Women Expressing Fibromyalgia’s Effects on their Everyday Lives (WE FEEL)

A National Survey
INTRODUCTION

Fibromyalgia is a serious condition that has a profound and negative impact on patients’ lives, including their daily activities and relationships. Unfortunately, most patients may not receive an official diagnosis for anywhere from a few months to more than five years after they first experience symptoms. However, if diagnosed earlier, fibromyalgia may have less of a negative impact on day-to-day activities. Getting treatment and support also helps improve a patient’s overall day-to-day life.

New results from Women Expressing Fibromyalgia’s Effects on their Everyday Lives (WE FEEL), a national survey of female fibromyalgia patients, illuminate the private, prolonged, and often agonizing physical and emotional struggles that women with this condition face. The survey also reveals constructive and concrete ways patients can help ease their suffering and feelings of isolation, including an earlier diagnosis and access to information and support.

SURVEY OVERVIEW

HealthyWomen, the nation’s leading independent source of health information for women, commissioned Edelman StrategyOne to conduct a 20-minute survey among 508 diagnosed, female fibromyalgia sufferers in the U.S. The survey was sponsored by Forest Laboratories, Inc.

Key objectives of the survey were to better understand:

- Patients’ perspectives on the diagnosis and treatment processes
- Relationships between fibromyalgia patients and their healthcare professionals (HCPs)
- The impact of fibromyalgia on patients’ day-to-day lives
- Types of support – from people to resources – that patients need or have successfully used

SURVEY DESIGN

Edelman StrategyOne, using the field services of Harris Interactive Service Bureau, conducted online surveys with a total of 508 adult females who have been professionally diagnosed with fibromyalgia. The 20-minute survey was fielded between May 5 and May 11, 2010.

The findings are nationally representative of diagnosed, female fibromyalgia sufferers in the U.S. The total sample of 508 yields a margin of error of ±4.4% at the 95% confidence level, which means that 95 out of 100 times that a sample of this size is drawn, the results will not vary by more than 4.4 percentage points in either direction. The statistical significance is reported at the 95% level.
EXECUTIVE SUMMARY

Fibromyalgia is a significant burden on patients

Nearly all patients (86%) who suffer from fibromyalgia rate their symptoms as moderate to severe.
- Nearly half (48%) rate their symptoms as severe and most (85%) consider fibromyalgia a burden on their lives.

Patients with fibromyalgia report a variety of symptoms with the top ones being widespread pain, sleep disturbances, and stiffness.
Many patients face skepticism

- Sixty-four percent are concerned about their fibromyalgia being taken seriously.
- Nearly four in five (79%) look for fibromyalgia healthcare professionals who will "take their symptoms seriously".

Most patients suffer undiagnosed for years

Most fibromyalgia patients experience a delay between the time they first experience symptoms to the time they're properly diagnosed by a healthcare professional.

- Only 19% were diagnosed immediately.
- For more than half of sufferers (54%), diagnosis took a year or more.
- For one in four, it took five years or more.
The top reasons for this delay in diagnosis are both HCP and patient-driven.

- The healthcare provider did not automatically connect the symptoms with fibromyalgia (50%).
- The individual symptoms were treated as separate conditions (47%).
- The patient was not aware that fibromyalgia was a condition (48%).

Seven in ten (71%) seek diagnosis only after they can no longer tolerate their symptoms.
- Other motivators include those related to relationships (47%), work (32%), and loved ones (17%).
An earlier diagnosis is important

More patients who reported severe symptoms also reported a longer time from symptom onset to diagnosis.

Further, patients diagnosed within a year are significantly less likely to experience daily challenges in management of their households, relationships and careers.

- Nearly half (48%) of those whose diagnosis took five years or more stopped exercising, compared to one third (33%) of those who were diagnosed within one year.
- More than half (54%) of those whose diagnosis took five years or more said their work or career has been negatively impacted, versus only 41% of those who were diagnosed within one year.

Q1105. In which, if any, of the following ways has fibromyalgia affected your life? Please select all that apply.
Fibromyalgia negatively impacts career and household management, and challenges relationships and intimacy

Dealing with debilitating symptoms and the effect they have on everyday life can be overwhelming and upsetting for patients as well as their families, co-workers, and loved ones.

Fibromyalgia makes it difficult for patients to work, keep up their households, exercise, and maintain relationships.

- Two thirds (67%) of women said they can no longer keep up with household chores.
- Nearly half (47%) said their job or career has been negatively affected.
- Nearly one third (31%) said fibromyalgia has affected their ability to experience intimacy.

![Impact of Fibromyalgia on Day-to-Day Life](chart.png)
A fibromyalgia diagnosis is a double-edged sword; patients experience both positive and negative emotions following diagnosis.

- On the positive side:
  - Nine in ten (91%) are relieved to finally connect a condition with their symptoms.
  - Many (67%) feel hopeful that they have a manageable condition.

- On the negative side:
  - Six in ten (60%) feel upset that they have a chronic condition that needs to be managed.
  - Half (49%) feel angry that diagnosis took so long.
  - Forty-four percent feel fearful that they won’t be able to manage the condition on their own.
Patients often lack adequate support and resources

Concerns about being taken seriously do not seem to keep patients from telling their loved ones about their condition. Unfortunately, these loved ones are less likely to provide additional support to patients.

- While 85% of patients told close friends about the condition, only 28% felt that these friends were more supportive after diagnosis.
- While two thirds (66%) of patients told their children about the condition, one third (33%) said their children were more supportive after diagnosis.
- While 65% of patients told their spouse/significant other about the condition, less than half (43%) said their spouse/significant other was more supportive after diagnosis.
- Among the groups that offered more support, spouses/significant others offered the highest levels of support.

HCPs are the top source of support for fibromyalgia patients.

- Half of patients (49%) say they rely on their healthcare provider for support. However, fewer (40%) patients believe HCPs fully understand how their condition affects them.
- Four in ten patients (43%) rely on their spouse or significant other for support. However, only 27% of patients believe their spouse or significant other fully understands how their condition affects them.
- One in five patients (19%) relies on other people with fibromyalgia. Nearly half (48%) believe that other people with fibromyalgia fully understand how their condition affects them.
- One in five patients (19%) has no support.

Patients do not feel they have the informational tools and resources needed to help them live the best life possible.

- Only one in four (25%) agree that they have the tools and resources available to help them manage their fibromyalgia.
Both treatment and support from loved ones were helpful in improving fibromyalgia symptoms and day-to-day life

Since being treated, 51% of patients believe that their overall day-to-day life has improved. And when combined with increased support from loved ones, improvements in day-to-day life appear to be enhanced. For example, a greater number of patients who received more support from their spouse report that their day-to-day life has improved due to treatment (56%), compared to those who received the same amount of or less support (47%) since being treated.

- Respondents say the following types of treatment have improved their symptoms:
  - Prescription drug therapy (58%)
  - Exercise (46%)
  - Alternative therapies (43%), such as massage, acupuncture, meditation, and chiropractic care

- Support from their spouse or significant other. A greater number of patients who received more support from their spouse reported that their day-to-day life had improved due to treatment (56%), compared to those who received the same amount of or less support (47%) since being treated.

- Support from their children. Nearly two-thirds (61%) of those who received more support from their children reported that treatment had improved their day-to-day life compared to those who received the same amount of support or less (48%).