

Understanding the Social and Emotional Impact on People Living With Indolent Systemic Mastocytosis:

Findings From a European Survey

Indolent systemic mastocytosis: the name doesn't tell the whole story

People living with indolent systemic mastocytosis (ISM) need to navigate challenges in every part of their life

For those with moderate to severe symptoms, these challenges can be even greater



What we already know

- About 85% of people living with systemic mastocytosis (SM) have ISM¹⁻³
- People living with ISM experience ongoing and debilitating symptoms (including **fatigue**, **anaphylaxis**, and **impaired brain function**) that can impact their quality of life. These symptoms can affect daily life^{4,5}
- Important findings from the Perceptions, Realities & Insights on SM (PRISM) patient survey showed that people living with ISM often experienced moderate to severe symptoms because of their disease⁶
- This PRISM analysis studied the emotional and social burden of ISM, its impact on daily function, mental well-being, and participation in work and relationships

Glossary

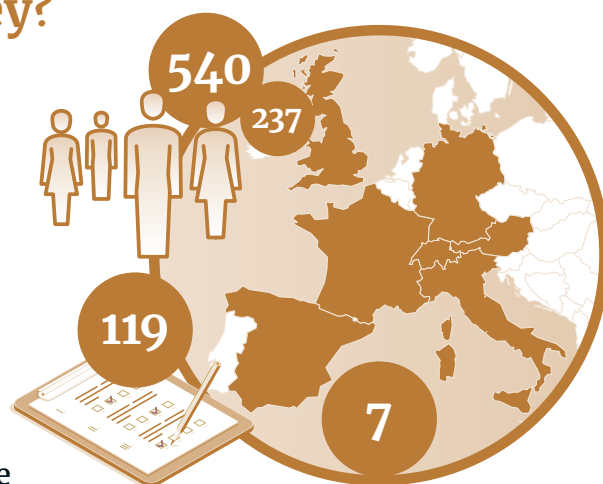
Anaphylaxis: A severe, potentially life-threatening allergic reaction

Impaired brain function: This includes difficulty with memory and thinking, migraines, and sleep problems

Fatigue: A feeling of tiredness or lack of energy

What is the PRISM patient survey?

- 540 adults with SM answered the survey
 - 237 were people living with ISM
- 7 European countries were involved
 - Austria, France, Germany, Italy, Spain, Switzerland, and the UK
- Surveys were completed between November 2022 and August 2023
- A 119-item questionnaire that asked about the symptoms, severity of SM, and impact on daily life



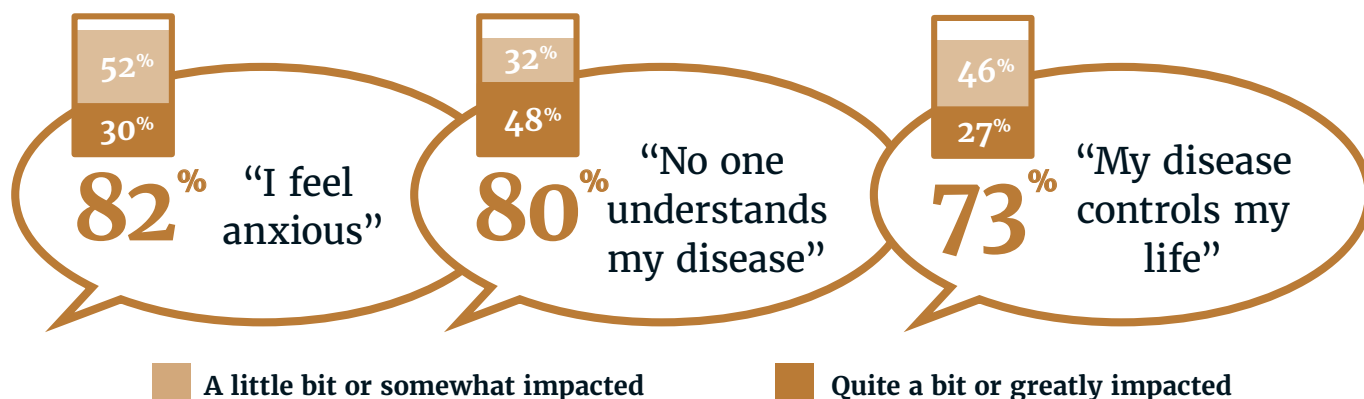
What did we find?

- About 2 out of 3 people living with ISM experienced moderate or severe symptoms

	Number	Average age	Female	Months since diagnosis
People living with ISM	237	~49	71%	~115
People experiencing moderate or severe symptoms	158	~47	76%	~92
People experiencing mild symptoms	79	~52	61%	~161

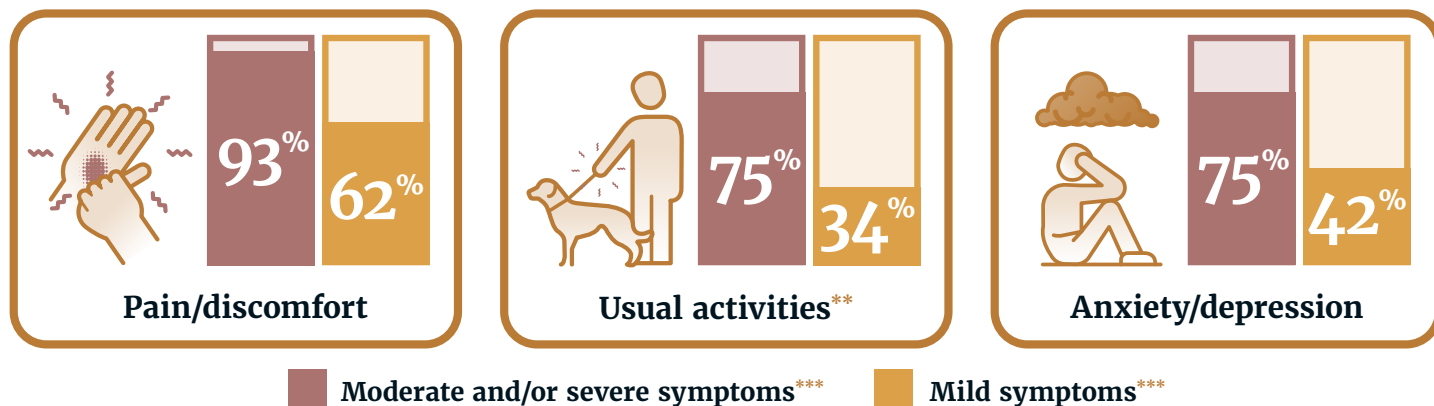
Symptoms were measured using the ISM-Symptom Assessment Form (©2018 Blueprint Medicines Corporation) which works out a total symptom score (TSS) based on how severe symptoms are. Each of 11 ISM symptoms are scored 0–10 (0=no symptom; 10=worst imaginable symptom.) These scores are summed to create a TSS (0–110). A TSS lower than 28 is classed as mild symptoms, and a TSS higher than or equal to 28 is classed as moderate and/or severe symptoms.

- The emotional and mental health of all people living with ISM is impacted by their disease*



*This constitutes a non-comprehensive list. These numbers represent the summed values of specific underlying scores. Patients scored each statement on a 1–5 scale, where 1 = no impact at all, 2 = a little bit, 3 = somewhat, 4 = quite a bit, and 5 = a great deal of impact.

- Most people living with ISM had problems with daily living*

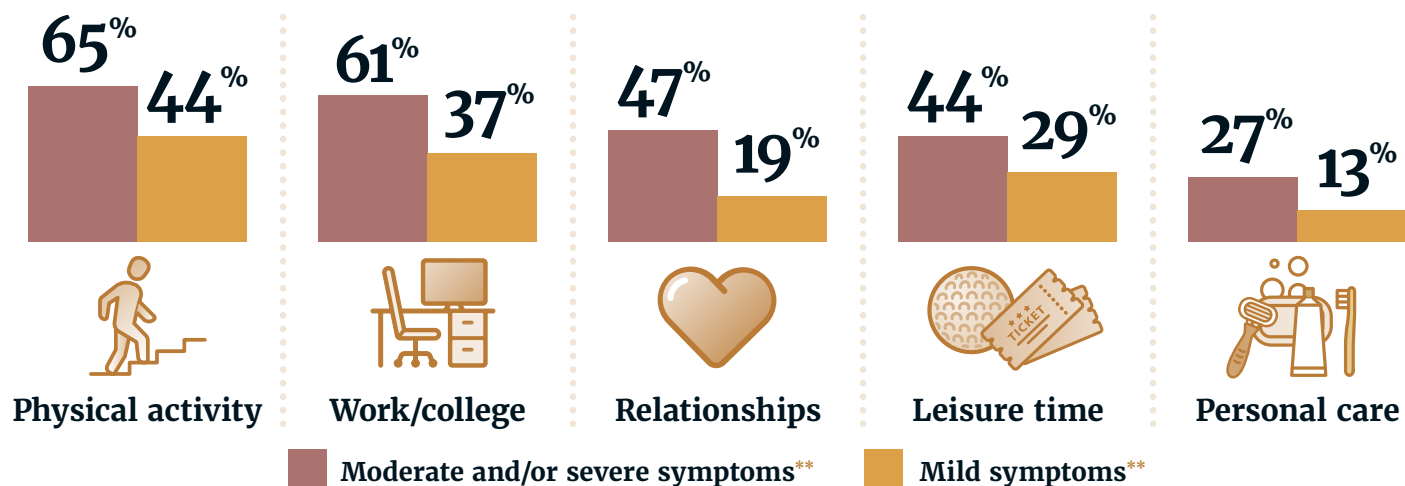


*This constitutes a non-comprehensive list. These numbers represent the summed values of specific underlying scores. The scale corresponds to the following categories: Slight problems/symptoms; moderate problems/symptoms; severe problems/symptoms; unable to do activity/extreme symptoms.

**Usual activities include work, study, homework, family, or leisure activities.

***A TSS lower than 28 is classed as mild symptoms, and a TSS higher than or equal to 28 is classed as moderate and/or severe symptoms.

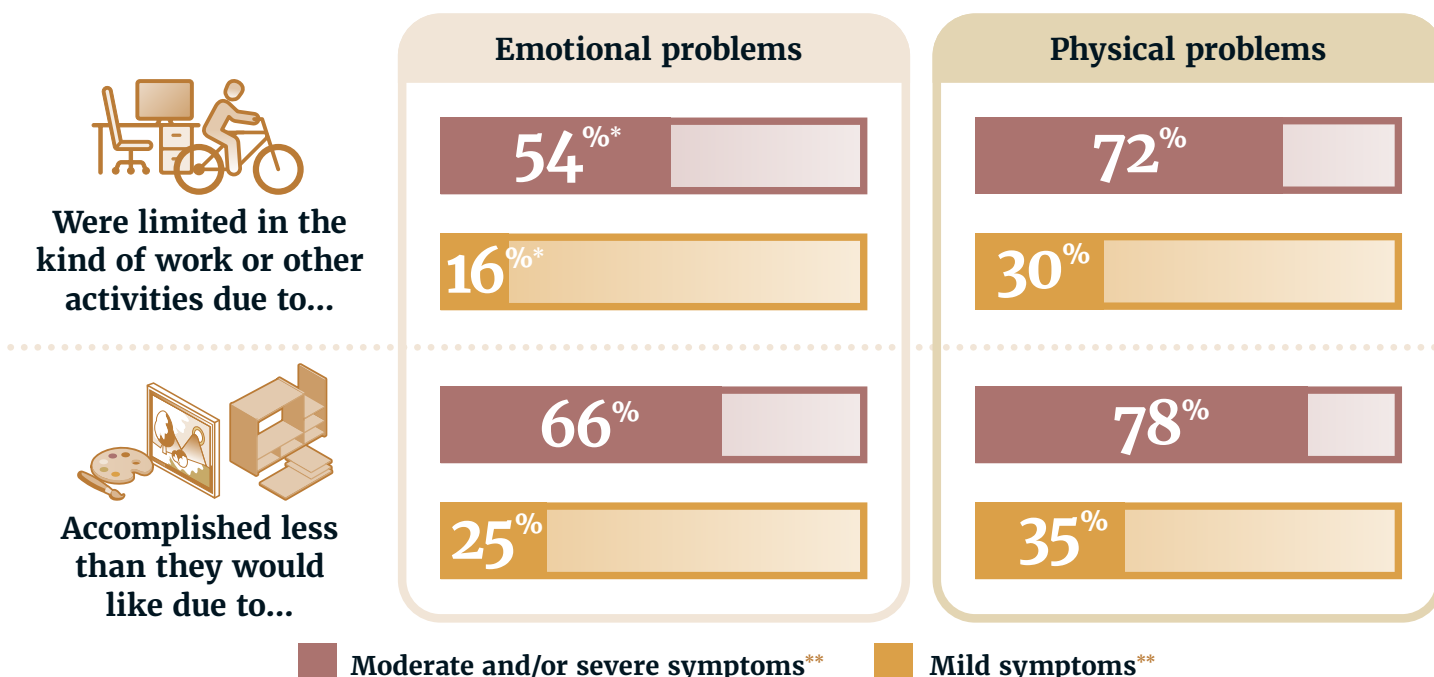
- Many people living with ISM had their social, leisure, and daily activities impacted by their disease*



*This constitutes a non-comprehensive list.

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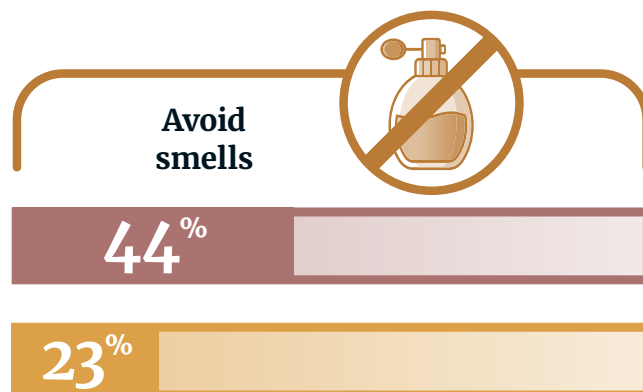
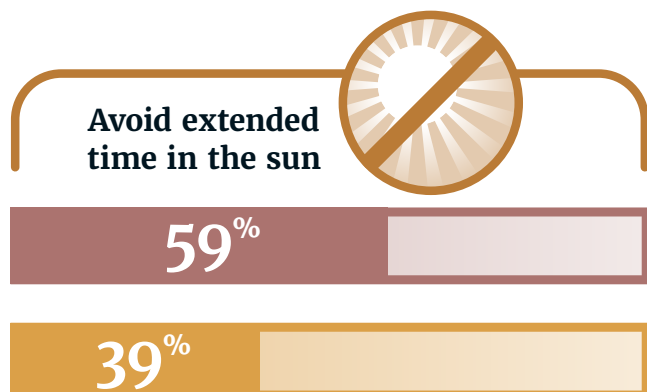
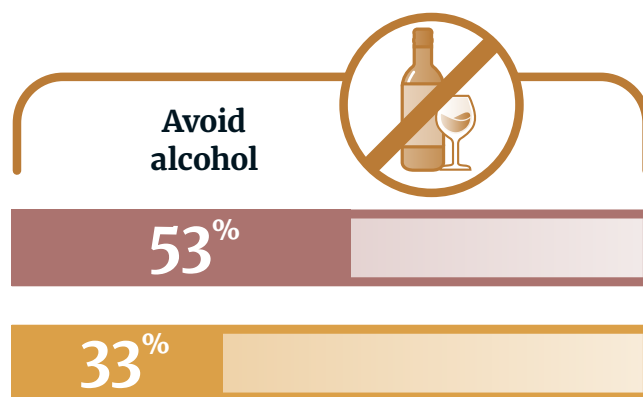
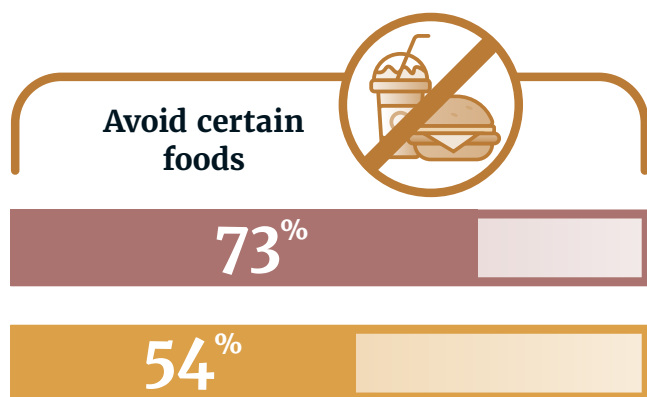
- People living with ISM had trouble doing their work and daily activities because their disease caused both emotional and physical problems



*Didn't do work or other activities as carefully as usual due to emotional problems.

**A TSS lower than 28 is classed as mild symptoms, and a TSS higher than or equal to 28 is classed as moderate and/or severe symptoms.

- People living with ISM needed to make changes to their daily life because of their



■ Moderate and/or severe symptoms** ■ Mild symptoms**

*This constitutes a non-comprehensive list.

**A TSS lower than 28 is classed as mild symptoms, and a TSS higher than or equal to 28 is classed as moderate and/or severe symptoms.

What does this mean?

- The PRISM patient survey revealed that ISM can have an impact on people's emotional and social well-being
- This underscores the importance of coordinated care approaches that support both physical and mental health to improve overall well-being

To gain a better understanding of SM, visit: www.navigatingSM.com

This summary is based on a presentation from EAACI 2025 called: The Socio-Emotional Impact of Indolent Systemic Mastocytosis: Insights From the PRISM Survey. Jessica Hobart, Ruben Mesa, Iván Alvarez-Twose, Amélie Beaux, Gabriela Coletti, Nicole Hegmann, Cristina Bulai Livideanu, Patrizia Marcis, Deepti H. Radia, Eugenia Ribada, Franziska Ruëff, Waltraud Schinhofen, Dakota Powell, Teresa Green, Cristian Perez, Massimo Triggiani.

1. Ungerstedt J, et al. *Cancers*. 2022;14:3942; 2. Sperr WR, et al. *Lancet Haematol*. 2019;6:e638–e649; 3. Cohen SS, et al. *Br J Haematol*. 2014;166:521–528; 4. Mesa RA, et al. *Cancer*. 2022;128:3700–3708; 5. van Anrooij B, et al. *Allergy*. 2016;71:1585–1593; 6. Triggiani M et al. Presented at EAACI 2024, 000405.