

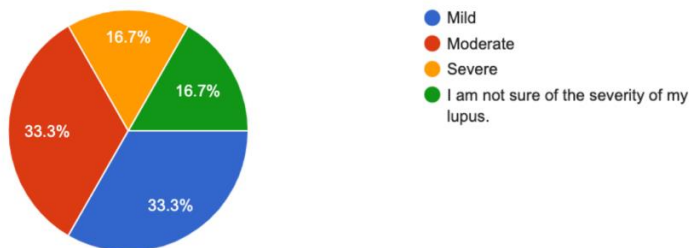
## LUPUS CANADA INFORMATIONAL SURVEY

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Lupus Canada shared a survey with our lupus community to gather information about lupus patients experiences with symptoms of lupus. This information is not for research but will be used to support and inform applications to Health Canada by pharmaceutical companies as part the regulatory requirements to bring drugs to market. The survey results are summarized without identifiers. This data will be shared with pharmaceutical companies to support applications for drug approval to Health Canada. The survey results may help regulators and health technology assessment bodies to understand what the benefit of new treatments is and who would benefit most from them, thereby improving their ability to make new treatments available for people with lupus.

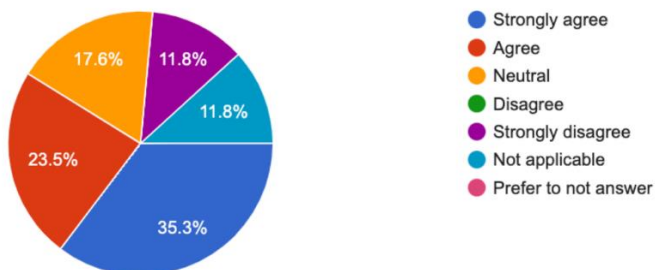
### 1. Is your Lupus?

- A. Mild = 33.3%
- B. Moderate = 33.3%
- C. Severe = 16.7%
- D. I am not sure of the severity of my lupus = 16.7%



### 2. If your lupus has impacted your work life please select one option below, strongly agree being that your lupus has strongly impacted your work life.

- A. Strongly agree = 35.3%
- B. Agree = 23.5%
- C. Neutral = 17.6%
- D. Disagree = 0%
- E. Strongly disagree = 11.8%
- F. Not applicable = 11.8%
- G. Prefer to not answer = 0%

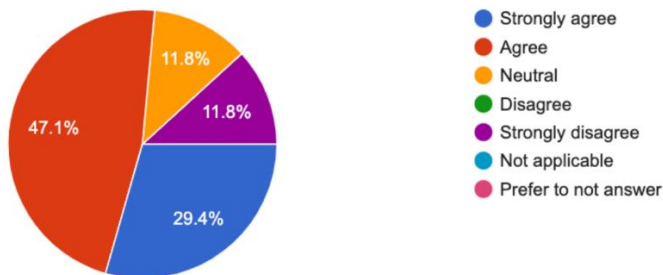


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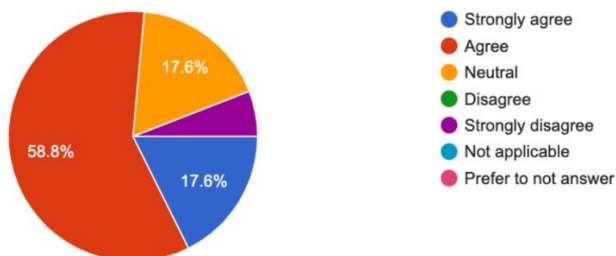
**3. If your lupus has impacted your home life please select one option below, strongly agree being that your lupus has strongly impacted your home life.**

- A. Strongly agree = 29.4%
- B. Agree = 47.1%
- C. Neutral = 11.8%
- D. Disagree = 0%
- E. Strongly disagree = 11.8%
- F. Not applicable = 29.4%
- G. Prefer to not answer = 0%



**4. If your lupus has impacted your ability to participate in daily life please select one option below, strongly agree being that your lupus has strongly impacted your ability to participate in daily life.**

- A. Strongly agree = 17.6%
- B. Agree = 58.8%
- C. Neutral = 17.6%
- D. Disagree = 0%
- E. Strongly disagree = 5.9%
- F. Not applicable = 17.6%
- G. Prefer to not answer = 0%

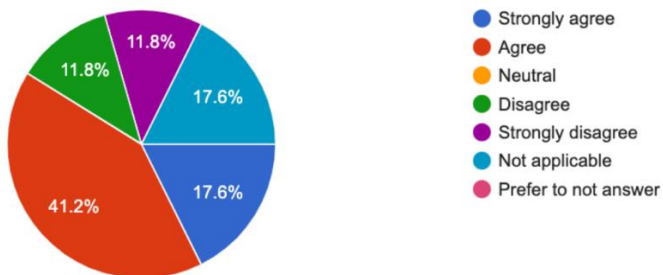


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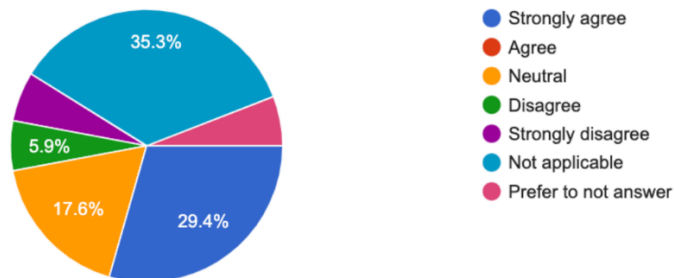
**5. If your lupus has impacted your productivity at work please select one option below, strongly agree being that your lupus has strongly impacted your productivity at work.**

- A. Strongly agree = 17.6%
- B. Agree = 41.2%
- C. Neutral = 0%
- D. Disagree = 11.8%
- E. Strongly disagree = 11.8%
- G. Not applicable- = 17.6.3%
- H. Prefer to not answer = 0%



**6. If your lupus has impacted your disability and insurance claims please select one option below, strongly agree being that your lupus has strongly impacted your disability and insurance claims.**

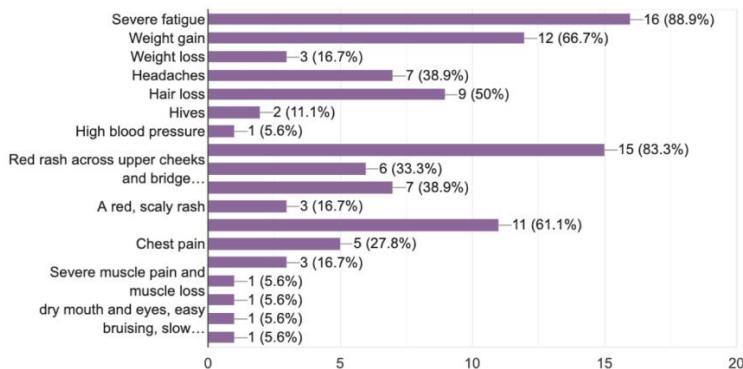
- A. Strongly agree = 29.4%
- B. Agree = 0%
- C. Neutral = 17.6%
- D. Disagree = 5.9%
- E. Strongly disagree = 5.9%
- F. Not applicable = 35.3%
- G. Prefer to not answer = 5.9%



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**7. While each person's symptoms or experience with lupus differs, which symptoms below are more bothersome to you? Please select any that are applicable to you.**

- A. Severe fatigue = 88.9%
- B. Weight gain = 66.7%
- C. Weight loss = 16.7%
- D. Headaches = 38.9%
- E. Hair loss = 50%
- F. Hives = 11.1%
- G. High blood pressure = 5.6%
- H. Joint Pain (swelling, redness, and heat) = 83.3%
- I. Red rash across upper cheeks and bridge of nose = 33.3%
- J. Unusual reaction to sunlight = 38.9%
- K. A red, scaly rash = 16.7%
- L. Sores inside the nose or mouth = 61.1%
- M. Chest pain = 27.8%
- N. Seizures or severe psychological symptoms = 16.7%
- O. Other
  - Severe muscle pain and muscle loss = 5.6%
  - Pleural effusion, pericarditis, pleurisy = 5.6%
  - Dry mouth and eyes and easy bruising = 5.6%
  - Anemia and vasculitis = 5.6%



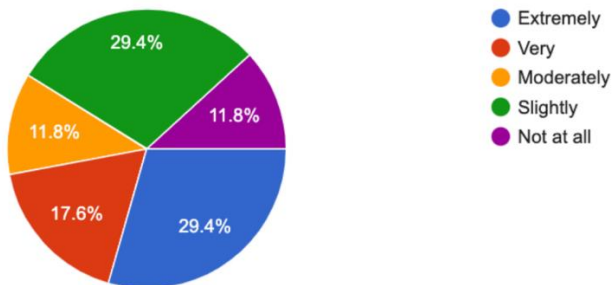
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### 8. Have you experienced depression, anxiety, and/or cognitive impairment related to your lupus?

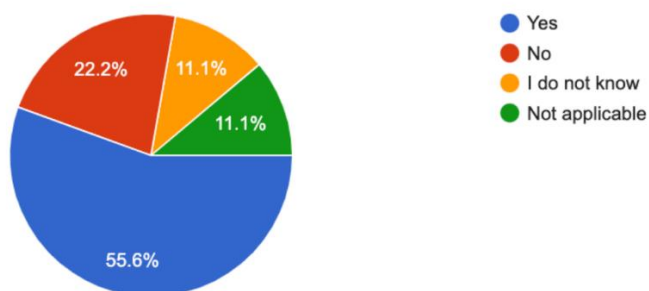
**Extremely being that you have experienced extreme depression, anxiety, and/or cognitive impairment due to your lupus.**

- A. Extremely = 29.4%
- B. Very = 17.6%
- C. Moderately = 11.8%
- D. Slightly = 29.4%
- E. Not at all = 11.8%



### 9. Has your depression, anxiety, cognitive impairment related to your lupus impacted your life?

- A. Yes = 55.6%
- B. No = 22.2%
- C. I do not know = 11.1%
- D. Not applicable = 11.1%

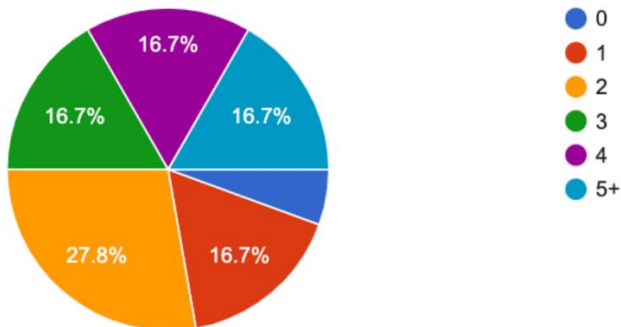


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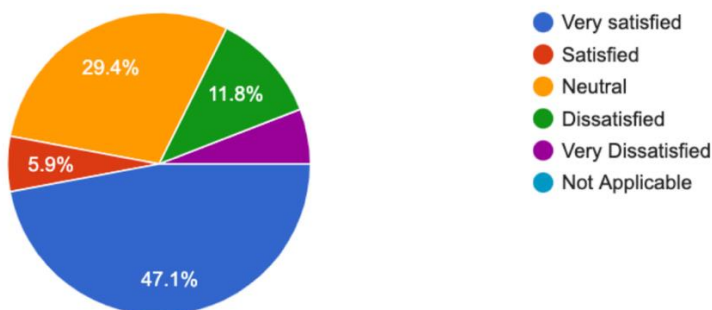
### 10. How many drugs are you currently taking to specifically manage your lupus?

- A. 0 = 5.6%
- B. 1 = 16.7%
- C. 2 = 27.8%
- D. 3 = 16.7%
- E. 4 = 16.7%
- F. 5+ = 16.7%



### 11. Are you satisfied with your current lupus treatments?

- A. Very satisfied = 47.1%
- B. Satisfied = 5.9%
- C. Neutral = 29.4%
- D. Dissatisfied = 11.8%
- E. Very Dissatisfied = 5.9%
- F. Not Applicable = 0%

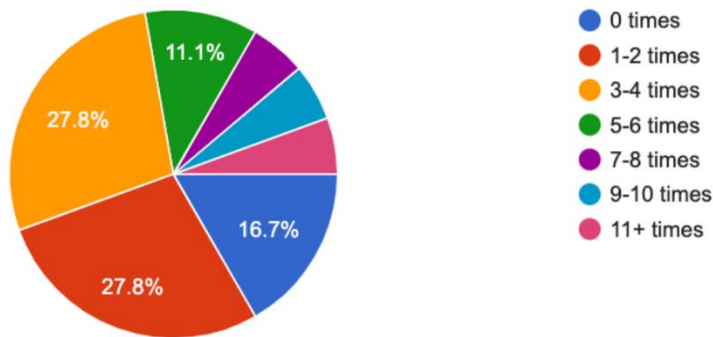


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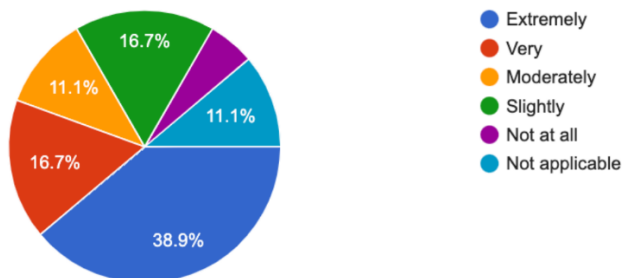
### 12. How often have you experienced flares in the past year?

- A. 0 times = 16.7%
- B. 1-2 times = 27.8%
- C. 3-4 times = 27.8%
- D. 5-6 times = 11.1%
- E. 7-8 times = 5.6%
- F. 9-10 times = 5.6%
- G. 11+ times = 5.6%



### 13. Have your lupus flares impacted your life? Extremely being that your lupus flares impact your life greatly?

- A. Extremely = 38.9%
- B. Very = 16.7%
- C. Moderately = 11.1%
- C. Slightly = 16.7%
- D. Not at all = 5.6%
- E. Not applicable = 11.1%





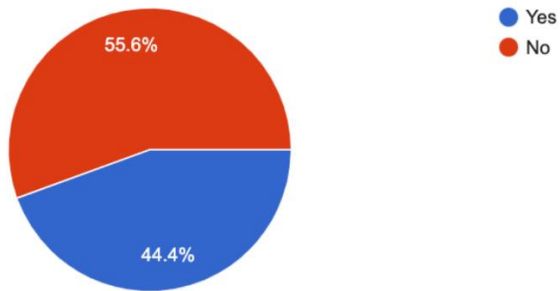
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**14. Have you had to go to the emergency department or be admitted to hospital because of the flare?**

A. Yes = 44.4%

B. No = 55.6%



**15. How often have you had to take oral corticosteroids (eg. prednisone) to help control your flares?**

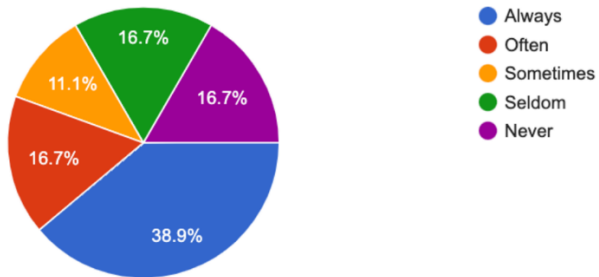
A. Always = 38.9%

B. Often = 16.7%

C. Sometimes = 11.1%

D. Seldom = 16.7%

E. Never = 16.7%



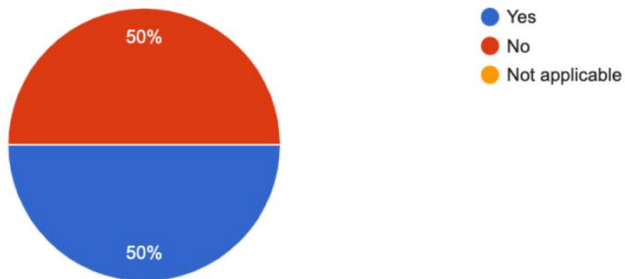


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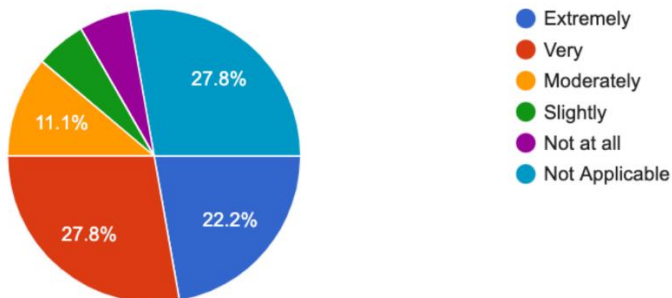
### 16. Do you take oral corticosteroids daily, self-medicating as needed?

- A. Yes = 50%
- B. No = 50%
- C. Not applicable = 0%



### 17. Have oral corticosteroids had any effects had on you?

- A. Extremely = 22.2%
- B. Very = 27.8%
- C. Moderately = 11.1%
- D. Slightly = 5.6%
- E. Not at all = 5.6%
- F. Not Applicable = 27.8%

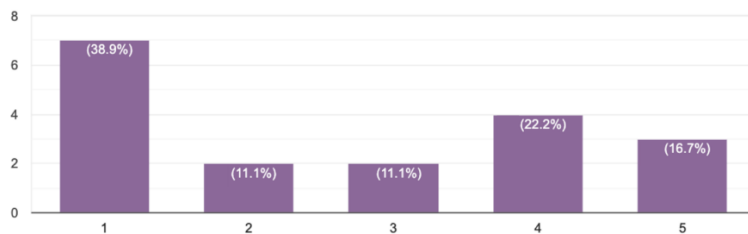


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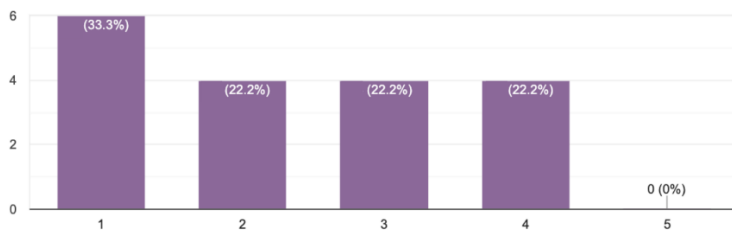
### 18. Do you worry about how much your lupus impacts your family life?

- A. 1 (Yes I worry a lot) = 38.9%
- B. 2 = 11.1%
- C. 3 = 11.1%
- D. 4 = 22.2%
- E. 5 (No, I do not worry at all) = 16.7%



### 19. Do you worry about how much your lupus impacts your daily life?

- A. 1 (Yes I worry a lot) = 33.3%
- B. 2 = 22.2%
- C. 3 = 22.2%
- D. 4 = 22.2%
- E. 5 (No, I do not worry at all) = 0%

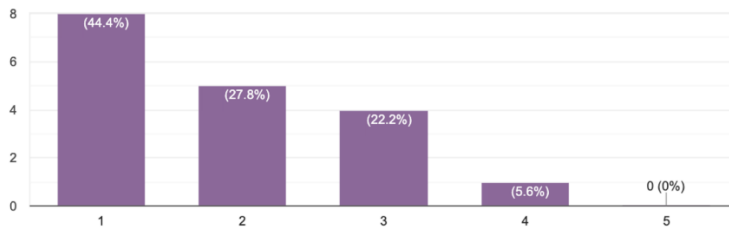


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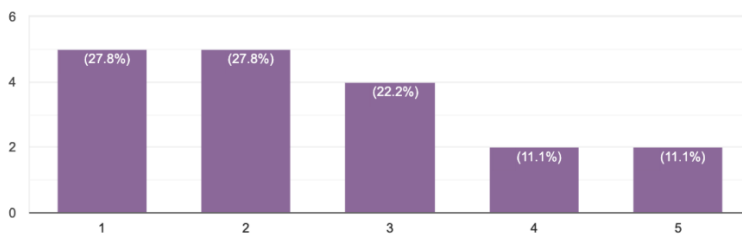
### 20. Do you worry about how much your lupus impacts your organs?

- A. 1 (Yes I worry a lot)= 44.4%
- B. 2 = 27.8%
- C. 3 = 22.2%
- D. 4 = 5.6%
- E. 5 ( No, I do not worry at all) = 0%



### 21. Do you worry about if your lupus impacts or will impact how much you can/will work?

- A. 1 (Yes I worry a lot)= 27.8%
- B. 2 = 27.8%
- C. 3 = 22.2%
- D. 4 = 11.1%
- E. 5 ( No, I do not worry at all) = 11.1%

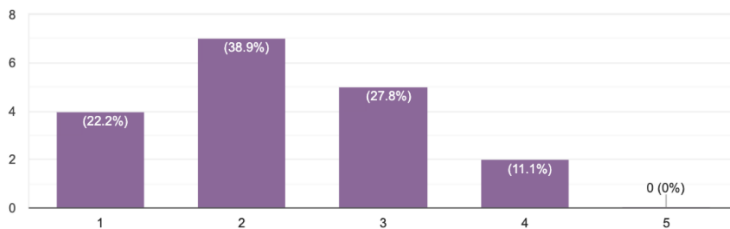


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### 22. Do you worry about the financial impact of living with lupus?

- A. 1 (Yes I worry a lot) = 22.2%
- B. 2 = 38.9%
- C. 3 = 27.8%
- D. 4 = 11.1%
- E. 5 ( No, I do not worry at all) = 0%



### 23. What advice do you think would be the most important to give someone recently diagnosed with lupus?

- A. Inform yourself about the disease from reliable sources (ie. Lupus Canada) = 50%
- B. Ask a lot of questions = 5.6%
- C. Know your limits and know that it is okay to need to say no sometimes = 38.9%
- D. It is very important to remember that you do not always have to do a day well, you just have to do the day. If you do not accomplish all that you meant to, be kind to yourself = 5.6%



### 24. How would you determine if your lupus treatment was effective?

- A. I have more energy = 27.8%
- B. I generally feel better = 55.6%
- C. I can do light activity = 11.1%
- D. I can exercise and play sports as I please = 5.6%