

# What 60,000 People Living With Multiple Sclerosis (MS) are Saying About MS Disease Modifying Treatments (DMTs), and What It Tells Us About Opportunities to Improve MS Care

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## Conclusions

Understanding the range of symptoms and the impact of MS on respondents’ lives will better allow medical professionals to treat the individual holistically, and not just the disease itself. Additionally, helping patients understand MS progression will allow specialists to set realistic expectations for treating the disease and to help their patients better prepare for the future.

## Background

People with multiple sclerosis (PwMS) value treatment discussions with their healthcare provider (HCP), yet significant education gaps exist for patients to start and remain adherent. To fill educational gaps on DMTs, many seek perspectives of other patients with first-hand experience by connecting on patient social networks. Often, PwMS provide greater detail with other patients than they have the time or comfort level to share with a HCP. Directly understanding the key challenges, concerns and habits of PwMS is crucial to improving tools and resources to help better manage MS and stay adherent.

## Objectives

Through one of the largest MS social networks, our objective was to further understand what topics related to DMTs were most important to PwMS and how they talk about, perceive, and report their experience with the DMT.

## Methods

Retrospective research was conducted on organic discussions within MyMSTeam.com, a social network >76,000 people diagnosed with MS. From January 2015 to April 2016, 3,300 verbatim comments were anonymized, coded, categorized, and analyzed in a rigorous manner by key themes. Analysis focused on 12 DMTs and discussions were overlaid with patient self-reported data on gender, age, date of diagnosis, MS type, current DMT and effectiveness ratings.

## Results

Analysis provided critical insight and identified obstacles in DMT treatment, from obtaining a prescription through remaining on or stopping therapy. Treatment was most often stopped due to AEs. (Figure 1) Overall, the top topics were side effects experienced (35%), reasons for stopping treatment (19%), perceived efficacy (18%), questions, hopes and concerns about starting a new DMT (18%), the “rituals” to mitigate side effects (6%), and insurance/financial hurdles to getting on or staying on treatment (4%). Injection-based DMT conversations were more focused on side effects and how to avoid them. Infusion discussions were more focused on getting on treatment and issues related to PML. (Figure 2) Members describe DMT effectiveness in multiple ways, from slowed lesion growth to increased energy and mobility. (Figure 3) For Tysabri® (natalizumab), the most common topic discussed was “energy” experienced post infusion at about day 14 and then reports of increased fatigue days prior to the next infusion and extreme fatigue day of treatment. (Figure 4) Patients who experienced tolerability issues with the DMTs shared their own experiences and perceptions on how to manage through these issues. The flu-like symptoms with interferons and GI effects with Tecfidera® (dimethyl fumarate) were the most commonly reported. Even when mitigation strategies were not published or where nurse training was not provided, the patient community themselves arrived at remarkably common themes and practices based on their own experiences and perceptions. (Figures 5 and 6).

Figure 1) Stated Reasons for Stopping Treatment

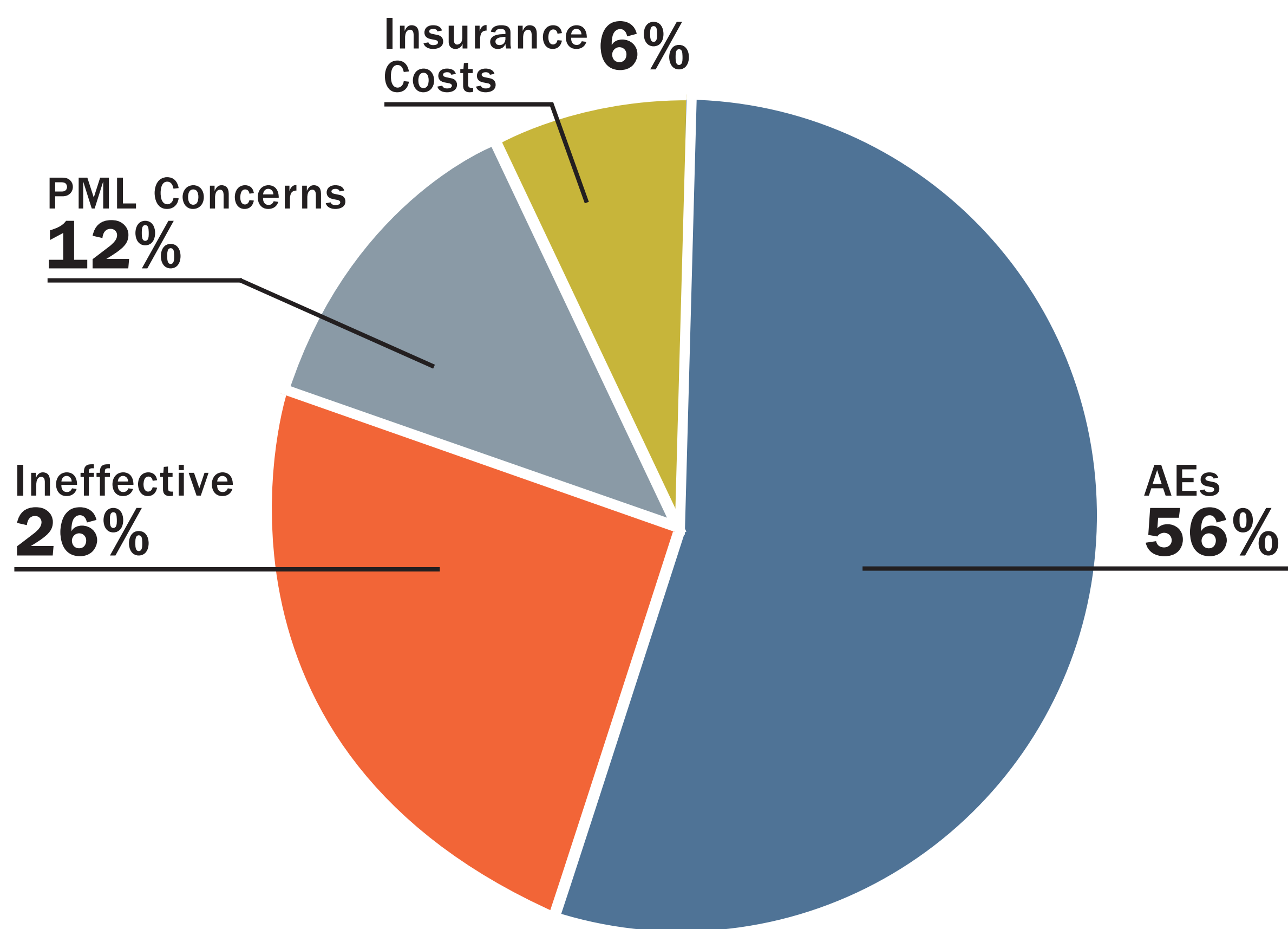


Figure 2) Discussion Topics by Treatment Type

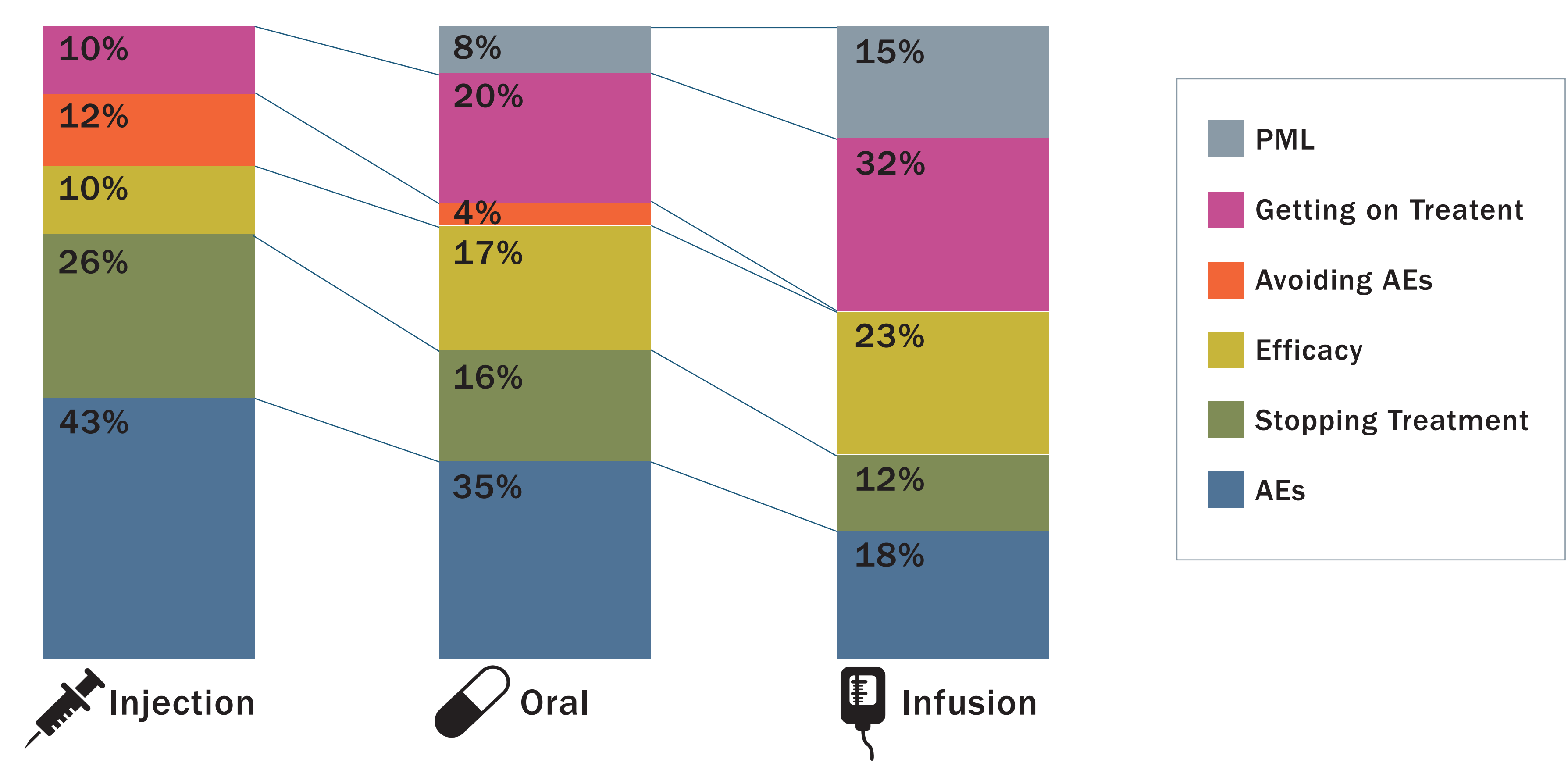


Figure 3) How People Living With MS Discuss Effectiveness

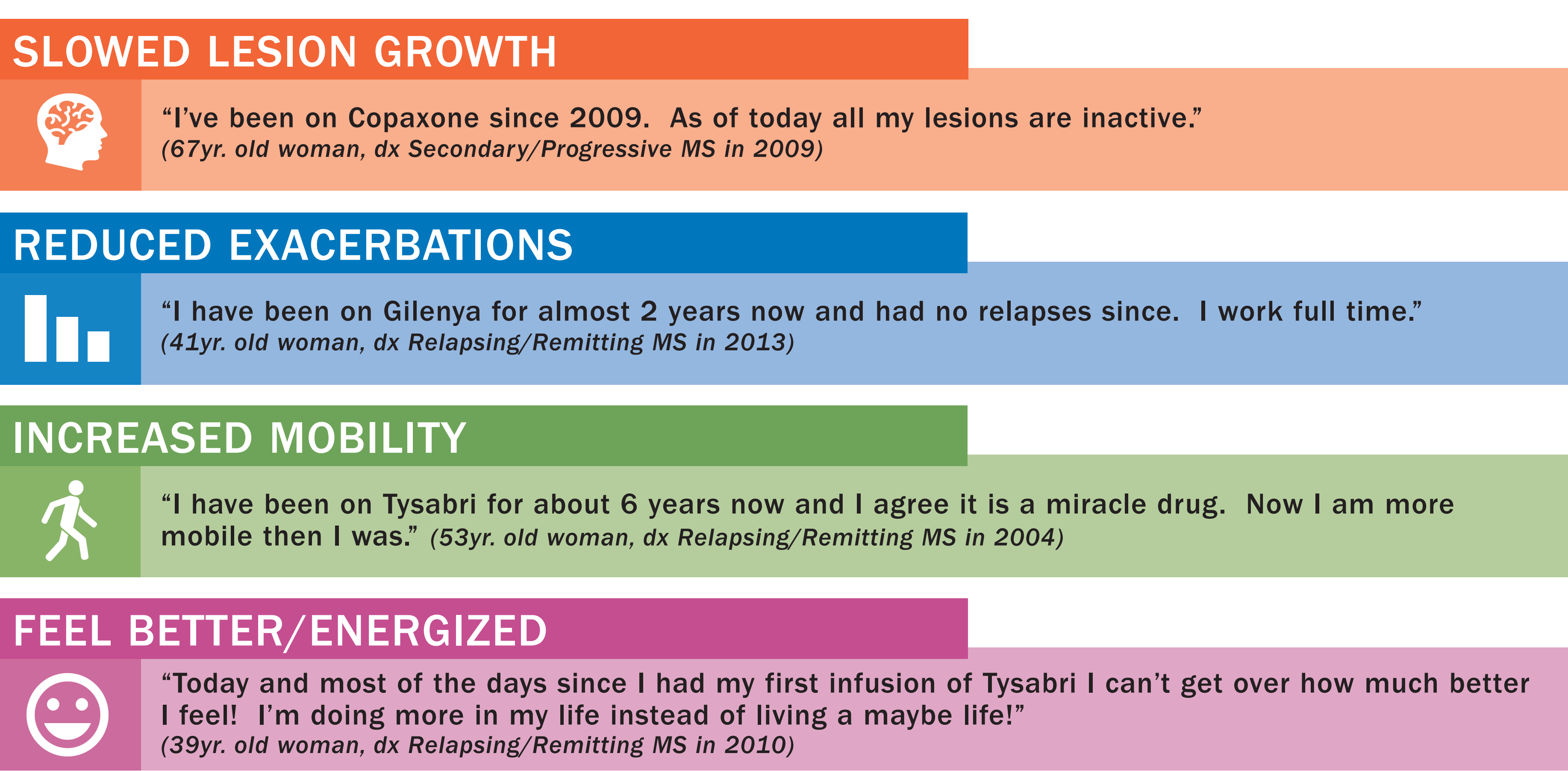


Figure 4) Patient Described Energy Cycle With Tysabri® (natalizumab)

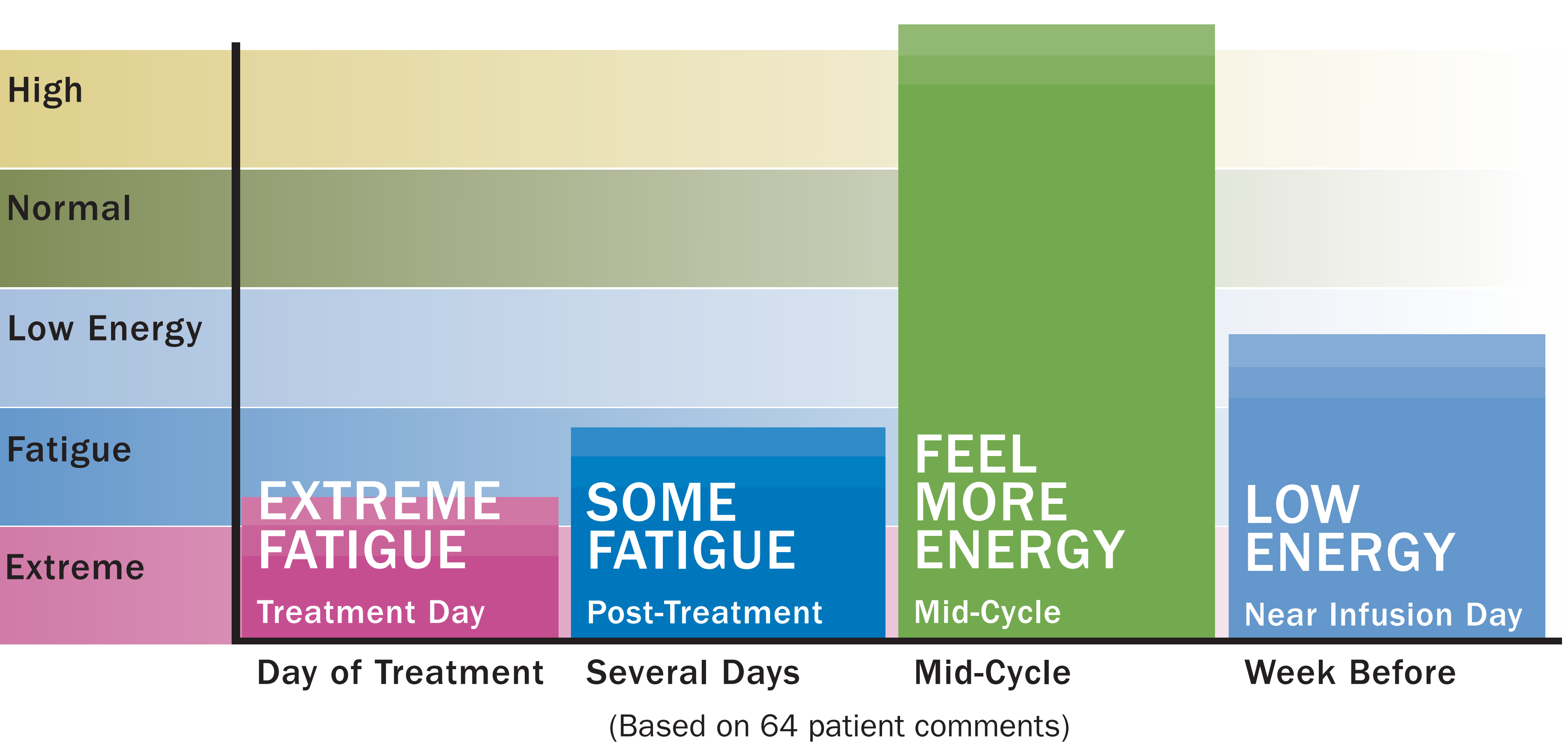


Figure 5) Patient Perspectives on Rituals for Mitigating Tecfidera® (dimethyl fumarate) AEs



Figure 6) Ritual for Staving Off Interferon AEs Based on Patient Discussion and Perceptions

