

Appendix A. LupusQoL Questionnaire

The following questionnaire is designed to find out how SLE affects your life. **Read** each statement and then circle the response, which is **closest to how you feel**. Please try to answer all the questions as honestly as you can.

How often over the last 4 weeks

1. Because of my Lupus I need help to do heavy physical jobs such as digging the garden, painting and/or decorating, moving furniture

All of the time most of the time a good bit of the time occasionally never

2. Because of my Lupus I need help to do moderate physical jobs such as vacuuming, ironing, shopping, cleaning the bathroom

All of the time most of the time a good bit of the time occasionally never

3. Because of my Lupus I need help to do light physical jobs such as cooking/preparing meals, opening jars, dusting, combing my hair or attending to personal hygiene

All of the time most of the time a good bit of the time occasionally never

4. Because of my Lupus I am unable to perform everyday tasks such as my job, childcare, housework as well as I would like to

All of the time most of the time a good bit of the time occasionally never

5. Because of my Lupus I have difficulty climbing stairs

All of the time most of the time a good bit of the time occasionally never

6. Because of my Lupus I have lost some independence and am reliant on others

All of the time most of the time a good bit of the time occasionally never

7. I have to do things at a slower pace because of my Lupus

All of the time most of the time a good bit of the time occasionally never

8. Because of my Lupus my sleep pattern is disturbed

All of the time most of the time a good bit of the time occasionally never

How often over the last 4 weeks

9. I am prevented from performing activities the way I would like to because of pain due to Lupus

All of the time most of the time a good bit of the time occasionally never

10. Because of my Lupus, the pain I experience interferes with the quality of my sleep

All of the time most of the time a good bit of the time occasionally never

11. The pain due to my Lupus is so severe that it limits my mobility

All of the time most of the time a good bit of the time occasionally never

12. Because of my Lupus I avoid planning to attend events in the future

All of the time most of the time a good bit of the time occasionally never

13. Because of the unpredictability of my Lupus I am unable to organise my life efficiently

All of the time most of the time a good bit of the time occasionally never

14. My Lupus varies from day to day which makes it difficult for me to commit myself to social arrangements

All of the time most of the time a good bit of the time occasionally never

15. Because of the pain I experience due to Lupus I am less interested in a sexual relationship

All of the time most of the time a good bit of the time occasionally never not applicable

16. Because of my Lupus I am not interested in sex

All of the time most of the time a good bit of the time occasionally never not applicable

17. I am concerned that my Lupus is stressful for those who are close to me

All of the time most of the time a good bit of the time occasionally never

18. Because of my Lupus I am concerned that I cause worry to those who are close to me

All of the time most of the time a good bit of the time occasionally never

19. Because of my Lupus I feel that I am a burden to my friends and/or family

All of the time most of the time a good bit of the time occasionally never

Over the past 4 weeks I have found my Lupus makes me

20. Resentful

All of the time most of the time a good bit of the time occasionally never

21. So fed up nothing can cheer me up

All of the time most of the time a good bit of the time occasionally never

22. Sad

All of the time most of the time a good bit of the time occasionally never

23. Anxious

All of the time most of the time a good bit of the time occasionally never

24. Worried

All of the time most of the time a good bit of the time occasionally never

25. Lacking in self-confidence

All of the time most of the time a good bit of the time occasionally never

How often over the past 4 weeks

26. My physical appearance due to Lupus interferes with my enjoyment of life

All of the time most of the time a good bit of the time occasionally never

(continued)

Appendix A LupusQoL Questionnaire *(Continued)*

The following questionnaire is designed to find out how SLE affects your life. **Read** each statement and then circle the response, which is **closest to how you feel**. Please try to answer all the questions as honestly as you can.

27. Because of my Lupus, my appearance (e.g. rash, weight gain/loss) makes me avoid social situations
All of the time most of the time a good bit of the time occasionally never not applicable

28. Lupus related skin rashes make me feel less attractive
All of the time most of the time a good bit of the time occasionally never not applicable

How often over the past 4 weeks

29. The hair loss I have experienced because of my Lupus makes me feel less attractive
All of the time most of the time a good bit of the time occasionally never not applicable

30. The weight gain I have experienced because of my Lupus treatment makes me feel less attractive
All of the time most of the time a good bit of the time occasionally never not applicable

31. Because of my Lupus I cannot concentrate for long periods of time
All of the time most of the time a good bit of the time occasionally never

32. Because of my Lupus I feel worn out and sluggish
All of the time most of the time a good bit of the time occasionally never

33. Because of my Lupus I need to have early nights
All of the time most of the time a good bit of the time occasionally never

34. Because of my Lupus I am often exhausted in the morning
All of the time most of the time a good bit of the time occasionally never

Please feel free to make any additional comments.

Please check that you have answered each question

Thank you, for completing this questionnaire

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