too will pass.

-Adam Scheuer

founder of iHaveUC.com