

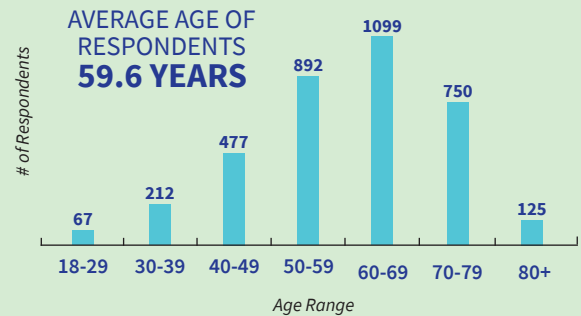
LIVING WITH Sjögren's

SUMMARY OF PATIENT SURVEY

The Living with Sjögren's patient survey was conducted by The Harris Poll on behalf of the Sjögren's Foundation and was designed to gain insight into the variety and severity of what adult Sjögren's patients living in the U.S. experience and how the disease impacts their quality of life. The following data demonstrates the serious and systemic nature of Sjögren's.

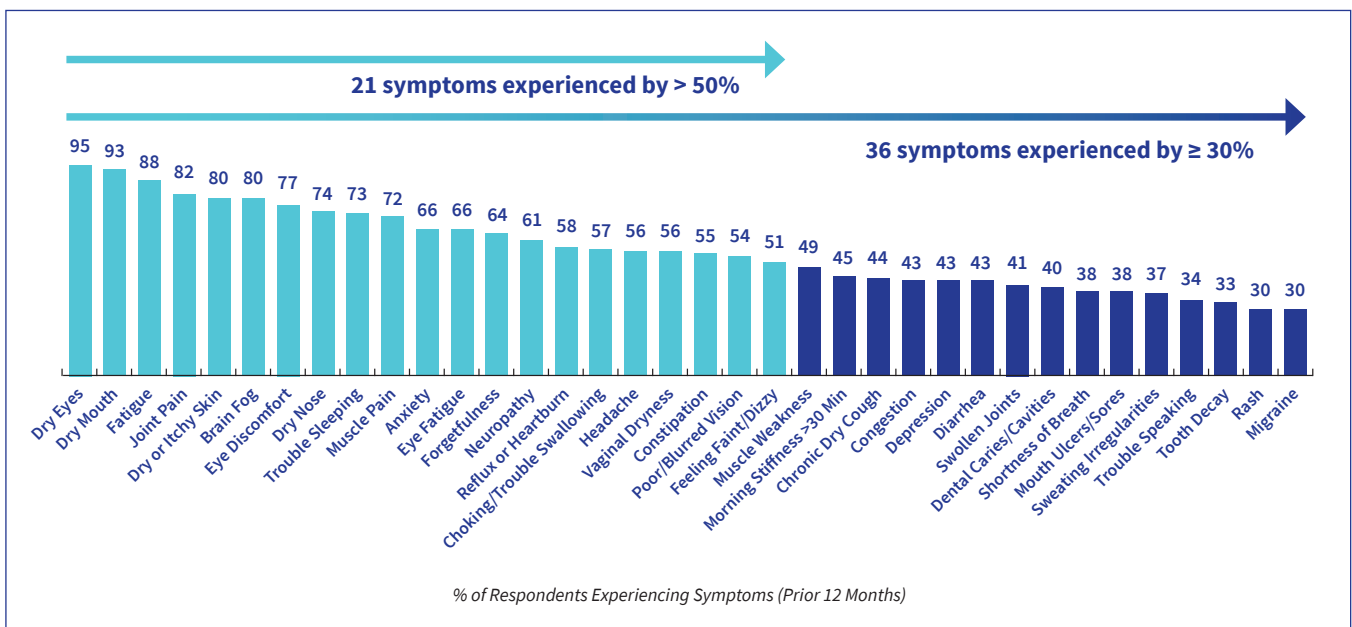
Demographic Profile

Respondents (n=3,622) ranged in age from 18 to 94 years old and were predominantly female (97%). The average age when receiving a diagnosis was 49.7 years, though 13.6% of respondents were diagnosed at 35 years or younger. When the shortest (5%) and longest (5%) times to diagnosis were removed, the average time to receive a diagnosis was 3 years. The median time to diagnosis was 1 year. More than half of all respondents believe they had Sjögren's in early adulthood (<35) or childhood (<18).



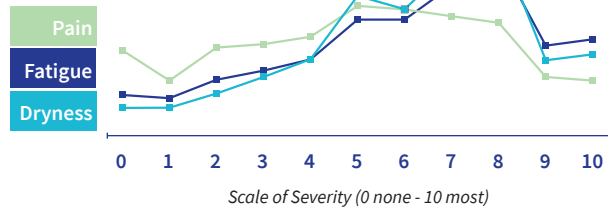
Symptoms Experienced in the Past Year

The complex and multi-system nature of Sjögren's means that patients experience a wide range of symptoms. Symptom frequency for the 48 symptoms provided ranged from 6% to 95% for the prior 12 months. A majority of respondents stated that 8 of these symptoms have a major or moderate impact on their life, including: fatigue (79%); dry eyes (75%); dry mouth (73%); joint pain (65%); trouble sleeping (64%) eye discomfort (60%); muscle pain (56%); and brain fog (54%).



Subjective Burden

When considering symptoms during the past two weeks, respondents rated the subjective burden (0-10 scale) of dryness as 6.5, fatigue as 6.4 and pain as 5.0. These averages are comparable to the data collected in 2016, with slight increases seen in both pain and fatigue.



25%

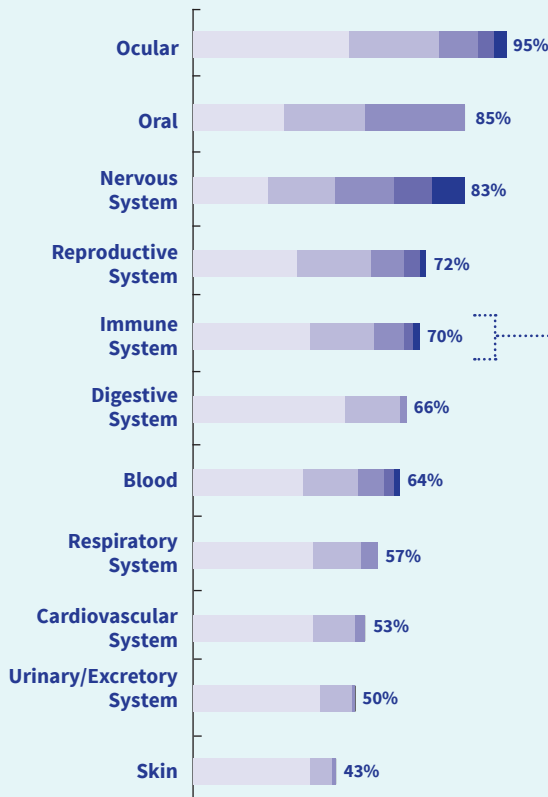
of respondents claimed **fatigue** had the greatest negative impact on their life.



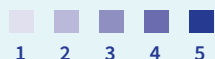
Diagnosed Conditions

More than 80% of respondents are diagnosed with at least one ocular, oral and nervous system-related condition. Gastroesophageal reflux disease (GERD) (55%) continues to be a leading medical issue diagnosed among Sjögren's patients, as are dryness-related conditions (dry eye, 94%; dry mouth leading to major dental work, 64%; and vaginal dryness, 58%). Other frequently diagnosed manifestations and comorbidities include: anxiety/depression (50%); neuropathy (45%); sinusitis (40%); irritable bowel syndrome (38%); Raynaud's syndrome (37%); and hypertension (36%).

Other Diagnosed Conditions by Type & System



% = total with a diagnosed condition

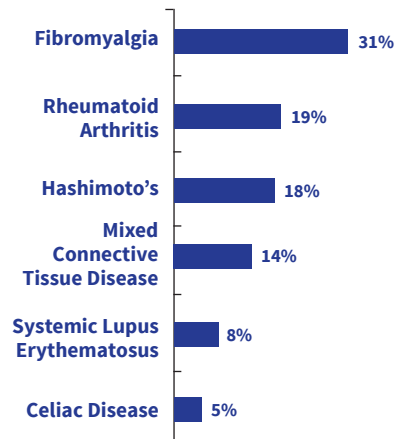


Colors indicate portion of total with a certain # of diagnosed conditions

Diagnosed Autoimmune Conditions

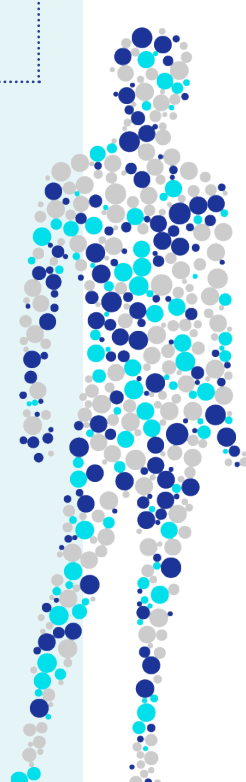
Seventy percent (70%) of respondents have at least one immune-related condition other than Sjögren's, and, within this group, 49% have two or more.

Reported Diagnosed Autoimmune Conditions



A majority of respondents have a blood relative with an autoimmune disease.

Of those who did, 18% have a blood relative with Sjögren's and 63% have a blood relative with another autoimmune disease.



Day to Day Impact

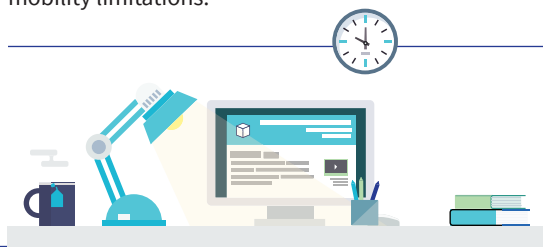
For the majority of respondents, living with Sjögren's makes every day a challenge (79%), and nearly one quarter of respondents feel their ability to be independent is greatly impacted. Additionally, many respondents experience a negative impact on their ability to exercise (55%), participate in hobbies, social activities, and extracurricular activities (52%), travel or take a vacation (44%), perform activities of daily living (36%) and drive (17%) due to their Sjögren's.

The majority of respondents stated they have had to make changes at home (79%) and or work (64%).

In the home, the majority of patients have had to stop or cut back on housework (76%) and many have had to hire additional service providers for help (33%). Nearly one quarter of respondents have had to modify their living space to accommodate their mobility limitations.



Sjögren's impacts the ability of many to enjoy (33%) or taste (17%) food and has led patients to make dietary adjustments (36%).



Work:

Many respondents have had to take days off (42%), work a reduced schedule of hours (30%), stop working altogether (30%) or make a career change (29%) because of their Sjögren's.

Financial Impact

The majority of respondents stated that Sjögren's adds a significant financial burden to their life (67%), with the greatest single cost, on average, being dental care (\$1,580). Across age groups, costs did not vary greatly, with respondents who reported costs spending an average of \$6,769 annually on disease management and care. The inability to work led 9% of respondents to apply for financial aid.

Mental & Emotional Burden

Respondents stated that living with Sjögren's causes a significant emotional burden (81%) and the majority struggle to cope with their disease (66%). Respondents aged 18-29 were most likely to report a significant emotional burden (91%) and those aged 30-39 were most likely to state that they struggle to cope with their disease (71%). Forty percent (40%) of all respondents stated they experience a great deal or a lot of negative impact on their mood, with younger respondents reporting this most frequently (18-29, 63%; 30-39, 58%). Additionally, anxiety and depression (50%) were common diagnoses in the group as a whole, and in those experiencing anxiety, 63% said it has a major or moderate impact on their life.

Respondents stated that personal relationships were negatively impacted by Sjögren's as well, including sex life (41%), relationships with friends and family (28%) and caring for children (11%).

Forty percent (40%) of respondents stated they have trouble remembering details related to work and home. Additionally, many respondents have an impaired ability to concentrate, both on a single task (39%) and multiple tasks (46%) and nearly half have trouble finding the correct word during conversations (45%).

81%

of respondents say living with Sjögren's causes a significant emotional burden.



“Brain fog” (80%)

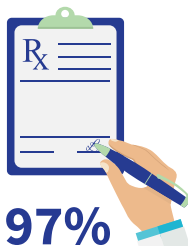
is a commonly experienced symptom in Sjögren's.

Treatment & Care

The complexities of Sjögren's lead many patients to require frequent care and the use of multiple treatments and medications. On average, respondents use 3.7 over-the-counter (OTC) products, 3.3 prescription products and see 4.4 health care providers, annually. On the higher end of care, 23% of respondents reported using 10+ medications (OTC and prescription combined) and see 6+ health care providers.

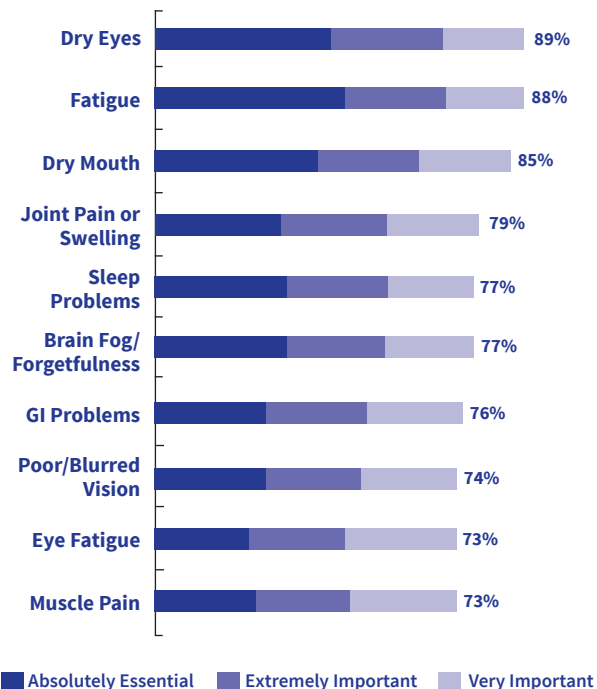
The most common currently used products are eye drops, artificial tears and eye ointments (85%) and vitamin D supplements (82%). Notably, 54% of respondents stated they currently exercise as a way to help manage their Sjögren's, while 32% stated that they used to exercise but no longer do. More than half of the respondents currently or have previously used anti-depressants, with those aged 18-29 (37%) and 50-59 (36%) the most likely to report current use.

Despite the high number of treatments and medications being used, more than 50% of respondents noted 21 symptoms in which they feel improved treatments are necessary.



97% of respondents somewhat or strongly agree that they wish there were **better treatments for their Sjögren's.**

Better Treatments Needed



About the Survey

The *Living with Sjögren's* patient survey was conducted by The Harris Poll on behalf of the Sjögren's Foundation and was available online between October 13 and November 8, 2021. This survey was open to all adult (≥18 years old) Sjögren's patients living in the United States and 3,622 completed responses were received. Data represents only the individuals surveyed.

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 4 million Americans, with an estimated 2.5 million patients currently undiagnosed. For more information, visit www.sjogrens.org or call (301) 530-4420.

Sjögren's Fast Facts

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



LEARN MORE sjogrens.org

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