

# LIVING WITH Sjögren's

## SUMMARY OF MAJOR FINDINGS

*Living with Sjögren's was conducted by Harris Poll on behalf of the Sjögren's Foundation, the only non-profit organization focused on increasing research, education and awareness for Sjögren's, an autoimmune disease that affects the entire body. The purpose of the survey was to gain an understanding from adults ages 18 and older who have been diagnosed with Sjögren's about the physical, emotional and financial impact of the disease on their lives.*

### Sjögren's Survey Patient Demographic Profile

The vast majority (96%) of Sjögren's patients who completed the survey were female. About one-third (32%) of respondents were 60 years of age or younger. On average, respondents said they were diagnosed with Sjögren's over a decade ago (12.3 years mean).



### Most Common Symptoms Experienced

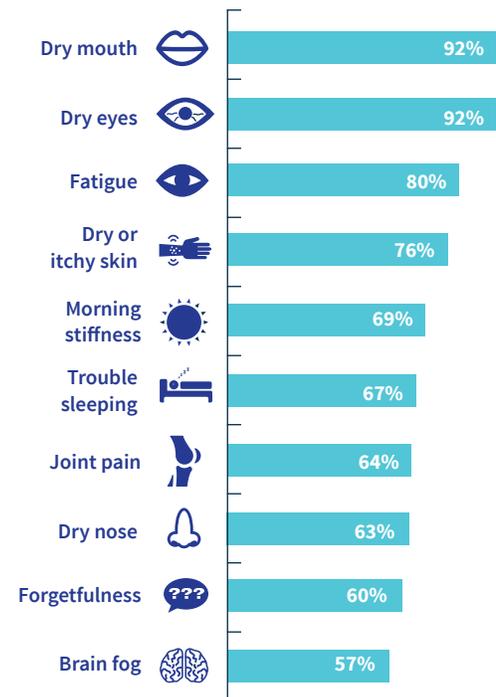
The vast majority of Sjögren's patients reported having experienced dry eyes (97%), dry mouth (97%), fatigue (94%), dry or itchy skin (93%), trouble sleeping (91%) and forgetfulness (90%) over the last year. Most said that their dry mouth (92%), dry eyes (92%), and fatigue (80%) symptoms occurred almost weekly or more frequently.

Patients 60 years of age and under said they were more likely than patients over age 60 to experience brain fog (i.e., confusion, forgetfulness, and lack of focus and mental clarity) (66% vs. 53%) and joint pain (67% vs. 62%) almost weekly or more frequently. Patients over 60 years of age reported that they were more likely than patients 60 years of age and under to experience dry nose (65% vs. 59%) and photosensitivity (sunlight) (64% vs. 56%) almost weekly or more frequently.

*Half of Sjögren's patients with severe dryness (53%) also have severe fatigue.*



### COMMON SYMPTOMS EXPERIENCED ALMOST WEEKLY OR MORE FREQUENTLY



LEARN MORE

[sjogrens.org](http://sjogrens.org)

### How Sjögren's Affects Daily Activities

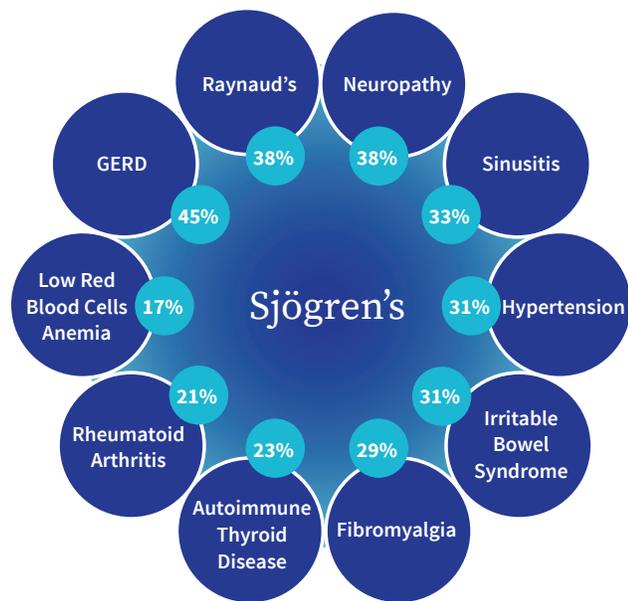
Over 7 in 10 Sjögren's patients (71%) agreed that their Sjögren's gets in the way of the things they need to do each day. Most commonly, nearly half (49%) of patients reported Sjögren's having a great deal or a lot of negative impact on participating in hobbies, social activities, and extracurricular activities. Around a third say it negatively impacts making diet adjustments (35%), performing activities of daily life (34%), traveling or taking a vacation (34%), and overall mood (33%).

Nearly 7 in 10 people living with Sjögren's (67%) agreed that they struggle to cope with their Sjögren's. Even more agreed that living with Sjögren's makes every day a challenge (86%).



### Other Diagnosed Health Conditions

There are many known comorbidities or manifestations of Sjögren's that can occur in conjunction with the disease. Survey respondents reported having been diagnosed by a health care provider with an average of five other health conditions, including Gastroesophageal Reflux Disease (GERD) (45%), Raynaud's (38%), Neuropathy (38%), Sinusitis (33%), Hypertension (31%), and Irritable Bowel Syndrome (31%).



### Visits to a Healthcare Professional

Sjögren's patients, on average, said they see almost five different healthcare professionals (4.6 mean) at least once a year to help manage their disease. Nearly 7 in 10 (68%) of patients surveyed said they see between two and five healthcare providers.



### Changes at Home Due to Sjögren's

The majority (79%) of Sjögren's patients surveyed say their disease has led them to make at least one day-to-day change around the house, such as stopping or cutting back on housework (74%) or hiring additional service providers to help with housecleaning or childcare (38%).

- Stop or cut back on housework **74%**
- Hire additional service providers (e.g., housecleaning, caregiving, childcare services, etc.) **38%**
- Modify my living space to accommodate my limited mobility **22%**
- Apply for Social Security Disability **15%**
- Seek alternative transportation services **14%**



### Changes at Work Due to Sjögren's

More than half (54%) of Sjögren's patients surveyed say they have made at least one change regarding work, including having to stop working (28%), reduce their schedule of hours (28%), and make a career change or take a less demanding job (27%) due to their Sjögren's.

- Take days off of work **30%**
- Stop working **28%**
- Work a reduced schedule of hours **28%**
- Make career change or take less demanding job **27%**
- Ask employer to make a more flexible schedule, ability **16%**

## Treatments and Medications Used

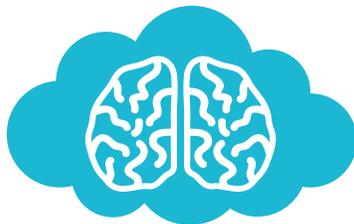
Today, there is no cure for Sjögren's, so patients must resort to using a multitude of treatments to help them cope with various symptoms. On average, Sjögren's patients said they use nearly nine (8.8 mean) medications and treatments to help with their Sjögren's symptoms, with an average of over four prescription medications or treatments. Patients living with Sjögren's for a longer period of time (5-9 years) reported using slightly more treatments than patients living with Sjögren's for a shorter period of time (0-4 years) (8.7 vs. 8.2 mean).

Virtually all patients (97%) reported using eye drops, artificial tears, or non-prescription eye ointments for treatment at some time, while a majority said they have used ibuprofen or other anti-inflammatory agents (81%), disease-modifying anti-rheumatic drugs (DMARDs) (67%) and OTC or prescription fluoride (67%), or corticosteroids (62%) for treatment. Younger patients (60 and under) were significantly more likely than patients over 60 to have used health food supplements/remedies (90% vs. 87%), exercise (88% vs. 83%), and alternative therapies (70% vs. 58%) to treat their Sjögren's.



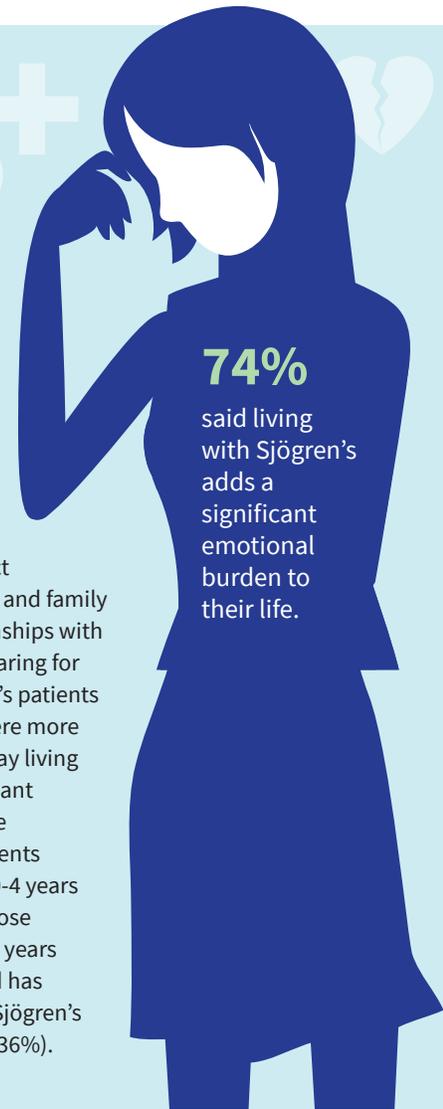
## Sjögren's Impact on Speech and Concentration

More than two in five (44%) patients said that Sjögren's has had a great deal or a lot of negative impact on finding the correct word during conversation. Slightly fewer said Sjögren's has had a great deal or a lot of negative impact on concentrating on more than one task at a time (38%) or remembering details at home or work (32%). Brain fog (55%) and forgetfulness (49%) were among symptoms that patients said have had a moderate to major impact on their lives in the last year.



## Emotional Burden of Sjögren's

Three-in-four patients (74%) said living with Sjögren's adds a significant emotional burden to their life, having at least some negative impact on relationships with friends and family (63%), sex life (59%), relationships with spouse/partner (55%), and caring for their children (19%). Sjögren's patients 60 years of age and under were more likely than those over 60 to say living with Sjögren's adds a significant emotional burden to their life (80% vs. 71%). Sjögren's patients diagnosed with the disease 0-4 years ago were more likely than those diagnosed with Sjögren's 5-9 years ago to say their overall mood has been negatively affected by Sjögren's a lot or a great deal (42% vs. 36%).



**74%** said living with Sjögren's adds a significant emotional burden to their life.

### NEGATIVE IMPACT ON RELATIONSHIPS



Relationship with friends and family

63%

Sex life

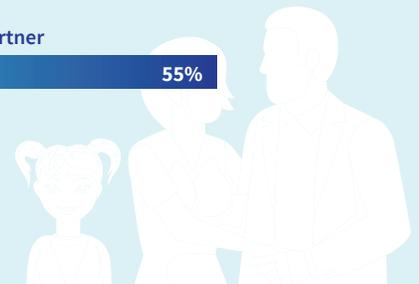
59%

Relationship with spouse/partner

55%

Caring for your children

19%



### Financial Impact of Sjögren's

Two in three (66%) Sjögren's patients said living with Sjögren's adds a significant financial burden to their life. Sjögren's patients 60 years of age and under reported spending more money, on average, on treatments and were more likely than those over 60 to say living with Sjögren's adds a significant

financial burden to their life (72% vs. 63%). When asked how much money they spent on different types of medical expenses in the past 12 months, patients said they spent the most, on average, on dental care followed by prescription medications, and healthcare appointments/co-payments.

**2 IN 3**

SJÖGREN'S PATIENTS SAY THE DISEASE



ADDS A SIGNIFICANT FINANCIAL IMPACT TO THEIR LIFE

### Hope for New Treatments

The vast majority (96%) of Sjögren's patients reported they wish there were additional treatments available. Four-in-five (82%) said that it is extremely important/absolutely essential that new systemic therapies addresses dryness symptoms throughout their body (eyes, mouth, skin, vagina). Respondents also identified the importance of the need for new treatments for fatigue (63%), brain fog/forgetfulness (53%), sleep problems (51%), joint pain or swelling (48%) and muscle pain (43%).



*"The Sjögren's Foundation is committed to accelerating the development of better diagnostic, management and therapeutics that will have the greatest potential impact on improving the quality of life for Sjögren's patients."*

- Steven Taylor, Sjögren's Foundation CEO

### About the Survey

Living with Sjögren's was conducted in the United States using a paper instrument by Harris Poll on behalf of the Sjögren's Foundation between May 11 and July 11, 2016. The research, conducted among 2,962 adults aged 18+ who reported having been diagnosed with Sjögren's by a medical professional or doctor, examined the variety and severity of experiences Sjögren's patients have with Sjögren's and the impact it has on their quality of life. Data was not weighted and therefore represents only the individuals surveyed. Because the sample was based on the individuals from Sjögren's Foundation's database who agreed to participate, it is not possible to estimate a theoretical sampling error.

### About the Sjögren's Foundation

The Sjögren's Foundation is the only non-profit organization focused on increasing research, education and awareness for Sjögren's, one of the most prevalent autoimmune disorders, affecting as many as four million Americans, with an estimated 2.5 million patients currently undiagnosed. For more information, visit [www.sjogrens.org](http://www.sjogrens.org) or call (301) 530-4420.

As many as **4 MILLION AMERICANS** have Sjögren's

with an estimated **2.5 MILLION PATIENTS** currently undiagnosed

**♀**

**9 OUT OF 10** Sjögren's patients **ARE WOMEN**

The average age of Sjögren's diagnosis is **40 YEARS**

It can occur in **ALL AGE GROUPS**

Frequency appears to **INCREASE WITH AGE**

It now takes an average of **2.8 YEARS** to receive a Sjögren's Diagnosis



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