

The Impact of MG in Your Life —

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In July 2016, MGFA conducted a patient survey, The Impact of MG in Your Life. Six hundred and eighty-one people responded although not everyone answered every question. Respondents followed a predictable pattern on age. Less than 1% were under 12 years old with the percentages going up for each age group. Only 9% were between 18 and 34 years old; while 50% were in the 55 to 75 year old category. Forty percent were male, while 60 percent were female. They responded to several important questions and many provided their story or in-depth viewpoint on the issues.



The MGFA will use this information in its advocacy activities with a goal of helping leaders within the health research funding and drug approval arena, primarily the NIH and FDA, to better understand the struggles faced by MG patients.

This information will also help us

to be more inclusive in how we talk about the disease so that what we say realistically portrays the impact of MG on people's lives.

Here's a synopsis of the results:

1. Does your MG regularly interfere with one or more aspects of your life, e.g. walking, talking, working, and socializing, despite your treatments? 80% said yes while 20% said no.
2. If you replied yes, how often do you experience significant symptoms? 46.6% said every day; 29.5% said most days; while 23.9% said at least weekly.

3. How severe are your symptoms? 2.7% said very severe; 18.2% were severe; 49.4% were moderate; 22.1% were mild while 7.5% were not severe at all.



4. How satisfied are you with your current treatments/medications? 8.2% were not satisfied at all; 23.5% were somewhat unsatisfied; 26.2% were somewhat satisfied; 19.5% were satisfied; and 22.5 were very satisfied.
5. Do you experience side effects from your medications or treatments? 70.4% said yes, while 29.6% said no.
6. If you answered yes, describe the impact of your medications side effects on your life? 7.3% said little or no impact; 4.06% fell between "little or no impact and annoying but manageable;" annoying but manageable received 51.3%; while 18% fell between "annoying but manageable" and "significantly impacts;" finally 19.3% chose significantly impacts my day to day activities.
7. Have you experienced long-term impacts on your overall health as a result of your medications/treatments (i.e. development of other conditions known to be risk factors for certain MG medications/treatments: diabetes, bone deterioration, glaucoma, liver or kidney damage, other? 45% said yes, while 55% said no.
8. If yes, describe their significance. Little or no impact 8.7%; between "Little or no ..." and "Concerning but manageable" 5.49%; Concerning but manageable 46%; between "Concerning ..." and "Major Impact" 21.4%; Major Impact 18.21%

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9. How many kinds of medications/treatments have you tried?
One 13%; Two 19%; Three 24%; Four or more 44.2%
10. How does MG affect your life? See the table...

Many patients took the time to share their experiences and feelings about MG and its impact on their lives. Here are some sample comments:

- We seldom spend time with friends. They have stopped inviting us; I guess due to me having to decline invitations on occasion due to my health issues.
- I've learned it is best for me to do 10-15 minutes of exercise 4-5 times daily.
- I appreciate I live in America & the freedom I have to make decisions. I appreciate I have health insurance & feel great sadness for those not as fortunate. I am very thankful &

appreciate my family & friends so much more. I can actually feel the love from others and their concern.

- The most difficult thing about MG is the fact that I look completely normal.
- MG has helped me to live life to the fullest every day.
- I am unable to drive, work, have a normal life. It's nothing close to manageable. And it's upsetting when I see you list it as such on your website.
- I was diagnosed with MG two years ago. It changed my life drastically! My husband & I live alone and he is my ROCK! Last year he was declared legally blind; therefore making me the primary driver. Another big challenge but with lots of love, patience, & a sense of humor we are learning to deal with "Our New Life." This is definitely not a choice but learning to make the BEST of what we have been given & we want to make "Our New Life" the best it can possibly be!
- I had to quit my job and go on disability so I can no longer support myself.

	Extremely	Moderately	Not at all
Your family life	22.01%	57.34%	20.66%
Your work life	45.21%	33.75%	21.04%
Your ability to function in general	21.71%	63.02%	15.27%
Your ability to walk	21.01%	50.37%	28.61%
Your ability to talk	9.00%	48.73%	42.28%
Your ability to drive	16.06%	35.76%	48.18%
Your ability to do housework	25.86%	49.48%	24.66%
Your ability to exercise	45.77%	40.12%	14.12%
Your ability to eat	8.79%	49.63%	41.58%
Your ability to breathe	10.33%	47.01%	42.66%
Your ability to get out of bed	7.54%	43.29%	49.17%



- The most difficult thing with having MG would have to be not knowing whether you going to have a good day or not. Most days I'm fine, but others I just feel as if I have no energy. Also giving up sports for a while was extremely hard for me. I've been playing sports since I could walk, but if it wasn't for basketball I would have never known I had MG.
- I went from a runner to someone who couldn't dress himself.
- I really don't want sympathy but it would be nice for others not to trivialize my disease as something that their doctor can cure or something vitamin C would cure.
- I am unable to both converse with a friend and share a meal without severe dysphagia and hand weakness.
- MG has slowly restricted my life. As if my world keeps shrinking.

- It took a while and an exceptional MD to find a medication balance that worked for me.
- The hardest thing about MG is that others don't understand the disease.
- The most difficult is loss of independence.
- It took 3.5 years to get diagnosed. I am 8 years old. ... I should be a normal kid out playing; instead I have to watch the amount I play...
- There are days where leaving the house seems insurmountable. But I'm a mom and a wife and I don't have the option to let MG win. I fight through the symptoms and [work with] the doctors to find the best treatments for me. It's frustrating to have so few options and lack of understanding about a disease that affects my daily life. A disease that has changed so much for my family. So for now I live with MG and it's a roller coaster in my life.

Stay tuned for a fuller report from the survey when MGFA will alert the community through an E-blast and our Facebook page.

In the meantime, thank you to everyone who took the time to answer the survey. We deeply appreciate your sharing.