Sjögren's FOUNDATION®

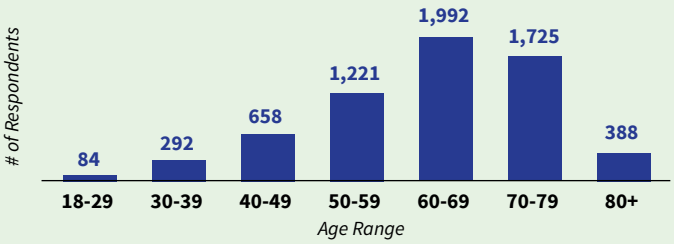
LIVING WITH Sjögren's®

2025 PATIENT SURVEY RESULTS SUMMARY

The 2025 *Living with Sjögren's*® patient survey was conducted by the Sjögren's Foundation®. This survey was designed to gain insight into the variety and severity of symptoms experienced by adults living with Sjögren's disease and better understand how Sjögren's disease impacts their quality of life.

Demographic Profile

Respondents (N=6,360) ranged in age from 18-98 years old and were predominantly female (95%) and white (85%). Nearly half (49%) of respondents were age 65 or older whereas 5.9% were under the age of 40.



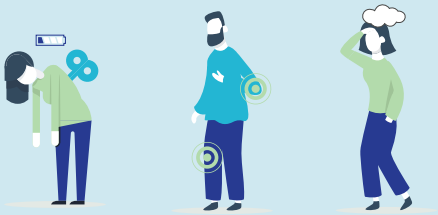
KEY TAKEAWAYS

Sjögren's disease is complex, heterogeneous, and presents relentless challenges to those living with the disease.

- **Symptoms are relentless and wide-ranging**, with dryness, fatigue, trouble sleeping, brain fog, and a variety of symptoms associated with pain affecting daily life rather than occasional flare-ups.
- **Fatigue is especially debilitating**, overshadowing other symptoms in how much it disrupts patients' ability to function, participate in daily activities, and maintain social commitments.
- **Sjögren's impacts sexual health**, affecting relationships with partners and the sexual function of people living with Sjögren's.
- **The disease's impact extends beyond physical symptoms**, as many people living with Sjögren's struggle to think clearly, concentrate, or remember — while also carrying a heavy emotional and mental health burden.

Greatest Symptom Impact

When asked which single symptom had the greatest negative impact on their lives over the past 12 months, 27% of respondents reported fatigue as the top symptom, followed by joint pain (11%) and brain fog (10%). Dry eyes, trouble sleeping, neuropathy, and tooth decay/dental caries were identified as the next most impactful symptoms, each by 8% of respondents, respectively.



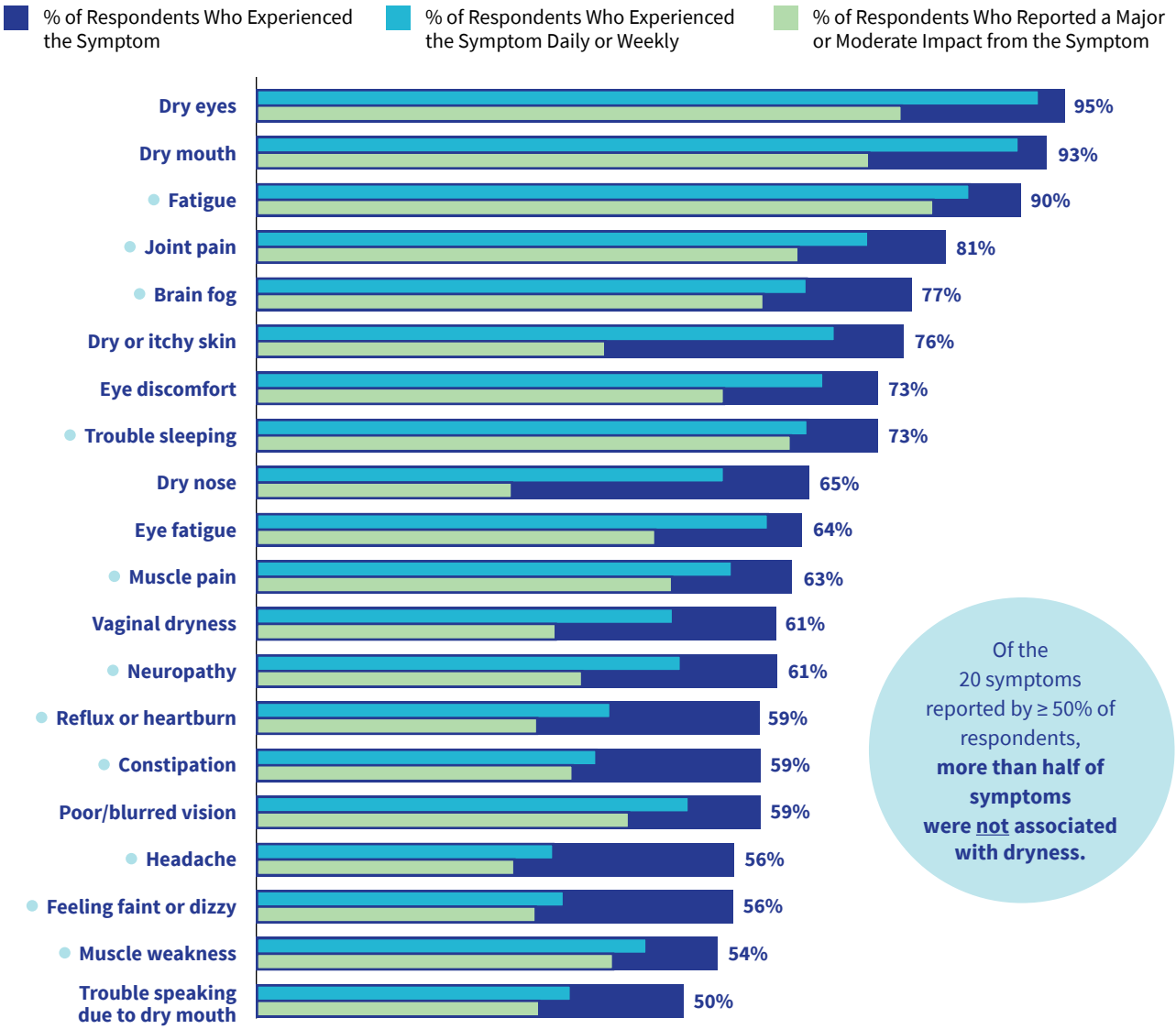
27% Fatigue

11% Joint pain

10% Brain fog

Top 20 Symptoms Experienced in Past 12 Months *(with Frequency and Severity)*

Sjögren's disease is a complex, multi-system disease, and patients experience a wide range of symptoms. Respondents selected symptoms experienced in the past 12 months from a list of 46 and then rated each by frequency and severity. For the top 20 symptoms, more than 60% reported experiencing that symptom on a daily or weekly basis. Many respondents rated the symptom as having a major or moderate impact on their life.



Of the 20 symptoms reported by ≥ 50% of respondents, **more than half of symptoms were not associated with dryness.**

Other Reported Symptoms *(% Experienced in Past 12 Months)*

- **Morning stiffness: 49%**
- **Choking/trouble swallowing: 48%**
- **Tooth decay/dental caries: 45%**
- **Swollen joints: 45%**
- **Diarrhea: 43%**
- **Congestion (sinuses): 39%**
- **Mouth ulcers/sores: 37%**
- **Shortness of breath: 37%**
- **Chronic dry cough: 34%**
- **Migraine: 31%**
- **Excessive sweating: 31%**
- **Flares/rash from sun exposure: 29%**
- **Pain during intercourse (dyspareunia): 28%**
- **Rash: 28%**
- **Urinary tract/bladder infection/cystitis: 23%**
- **Lymph node pain or swelling: 22%**
- **Tachycardia: 21%**
- **Parotid gland swelling and tenderness: 20%**
- **Difficulty with orgasm: 19%**
- **Congestion (lungs): 15%**
- **Inability to sweat: 14%**
- **Purpura/Petechiae: 11%**
- **Yeast infection in mouth: 10%**
- **Vaginal infection: 8%**
- **Bradycardia: 8%**
- **Salivary gland stones or infections: 6%**

Impact on Quality of Life

Sjögren's has a substantially negative impact on quality of life. Most respondents reported that Sjögren's negatively impacted their relationships, social lives, ability to work, finances, activities of daily living, and overall mental and emotional well-being.

Daily Life & Work

81% of respondents agreed, **"My Sjögren's gets in the way of the things I need to do each day."**

72% of respondents reported a **negative impact to** performing activities of **daily life** (e.g., getting dressed, cooking, cleaning).

57% of respondents reported their **job/career** or ability to work was **negatively impacted** by Sjögren's.

Mental Health & Emotional Burden

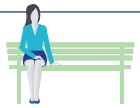
86% of respondents agreed, **"Living with Sjögren's adds an emotional burden to my life."**

52% of respondents reported a diagnosis of **anxiety** and **47%** reported a diagnosis of **depression.**

Relationships & Social Life

Respondents reported that their Sjögren's has **negatively impacted their relationship** with their **spouse/partner** (**59%**) and with **family members** (**67%**).

Nearly half (49%) of respondents agreed, **"I feel lonely because of my Sjögren's."**



Sexual Health & Function

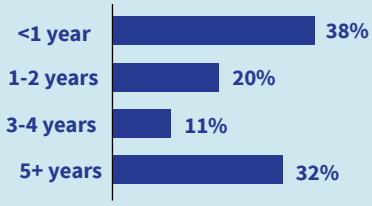
64% of respondents reported a **negative impact** to their **sex life.**

28% of all respondents reported **pain with intercourse**; **36%** of men reported **erectile dysfunction**.

19% of all respondents stated they have **difficulty with orgasm**.

Sjögren's Diagnosis Journey

Time to Diagnosis

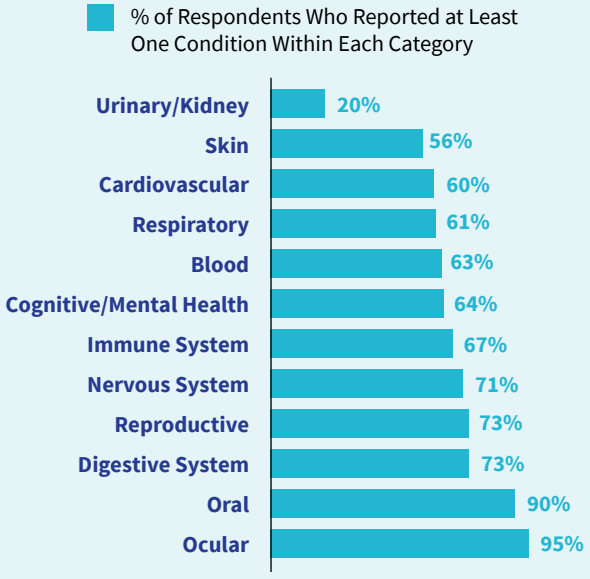


51.6 Years
average age of respondents when diagnosed with Sjögren's.

Healthcare Provider Diagnosed Conditions

Respondents were also asked to provide information about the conditions they have been formally diagnosed with by a healthcare provider. Diagnosed conditions impacting ocular and oral health were the most frequently listed, with conditions associated with digestive, reproductive, nervous, and immune systems following.

The most commonly reported immune system/ autoimmune-related diagnoses were rheumatoid arthritis (22%), Hashimoto's (16%), lupus (10%), and mixed connective tissue disease (9%). Additionally, 30% of respondents were also diagnosed with fibromyalgia.



2/3 of respondents (67%) reported having been diagnosed with at least **1 autoimmune condition in addition to Sjögren's.**

Treatment & Care

Respondents reported using a combined average of 7 total over-the-counter (OTC) and prescription treatments to help manage symptoms related to Sjögren's disease. For prescription treatments, 72% reported use of hydroxychloroquine (Plaquenil) or chloroquine, and 52% reported using other disease-modifying antirheumatic drugs (DMARDS). Twenty percent of respondents reported prior or current use of biologic therapies. Most patients had used or were currently using OTC eyedrops (96%), oral comfort agents (85%), and fluoride mouth rinse or toothpaste (82%). Dental complications were common, with nearly half of respondents requiring crown(s) or having frequent caries/cavities.

73%

of respondents **agreed**, "Living with **Sjögren's adds a financial burden to my life."**

Non-pharmacologic strategies were widely used by respondents, with 83% reporting using exercise to help manage their Sjögren's, 75% making dietary changes, and many reporting using complementary and alternative therapies, such as massage (60%), meditation (52%), and acupuncture (32%).

36%

of respondents **disagreed** that their **primary provider for the management of Sjögren's collaborated with their other healthcare providers.**

On average, respondents reported seeing 5 different providers per year, including providers in rheumatology (86%), primary care (80%), dentistry (74%), and ophthalmology/optometry (70%). While majority of respondents saw a rheumatologist (78%) for primary management of their Sjögren's, 12.5% reported they relied on a primary care provider.

Most respondents reported positive experiences with their healthcare providers: 85% felt that their test results were explained in ways that they understood, 82% felt their healthcare provider was knowledgeable about Sjögren's, and 80% expressed confidence in the care received.

Opportunities exist for providers to better address common and complex manifestations of Sjögren's disease including fatigue, brain fog, and trouble sleeping; neurological and gastrointestinal symptoms and conditions; and conditions impacting sexual health and function. **People with Sjögren's also identified a need for improved coordination of their care across subspecialties.**

THIS IS SJÖGREN'S: Findings from the 2025 survey are consistent with those from the 2021 *Living with Sjögren's* survey, which included 3,622 respondents. (See the 2021 *Living with Sjögren's* Summary, available on www.sjogrens.org, for more information.) Given the alignment of findings across datasets, the Sjögren's Foundation believes that the results presented here reflect the lived reality of individuals with the disease.

About the Survey

The 2025 *Living with Sjögren's* survey was conducted in the United States using an online instrument administered by The Harris Poll on behalf of the Sjögren's Foundation. The online survey instrument received Institutional Review Board (IRB) approval before it was launched and was open to adults aged 18 years or older with a diagnosis of Sjögren's disease. Data collection occurred between August 7 and September 4, 2025. A total of 6,360 completed responses were received.

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.

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