

L-Carnitine Questionnaire

Co-Enzyme Q10, L-Carnitine and Amitriptyline Usage in Cyclic Vomiting Syndrome

Did you ever take L-carnitine? (Carnitor or generic) (please circle answer) YES NO

If the answer is “No”, please skip all of these questions, yet answer the other questionnaires.

If the answer is “Yes”, please answer the following questions:

If you are a parent of a child with CVS, then the word “you” refers to “your child” throughout the survey questions.

1. How long did you take L-carnitine for (example: 2 months)?
2. Did you start L-carnitine and co-enzyme Q10 at about the same time? YES NO (please circle)
3. Did you start L-carnitine and anything else at about the same time? YES NO (please circle)
 - a. If “YES”, then what else did you start at that time?
4. How many times a day did you take L-carnitine (example: twice a day)?
5. What amount did you take each time you took L-carnitine (example: 1000 mg)?
6. Did you take L-carnitine with food?
7. What was your approximate weight at the time that you were taking L-carnitine (example: 50 lbs)?
8. What was the name of the manufacturer of L-carnitine (if known)?
9. What formulation did you take? (Please circle all that apply): GEL CAPSULES TABLETS LIQUID OTHER (please specify):

10. Do you have cyclic vomiting syndrome? YES NO DON'T KNOW (please circle)
If no, please skip to question #21
11. Prior to taking L-carnitine, did vomiting episodes occur at fairly regular intervals, in response to triggers/stressors (illness, etc.) or did they mostly occur at random?
(Please circle the best response):
REGULAR INTERVALS WITH STRESSORS AT RANDOM
 - a. Did L-carnitine change this vomiting pattern? YES NO (please circle)
If “Yes”, then please circle the pattern on L-carnitine treatment: (please circle)
 - i. REGULAR INTERVALS WITH STRESSORS AT RANDOM
 - b. If you answered “with stressors”, please circle all of the triggers or stressors that you believe have triggered vomiting episodes (please circle):
ILLNESS (colds, etc.) FASTING CERTAIN FOODS EXCITEMENT ANXIETY EXERCISE OTHER (please specify): _____
12. How frequent did you have vomiting episodes prior to starting L-carnitine in the last 12 months (examples: 4 episodes a year, every two weeks, no episodes, etc.)?
13. How frequent did you have vomiting episodes while taking L-carnitine (examples: 4 episodes a year, every two weeks, no episodes, etc.)?
 - a. If you have not had any episodes since you started taking L-carnitine, please check here: _____

14. How long did episodes of nausea and/or vomiting last prior to starting L-carnitine (examples: 12 hours, 4 days)?
15. How long did episodes of nausea and/or vomiting last while taking L-carnitine (examples: 12 hours, 4 days)?
16. How severe was the nausea prior to starting L-carnitine on a 1 to 10 scale, with 10 being the worst discomfort imaginable?
17. How severe was the nausea while taking L-carnitine on a 1 to 10 scale, with 10 being the worst discomfort imaginable?
18. How many times did you generally vomit during episodes prior to starting L-carnitine (examples: 6 per episode, 4 times per hour)?
19. How many times did you generally vomit during episodes while taking L-carnitine (examples: 6 times an episode, 4 times per hour)?
20. Do you generally have symptoms before nausea and vomiting start (“prodrome”)?
 - a. If so, what symptoms (please circle all applicable responses)? (please circle)
 BEHAVIORAL CHANGES/LETHARGY/IRRITABILITY
 CHANGE IN SECRETIONS (bowel movements, tears, sweat, saliva, etc.)
 CHANGES IN APPETITE/THIRST
 OTHER, please specify: _____
 - b. Did L-carnitine affect these symptoms? YES NO (please circle).
 If “Yes”, how?
21. Did you suffer from headaches severe enough to change your routine or cause significant distress prior to starting L-carnitine? YES NO (please circle).
 If “No”, skip to the question #22.
 - a. How often did you have headaches prior to starting L-carnitine (examples: three times a week, once every 2 weeks)?
 - b. How often did you have headaches while taking L-carnitine (examples: three times a week, once every 2 weeks)?
 - c. How long did headaches last prior to starting L-carnitine (examples: 2 hours, all day)?
 - d. How long did headaches last while taking L-carnitine (examples: 2 hours, all day)?
 - e. How severe was the average headache prior to starting L-carnitine on a 1 to 10 scale, with 10 being the worst headache imaginable?
 - f. How severe was the average headache while taking L-carnitine on a 1 to 10 scale, with 10 being the worst headache imaginable?
22. Did you suffer from muscle cramps severe enough to change your routine or cause significant distress prior to starting L-carnitine? YES NO (please circle).
 If “No”, skip to question #23.
 - a. How often did you have muscle cramps prior to starting L-carnitine (examples: three times a week, once every 2 weeks)?
 - b. How often did you have muscle cramps while taking L-carnitine (examples: three times a week, once every 2 weeks)?
 - c. How long did muscle cramps last prior to starting L-carnitine (examples: 2 hours, all day)?
 - d. How long did muscle cramps last while taking L-carnitine (examples: 2 hours, all day)?
 - e. How severe were the average muscle cramps prior to starting L-carnitine on a 1 to 10 scale, with 10 being the worst muscle cramps imaginable?
 - f. How severe were the average muscle cramps while taking L-carnitine on a 1 to 10 scale, with 10 being the worst muscle cramps imaginable?

23. If L-carnitine helped to relieve some symptoms much more than others, please write in those symptoms that have improved:

Please write in any symptoms that did not improve:

24. If there was an improvement after giving L-carnitine, how long after starting it did you notice the beginning of improvement (examples: immediately, three months)?

a. How long after starting it did the improvement take to reach its full extent (examples: immediate, three months, still improving after 6 months)?

25. Did you have more “energy”, endurance or muscle strength while taking L-carnitine? (please circle)

YES, STRONGLY

YES

SORT OF EQUAL/NOT SURE

NO CHANGE

NO, I AM/WAS WORSE

I HAVE NOT TAKEN L-CARNITINE LONG ENOUGH YET TO KNOW

26. Did L-carnitine help with any symptom not mentioned here? If so, please list the symptoms and how it/they were helped by L-carnitine.

27. Did you stop any medications because of positive effects from L-carnitine? YES NO (please circle)

a. If so, please cross out the name of any treatment that you **stopped taking** since you have started L-carnitine, and circle any that you decreased the dosage.

AMITRIPTYLINE (Elavil)

ONDANSETRON (Zofran)

CYPROHEPTADINE (Periactin)

SUMATRIPTAN (Imitrex)

PROPRANOLOL (Inderal)

IV FLUIDS

TOPIRAMATE (Topamax)

FREQUENT FEEDINGS

DIPHENHYDRAMINE (Benadryl)

Other: _____

L-CARNITINE (Carnitor)

28. Did you have any side effects while on L-carnitine? YES NO (please circle).

If “No”, skip to question #29.

If there were more than one side effect, please answer the following questions for each side effect (separate responses by an “ / ”).

a. What was the side effect?

b. How long after starting L-carnitine did the side effect occur?

c. Did the side effect go away or improve substantially with time? (please circle)

YES NO STOPPED L-CARNITINE SO I DON'T KNOW

d. Was the side effect severe or bothersome enough to cause you to stop taking L-carnitine? YES NO (please circle).

e. How severe was the side effect on a 1 to 10 scale, with 10 being the worst.

29. Did L-carnitine change your stools (BMs)? (please circle)

BECAME LOOSER, WHICH WAS A SIGNIFICANT PROBLEM

BECAME LOOSER, BUT NOT A SIGNIFICANT PROBLEM

BECAME LOOSER, WHICH WAS GOOD BECAUSE CONSTIPATION IMPROVED

BECAME LOOSER AT FIRST, THEN MUCH BETTER LATER

NO CHANGE

CAUSED CONSTIPATION AT FIRST, THEN MUCH BETTER LATER

CAUSED CONSTIPATION, BUT NOT A SIGNIFICANT PROBLEM

CAUSED CONSTIPATION, WHICH WAS A SIGNIFICANT PROBLEM

30. Did L-carnitine cause you to have an unpleasant odor?
 YES, WHICH WAS A SIGNIFICANT PROBLEM
 YES, BUT NOT A SIGNIFICANT PROBLEM
 YES, AT FIRST, THEN MUCH BETTER LATER
 NO CHANGE
- a. If yes, what was the odor? FISH-LIKE OTHER: _____
31. Are you still taking L-carnitine? YES NO (please circle)
 If "Yes", skip to question #32.
- a. Why did you stop L-carnitine? (please circle all applicable responses)
 DIDN'T WORK WELL ENOUGH
 EPISODES IMPROVED BY THEMSELVES
 I AM ON A BETTER THERAPY, please specify: _____
 TOO EXPENSIVE
 FORGOT TO REFILL
 SIDE EFFECTS
 OTHER, please specify: _____
- b. When you stopped L-carnitine did any improvement go away? YES NO N/A, and if so, what got worse?
 i. How long after stopping L-carnitine did any improvement go away?
- c. When you stopped L-carnitine did any side effects go away? YES NO N/A, and if so, what side effects?
 i. How long after stopping L-carnitine did any side effects go away?
32. Do you believe that the improvement that you received on L-carnitine, if any, justified the side effects that you experienced?
 YES, STRONGLY
 YES
 SORT OF EQUAL/NOT SURE
 NO
 NO, STRONGLY
 I HAVE NOT TAKEN L-CARNITINE LONG ENOUGH YET TO KNOW
 I HAVE HAD NO SIDE EFFECTS
33. Did insurance pay for the L-carnitine?
 YES
 YES, BUT ONLY ON APPEAL
 NO, IT WAS DENIED
 DIDN'T TRY
 DON'T HAVE INSURANCE
- a. What kind of insurance? (Please circle): PPO HMO MEDICAIDE OTHER, please specify _____
34. How much a month did you personally pay for the L-carnitine?
35. Do you believe that the improvement that you received on L-carnitine, if any, justified the costs that you paid?
 YES, STRONGLY
 YES
 SORT OF EQUAL/NOT SURE
 NO
 NO, STRONGLY
 I HAVE NOT TAKEN L-CARNITINE LONG ENOUGH YET TO KNOW

36. Would you recommend L-carnitine to a friend or relative with CVS?
 YES, STRONGLY
 YES
 SORT OF EQUAL/NOT SURE
 NO
 NO, STRONGLY
 I HAVE NOT TAKEN L-CARNITINE LONG ENOUGH YET TO KNOW
 OTHER, please specify: _____
37. How did you hear about L-carnitine? (please circle all applicable responses)
 PHYSICIAN (non-CVS specialist)
 CVS SPECIALIST
 CVSA NEWSLETTER
 CVSA WEBSITE
 CVS LIST SERVER/BULLETIN BOARD
 MEDICAL INTERNET SITE OR BOOK
 LECTURE/CONFERENCE ON CVS
 "WORD OF MOUTH" FROM ANOTHER PATIENT OR FAMILY
 RELATIVE/PARENT OF RELATIVE WHO IS TAKING L-CARNITINE
 OTHER, please specify: _____
38. How was the decision to try L-carnitine made? (please circle the one best answer)
 BY MY PHYSICIAN
 JOINTLY BETWEEN MY PHYSICIAN AND MYSELF
 BY MYSELF
39. What does your physician think about your taking L-carnitine?
 HIGHLY SUPPORTIVE, MY PHYSICIAN STRONGLY RECOMMENDED IT
 SUPPORTIVE, MY PHYSICIAN SUGGESTED IT
 SUPPORTIVE, BUT I SUGGESTED IT TO MY PHYSICIAN
 PARTIALLY SUPPORTIVE; TOLD ME THAT IT MIGHT HELP, BUT THAT WAS NOT LIKELY
 UNCLEAR/CONFLICTED/DOESN'T KNOW IF IT IS A GOOD IDEA OR NOT
 NON SUPPORTIVE, TOLD ME THAT IT WAS UNLIKELY TO HELP
 NON SUPPORTIVE, TOLD ME TO STOP TAKING IT
 MY PHYSICIAN DOESN'T KNOW BECAUSE I DON'T THINK THAT HE/SHE WOULD BE SUPPORTIVE
 MY PHYSICIAN DOESN'T KNOW AS IT NEVER CAME UP OR I HAVEN'T SEEN A PHYSICIAN LATELY
40. Were any other co-factors, vitamins, medications, diets or other therapies started at about the same time that L-carnitine was started?
 YES NO. If so, what?
41. Does anyone else in the family take L-carnitine? YES NO. If so, how are they related, what symptoms are being treated, and what was the response? (please explain below)
- a. If the relative has cyclic vomiting, migraine or muscle cramps and will complete a separate survey, please check here _____.
42. To your knowledge was a L-carnitine blood level drawn? YES NO DON'T KNOW.
 Note: Blood levels are rarely performed, so do not be alarmed if your answer is "No".
- a. If so, was it obtained on or off of L-carnitine, and what was the result (example: blood drawn before starting L-carnitine and result was normal)?
43. Is there any question about L-carnitine that we should have asked but didn't (please tell us the question and your answer)?
44. Is there anything else that you wish to tell us about your experience with L-carnitine?