

# Unmasking Rheumatoid Disease: The Patient Experience of Rheumatoid Arthritis

a white paper from the Rheumatoid Patient Foundation



**Rheumatoid  
Patient  
Foundation**

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# About the RPF



Kelly Young, Founder  
Rheumatoid Patient Foundation

*"Our vision is a world where no one suffers from rheumatoid disease."*

## More information at:

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## ABOUT THE RHEUMATOID PATIENT FOUNDATION

Rheumatoid Patient Foundation (RPF) is a 501c(3) non-profit organization dedicated to improving the lives of people with rheumatoid diseases such as rheumatoid arthritis and juvenile arthritis. RPF was founded in 2011 to address the significant lack of disease education, comparatively low levels of research funding, and difficulty obtaining adequate treatment. RPF is committed to creating pathways to better clinical care and disease outcomes through education, awareness, and participation in patient-centered research.

### ***We understand RA***

Millions of us have fought the crippling pain and damage of rheumatoid disease with remarkable resilience. We face multiple procedures and harsh treatment side effects with optimism, humor, and compassion.

RA is a serious disease, but symptoms can be visibly subtle, making it difficult to understand. Lack of awareness of RA makes it even more isolating. Too often, even doctors doubt how much RA patients endure.

We understand because we are patients and caregivers who live with RA. Together we will transform the future for everyone diagnosed with the disease.

### ***Together we can do more:***

- To create greater public **awareness** of the nature of rheumatoid disease.
- To develop resources to **support** patients in effective healthcare decisions and in advocating for themselves and others.
- To **advocate** for quality healthcare, appropriate disability accommodations, applicability of scientific research, accurate media coverage, and fair governmental policies.
- To **contribute** to and promote scientific discovery that leads to a cure.



# Foreword



***From John M. Davis, III, MD -- Consultant in the Division of Rheumatology at Mayo Clinic in Rochester, Minnesota; Assistant Professor of Medicine; and Research Chair of the Division of Rheumatology***

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It is absolutely crucial to take into account the patient's point of view when evaluating the activity and impact of rheumatoid disease. There remain many limitations in the objective clinical markers that are available, so it is important that rheumatologists humbly consider the patient's experience of the disease when evaluating disease activity. Ultimately, it is our job to partner with patients to identify and implement an individualized care plan aiming to relieve their suffering and optimize their health outcomes.

So I applaud the efforts of the RPF in evaluating the experiences of the patient community regarding the sensitivity of rheumatology care to the needs, viewpoints, and perspectives of patients.

*"It is absolutely crucial to take into account the patient's point of view when evaluating the activity and impact of rheumatoid disease."*



***From Julia F. Simard, PhD -- Epidemiologist, Assistant Professor at Stanford University School of Medicine***

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The mission of the RPF is clear and critically important in understanding and managing rheumatoid disease. Not only does RPF provide support for patients and caregivers, but it can give all of us insights into the experiences of those we are trying to help in our research and in clinical practice.

# Background

## ABOUT THIS REPORT

One goal of RPF is to create greater understanding of the nature of rheumatoid disease. Describing actual patient experiences is one significant method of contributing to this goal. This white paper reports the results of a survey of a large number of people living with rheumatoid disease. Each patient completed the survey by the use of a secure online portal.

## RESEARCH OBJECTIVES

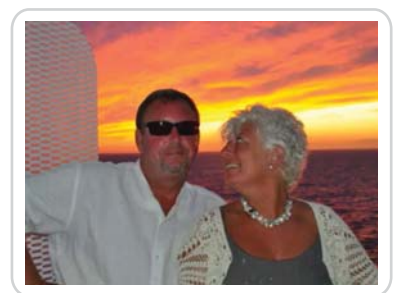
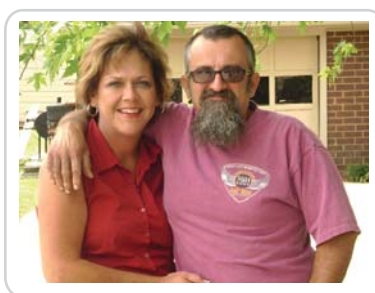
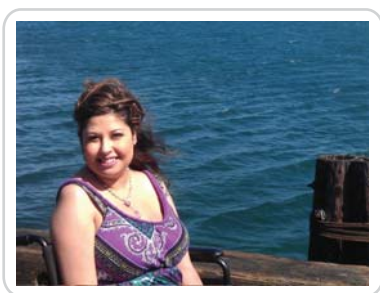
This survey was created to gain insights from the RA patient population as relates to disease onset, symptoms, treatments, rheumatology care and personal experiences. The purpose of this survey was to obtain specific insights into how the disease affects patients and to gain understanding of their broad experience as rheumatoid disease patients.

## METHODS

In 2011, RPF introduced a 29-item questionnaire, which included multiple-choice, multiple-response, and open-ended questions. The survey was made available to RA patients via the RPF website, the website rawarrior.com, and their respective social media outlets on Facebook and Twitter. The questionnaire was hosted in a secure survey system preventing multiple entries. A brief poll was subsequently issued as well, to address a topic not included on the survey. 1,465 RA patients responded to the online questionnaire; 288 RA patients responded to the poll.

## KEY FINDINGS

The findings from this survey reveal a wide array of patient experiences and demonstrate trends that differ from conventional beliefs of rheumatoid disease.



# Survey Results: The Patient Experience



## Patient Demographics & Basic Information

The majority of participants were female (93%), and the median age was 47 years. A quarter of the patients surveyed had been diagnosed within the past 12 months and the average length of time since diagnosis was 6.6 years. Ninety-four percent of all patients surveyed had been treated at some point with DMARD or Biologic medications.

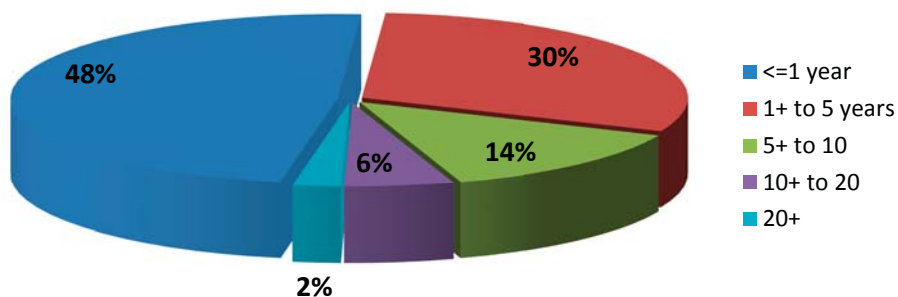
<b>Gender:</b>	<b>Female</b> 93%	<b>Male</b> 7%
<b>Age:</b>	<b>Median</b> 47 Years	<b>Range</b> 78 Years
<b>Average Time Elapsed Since Diagnosis:</b>		6.6 Years
<b>Percentage Diagnosed Within Past 12 Months:</b>		25%

**"I would like most for the [diagnosing] to be changed to reflect the way RA really acts...It doesn't follow guidelines, it doesn't follow the 'standard' symptoms, and it is different in EACH and EVERY patient."**  
--Survey Response

Sixty-nine percent of patients reported that they had tested positive for either Rheumatoid Factor or anti-CCP. The remainder tested negative for both, had never been tested, or did not know.

Fifty-two percent of patients reported that they had RA symptoms for longer than a year prior to diagnosis. Twenty-two percent reported having symptoms for five or more years prior to diagnosis.

### For how long did you have symptoms before diagnosis



# Survey Results: The Patient Experience

**"My rheumatologist always measures my temperature. It is consistently in the 99.5 - 100.4 range...Even when I don't have visible joint swelling, I still have the low-grade fever."**

-- Tina, RA Patient



**"My disease was diagnosed early on. I responded well to the medications and only have slight joint deformity in one thumb. But even with all that I don't get complete pain relief."**

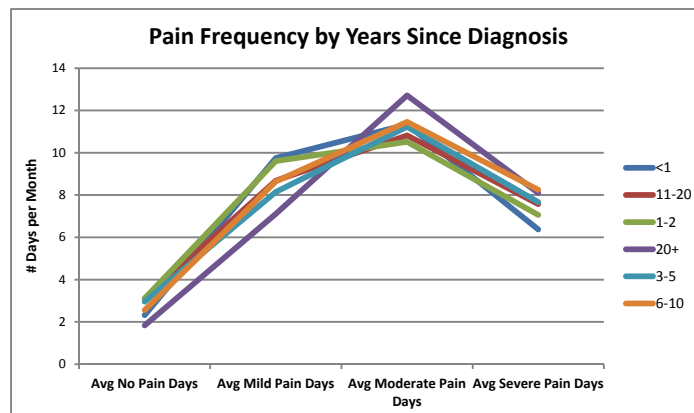
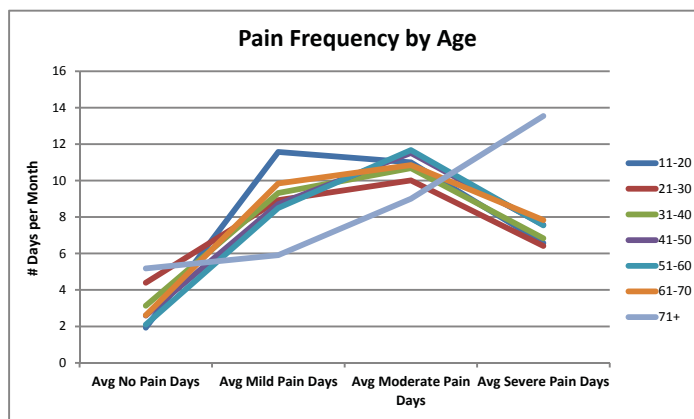
-- Kathy, RA Patient

## Symptoms – Fever and Fatigue

Eighty percent of patients reported that they sometimes have low-grade fevers, and 99% reported sometimes experiencing RA-related fatigue. Patients who experienced fatigue more frequently, however, were more likely to experience low-grade fevers as well

## Symptoms – Pain

Sixty-eight percent of patients reported having zero pain-free days in an average month. On average, respondents experienced only 2 pain-free days per month. Thirty-one percent of survey respondents reported moderate to severe pain at least 15 days out of the average month. Most age groups experienced similar pain – with the exception of the oldest group (aged 71+ years, n=11). The length of time since a patient's diagnosis did not appear to have any effect on the patients' reported pain levels.



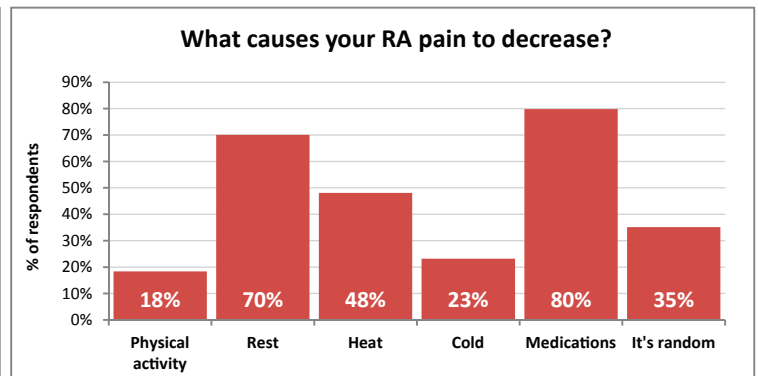
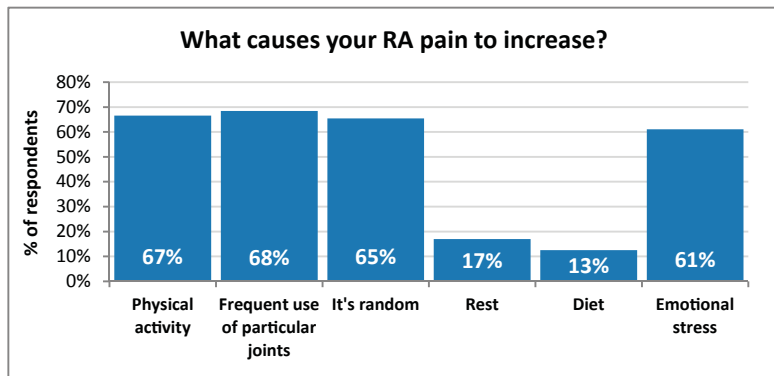
*The length of time since a patient's diagnosis did not appear to have any effect on the patients' reported pain levels.*



# Survey Results: The Patient Experience

## Symptoms – Pain

Physical activity increases pain for 67% of respondents, while 18% said activity decreases pain. The top three factors cited as decreasing RA pain were medications, rest, and heat. Medications were reported to decrease pain levels in 80% of respondents.



**"I see people walking, biking and jogging every morning when I drive my kids to school – I would LOVE to be able to do that. I WANT to be able to do that, but I know it's not possible. For me to go for a walk means pain and fatigue the rest of the day and that would rob me of my time with my kids – and that I think is what so many people don't get. RA is a balancing act. The thing with RA is that it steals away the things you want to do and leaves you to struggle with the things you have to do. I don't have to exercise...but I want to."**

-- LeighAnn, RA Patient



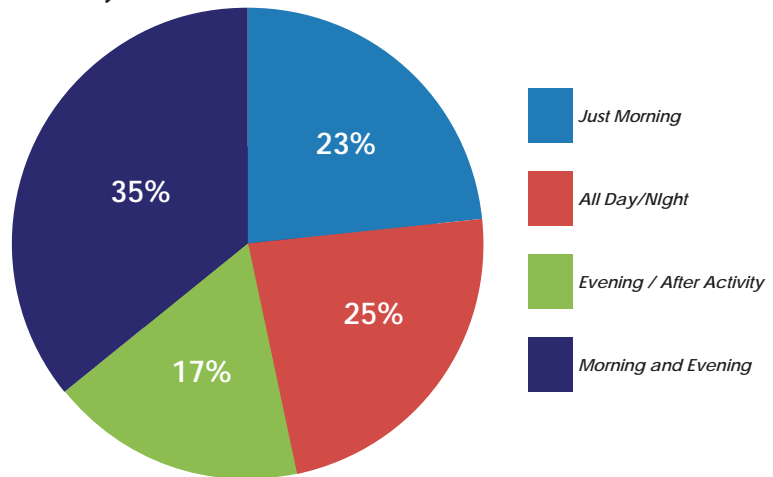
# Survey Results: The Patient Experience



**"My feet have never swelled or looked inflamed. Yet, the joints were totally destroyed by RA & I've had 6 surgeries to rebuild them. Joint destruction happens without obvious outside signs. It's tough to feel so bad when you look so 'normal.'"**  
-- Ann, RA Patient

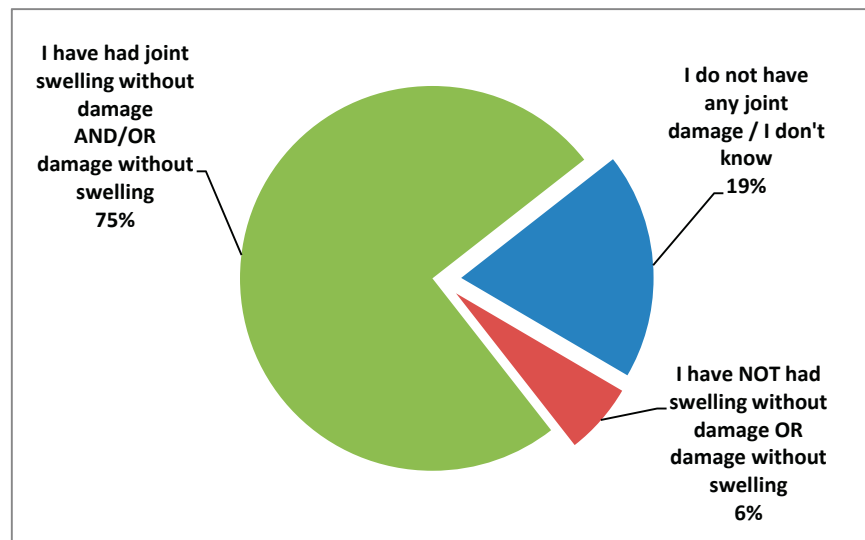
## Symptoms – Pain & Stiffness

Twenty-three percent of respondents reported that they experience the most joint pain and stiffness in the morning – consistent with the concept of "morning stiffness." However, a quarter of the respondents stated that the joint pain and stiffness lasts all day and night, and 52% experience some or most of their joint pain and stiffness in the evening or after a period of activity.



## Symptoms – Swelling

Forty-two percent of patients reported that they generally experienced a weak association or no association between visible swelling and other symptoms in the same joint, such as pain, stiffness or weakness. Seventy-five percent of respondents reported either experiencing joint damage without swelling or dramatic joint swelling without damage, indicating that the two are frequently unassociated.





# Survey Results: The Patient Experience

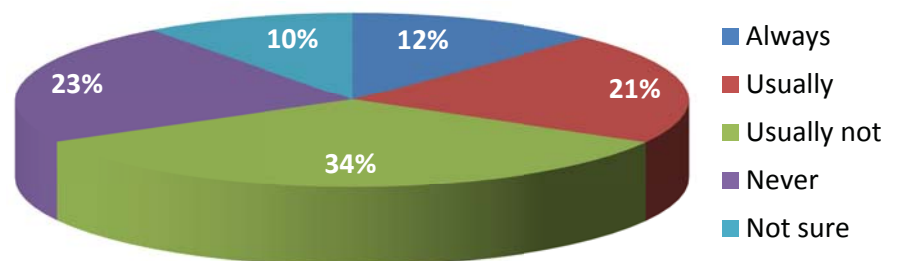
**"My** rheumatologist seemed truly shocked when on my last visit I told him that I hurt everyday. I'm not sure which one of us had the more confused look, him that I hurt everyday or me shocked that he did not understand this. On an average day, I don't hurt badly but I am certainly nowhere close to being pain free."

--Terry, RA patient

## Rheumatology Treatments and Care

One third of respondents stated that they Always or Usually have RA symptoms that their rheumatologists do not believe or understand, which may indicate gaps in doctor-patient communications and/or gaps in education.

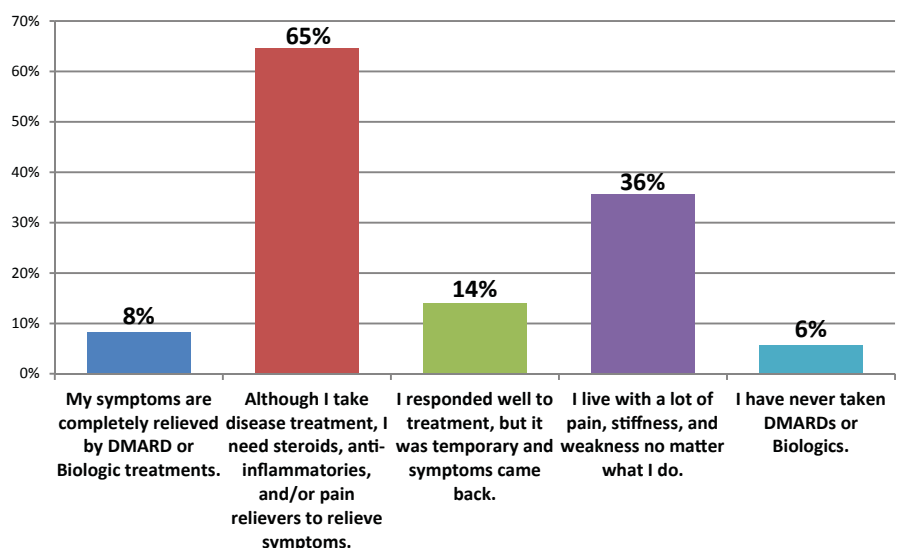
**I have had RA symptoms that my rheumatology specialist does not believe or understand.**



**86% of patients stated their symptoms were not completely relieved by DMARD or biologic treatments**

The majority of respondents stated that additional medications were needed beyond disease treatment to help control remaining RA symptoms. Only 8% of respondents stated that their symptoms were completely relieved by DMARD or biologic treatments, while 36% of patients stated that they continue to live with a lot of symptoms regardless of any treatments.

**How has your RA responded to medical treatment?**





The thing I'd want most in rheumatology care is...

"Compassionate care with a team approach to treating my disease and its symptoms, and professionals who never downplay the role pain has in your daily life."



The thing I'd want most in rheumatology care is...

"Compassionate care with a team approach to treating my disease and its symptoms, and professionals who never downplay the role pain has in your daily life."

Word cloud representing what patients say is most important in rheumatology care:





# Survey Findings



**"People in general do not tend to believe what they cannot see. The disbelief that RA patients suffer from family, friends and public in general is not malicious; it is ignorance of how someone can 'look' okay outside and inside be in such distress."**

-- Angie, RA Patient

## SUMMARY OF FINDINGS

Many of the results from this survey indicate patient experiences that fall outside of the standard model of RA that is presented in current medical literature. For example, although exercise is often touted as being beneficial for RA by improving mobility and lessening symptoms, two thirds of the participants reported that exercise caused an increase in RA-related pain.

The survey data also challenge the concept of "morning stiffness" that tends to go away after a patient gets out of bed and begins his or her day. While nearly a quarter of the respondents seem to follow this trend, the majority of them do not, citing more pain and stiffness at different times throughout the day.

There is also often a perception that joint swelling and damage are directly related. However, the data suggest that patients do not report a clear link between swelling and damage in a given joint.

The patient responses recorded from this survey indicate that the majority of patients continue to live with pain and symptoms from RA, despite receiving disease treatment. More than two-thirds of respondents reported living with RA pain every day. The severity and frequency of RA pain did not change based on age, except for the most elderly age group, and, remarkably, pain patterns remained consistent irrespective of the length of time since diagnosis.

Most respondents also reported some level of concern regarding the medical care that is available to them.

*Patient experiences and symptoms do not always mirror the archetype of RA that is traditionally presented in literature*



# Survey Findings

## CONCLUSIONS

The data collected from this survey indicate that patient experiences and symptoms do not always mirror the archetype of RA that is traditionally presented in literature. Additional research would be valuable to challenge conventional thinking in these areas. Where discrepancies are found, steps could be taken to educate the medical community and broaden understanding of the varying ways RA presents itself in actual patient populations and subsets.

It is also clear that currently available treatments are often insufficient for relieving the pain and other symptoms caused by RA, and that there remains a significant portion of the patient population that does not respond to existing treatments. Additional research should explore classifications of various patient populations and subsequent responses to treatments.

**LIMITATIONS:** Sample was self-selected from educational and support based websites. Women and younger patients were over-represented. Patients self reported as being diagnosed with RA.



**"I want to be listened to. Do not disregard what I say just because it isn't 'classical presentation.'"**

-- Survey Response