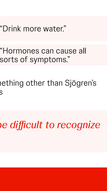


CONNECTING THE DOTS IN SJÖGREN'S DISEASE

New research reveals how women experience Sjögren's disease (SjD), from seemingly unrelated symptoms that can delay diagnosis to a persistent whole-body, whole-life burden and the search for meaningful disease control.*

SjD is a systemic autoantibody-driven disease that can affect multiple parts of the body, disproportionately affecting women, who are nine times more likely than men to have SjD.1 Often associated with dry eyes and dry mouth, it can affect areas including the joints, lungs, kidneys and nervous system.2



Missed connections: When one disease looks like many symptoms

95% were told their symptoms were unrelated to each other before diagnosis

What patients heard:

- **73%** "You're probably stressed or anxious."
- **67%** "Use some eye drops."
- **57%** "Drink more water."
- **53%** "Hormones can cause all sorts of symptoms."

60% said they were told their symptoms were something other than Sjögren's disease more than five times before diagnosis

When symptoms are seen separately, it can be difficult to recognize the bigger picture of SjD.



When answers take years

79% waited 3–9 years from first experiencing symptoms to receiving an SjD diagnosis

The search for answers:

- **56%** saw four or more healthcare professionals before someone seriously investigated their symptoms
- **43%** said symptoms became more severe before diagnosis
- **24%** experienced symptoms spreading to new areas of the body
- **56%** said worsening symptoms ultimately led to their diagnosis

68% believe their symptoms could have been better managed had they been diagnosed earlier

Patients linked delays in diagnosis with:

- **86%** worsening fatigue
- **84%** increased pain
- **70%** emotional distress
- **63%** worsening inflammation

> *"I knew something was wrong, but it took a long time for others to understand what I was experiencing. that waiting period was the hardest part of the whole experience."*

While women search for answers, symptoms can worsen and affect new areas of the body.



A whole-body disease with a whole-life impact

66% say symptoms significantly affect daily life every day or most days

37% say the disease has caused them to delay major life decisions

Where women report SjD affects the body:

- **98%** mouth
- **93%** eyes
- **72%** joints
- **69%** skin
- **48%** muscles
- **39%** reproductive system

> *"What worries me most is not being able to fully participate in life's special moments simply because I do not have the energy."*

SjD affects almost every aspect of day-to-day life:

- **88%** daily function, including sleep disruption and limited physical activity
- **84%** emotional wellbeing and relationships
- **54%** workplace disruption
- **50%** social life, including avoiding or limiting social experiences
- **74%** financial strain

The impact of SjD can reach beyond physical symptoms, affecting how women function, work, connect with others and plan for the future.

When treatment does not equal control

98% have been prescribed symptom-directed treatments

68% feel they are managing individual symptoms rather than controlling their disease

What women experience despite treatment for their symptoms:

- **53%** say symptoms have stayed the same or worsened since beginning treatment
- **67%** feel inflammation in their body is not fully controlled
- **63%** continue experiencing flares or periods of increased inflammation despite treatment
- **63%** feel symptoms remain poorly controlled even after

> *"Despite taking medication my symptoms are not improving and that worries me."*

Being treated is not necessarily the same as feeling in control of SjD. Many women continue to experience persistent symptoms and uncertainty about what comes next.

Looking ahead: What SjD could mean for the future

> *"What worries me most is how this will impact my life overall in the future not just the symptoms I feel right now."*

- **78%** worry about the long-term impact of SjD
- **77%** worry SjD will continue to spread to other parts of their body
- **74%** worry about severe or life-threatening complications

> *"The biggest concern is not knowing how my condition will change in the future, even with treatment."*

- **75%** would like to be better informed by their doctor about new medical advancements
- **46%** were not informed or still need more information about the systemic nature of SjD
- **42%** do not fully understand how their disease may progress over time

Women are looking beyond day-to-day symptoms to what SjD could mean for their whole body and future, and many still want more information about the systemic nature of the disease and how it may progress.

*Johnson & Johnson commissioned a survey of 1,000 women across the United States, Germany and Brazil. Research was conducted from June 8–23, 2025. The 20-minute online survey included 300 women with SjD, 300 women with rheumatoid arthritis (RA) and 400 women without RA or SjD. Participants were 18 years or older. Quotas were set to ensure that the number of participants were equivalent to reflect the female population in each market. Five in-depth interviews with US healthcare professionals were also conducted to provide additional context to the survey findings.

References
1. National Institute of Health. Sjogren's Disease. https://www.niams.nih.gov/health-info/sjogrens-disease. Last accessed: October 2026.
2. Carsons SE, Patel RC. Sjogren Syndrome. [Updated 2022 Jul 25]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 Jan. Available from: https://www.ncbi.nlm.nih.gov/books/NBK430548/

Johnson&Johnson