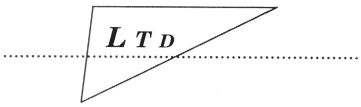
QA



NIDDK

Liver Transplantation Database

QUALITY OF LIFE FORM: ADULTS

04/25/1990

FORM KEYS

Patient ID _____-_____

Evaluation Timepoint _____

Follow-up Year (0-5) _____

COMPLETION LOG

Data Collector ID _____-_____
Center Initials

DATE

Data Collection _____/_____/_____

Data Entry _____/_____/_____

Sysid _____

Verification _____/_____/_____

Cleaned _____/_____/_____

Transfer _____/_____/_____
MM DD YY

EVALUATION TIMEPOINT

__ 1. Initial Evaluation

__ 2. Immediate Pre-transplant

__ 3. Post transplant, Year _____

__ 4. Evaluation Pre-transplant Year 1

__ 5. Evaluation Pre-transplant Year 2

__ 6. Evaluation Pre-transplant Year 3

__ 7. Evaluation Pre-transplant Year 4

THIS FORM WAS FILLED OUT (check one)

____ by the patient without assistance

____ by the patient with assistance from the LTD study coordinator

____ by the patient shortly after the transplant, without assistance

____ by the patient shortly after the transplant, with assistance from the LTD study coordinator

____ by the next of kin of the patient

Name _____

Relationship _____

QA

QUALITY OF LIFE FORM: ADULTS
NIDDK Liver Transplantation Database

PATIENT ID _____-_____

INTRODUCTION

As a participant in this study of liver transplantation, you are asked to fill out this questionnaire about your general health. Please fill out the form as honestly as you can, describing how you have felt and how well you have been able to function. Try to avoid exaggerating your symptoms as well as underestimating them. The information that you give will not be revealed to the doctors or nurses who are taking care of you but will be kept confidential. The information will not affect your medical care in any way, nor will it affect whether or when you receive a liver transplant.

Filling out this form is voluntary. If you do not want to answer certain questions, just cross them out on the form. This questionnaire will be given to you before or shortly after the transplantation, and yearly thereafter. If you are too sick to fill out this form, the LTD study coordinator will help you by reading the questions and recording the answers for you. If the form cannot be filled out before your transplantation, you may be asked to fill it out afterwards when you will be better able to answer the questions. If that is the case, we ask you to answer the questions based upon how you felt before the transplant. If you are too sick to answer the questions, we may ask your next of kin to answer the questions for you but only the first 16 questions will be asked.

A. GENERAL INFORMATION

What is your name? _____ _____ _____
(First) (Initial) (Last)

1. What is today's date? _____/_____/_____
MM DD YY

2. What is your date of birth? _____/_____/_____
MM DD YY

3. What is your sex? (check one)

__ 1. Male
__ 2. Female

4. What is your current marital status? (check one)

__ 1. Never married
__ 2. Married/cohabitating
__ 3. Separated
__ 4. Divorced
__ 5. Widowed

5. With whom do you live? (check one)

__ 1. Live alone
__ 2. With spouse or partner
__ 3. With spouse/partner and children
__ 4. With children only
__ 5. With parents only
__ 6. With other family members or friends
__ 7. Other _____
specify (30 char)

6. Besides yourself, how many other people live in your household? _____ people

7. How many years of education have you completed? _____ years

8. What is the highest education degree you have obtained? (check one)

__ 1. Never graduated from high school
__ 2. High School diploma
__ 3. Trade School degree beyond high school
__ 4. College/University degree
__ 5. Advanced degree (M.A., M.S., Ph.D., M.D., J.D., etc.)

9. Do you currently smoke cigarettes (check one)

__ Yes
__ No

IF YES

9.1 What is the average number of cigarettes that you smoke each day? (check one)

__ 1. Less than 1/2 pack
__ 2. 1/2 to 1 pack
__ 3. 1 to 2 packs
__ 4. More than 2 packs

10. Do you currently drink alcohol? (check one)

__ Yes
__ No

IF YES

10.1 How many drinks of alcohol do you have in a typical week (one drink = 1 bottle beer or 1 glass of wine or one mixed drink)?

_____ drinks per week

B. WORK

Many patients with liver problems are not able to work or to take care of their household. These questions are meant to record your work experience.

11. Since finishing school (high school, college or trade school) how many years have you worked either full-time or part-time?

_____ years

12. What is your current occupation? _____
specify (30 char)

QUALITY OF LIFE FORM: ADULTS
NIDDK Liver Transplantation Database

PATIENT ID _____-_____

13. What is your current work activity or employment status? (check one)

__ 1. Employed full-time
__ 2. Employed part-time
__ 3. Employed, but temporarily laid off
__ 4. Unemployed, looking for work
__ 5. Unemployed, not looking for work
__ 6. Unemployed, unable to work because of health
__ 7. Homemaker
__ 8. Student full-time
__ 9. Student part-time
__10. Retired
__11. Other _____
specify (30 char)

14. Does your health keep you from working for pay or from being a homemaker or from going to school? (check one)

__ Yes
__ No

15. Are you limited in the kind of work for pay, house work, or school work you can do because of your health? (check one)

__ Yes
__ No

16. Are you limited in the amount of work for pay, house work or school work you can do because of your health? (check one)

__ Yes
__ No

17. How satisfied are you with your present work situation or your present ability to function as a homemaker or a student? (check one)

__ 1. Completely satisfied
__ 2. Very satisfied
__ 3. Satisfied
__ 4. Neutral
__ 5. Dissatisfied
__ 6. Very dissatisfied
__ 7. Completely dissatisfied
__ 8. Doesn't apply

QUALITY OF LIFE FORM: ADULTS
NIDDK Liver Transplantation Database

PATIENT ID _____-_____

C. HEALTH

These questions deal with your general health and how it affects your everyday life and ability to work.

18. How would you rate your overall health at the present time? (check one)

__ 1. Excellent
__ 2. Good
__ 3. Fair
__ 4. Poor

19. Compared to one year ago, how would you rate your health? (check one)

__ 1. Better
__ 2. About the same
__ 3. Worse

20. During the last month, how much bodily pain have you had? (check one)

__ 1. None
__ 2. Mild
__ 3. Moderate
__ 4. Severe

21. During the past month, how many days have you been sick in bed for at least part of the day?

_____ days

22. During the past year, how many days would you estimate that you have been in the hospital as an inpatient?

_____ days

23. During the past year, how many days would you estimate that you have been out of work because of your health?

_____ days

24. Does your health currently limit the kind of vigorous activities that you can do, such as running, heavy lifting, sports? (check one)

__ Yes
__ No

25. Do you now have any trouble walking several blocks or climbing a few flights of stairs because of your health? (check one)

__ Yes
__ No

26. Do you now have any trouble walking a single block or climbing one flight of stairs because of your health? (check one)

__ Yes
__ No

27. Do you currently have trouble bending, lifting or stooping because of your health? (check one)

__ Yes
__ No

28. Overall, how satisfied are you with your health at the present time? (check one)

__ 1. Completely satisfied
__ 2. Very satisfied
__ 3. Satisfied
__ 4. Neutral
__ 5. Dissatisfied
__ 6. Very dissatisfied
__ 7. Completely dissatisfied

29. Which of the eight following statements best describes your state of health, how you feel and your level of activity? (check one)

__ 1. Normal; no complaints, no evidence of disease.
__ 2. Able to carry out normal activity; minor symptoms.
__ 3. Able to carry out normal activity with effort, some symptoms.
__ 4. Able to care for myself but unable to carry on normal activity or do active work.
__ 5. Requiring occasional assistance but able to care for most of my own needs.
__ 6. Requiring considerable assistance and frequent medical care.
__ 7. Disabled; requiring special care and assistance.
__ 8. Worse off than any of these statements suggest.

30. Is your present state of health causing problems with your: (check one for each question)

30.1 Job or work (that is: paid employment)

__ Yes
__ No

30.2 Looking after the home (examples: cleaning, cooking, doing odd jobs)

__ Yes
__ No

30.3 Social life (examples: going out, seeing friends, going to a show)

__ Yes
__ No

30.4 Home life (that is: relationships with other people in your home)

__ Yes
__ No

30.5 Sex life

__ Yes
__ No

30.6 Interests and hobbies (examples: sports, arts and crafts, do-it-yourself)

__ Yes
__ No

30.7 Vacations (examples: summer or winter vacations, weekends away)

__ Yes
__ No

QUALITY OF LIFE FORM: ADULTS
NIDDK Liver Transplantation Database

PATIENT ID _____-
_____

D. SYMPTOMS

Below is a list of problems and complaints that people sometimes have. Please read each item carefully and circle the number on the right hand side that best indicates how much you were distressed by each symptom during past month. Circle only one number for each item.

		Not at all	A little bit	Moder-ately	Quite a bit	Extremely
__	31. Fatigue or lack of energy	0	1	2	3	4
	32. Muscle weakness	0	1	2	3	4
	33. Poor appetite	0	1	2	3	4
	34. Excess appetite or overeating	0	1	2	3	4
__	35. Nausea or vomiting	0	1	2	3	4
	36. Abdominal pains or discomfort	0	1	2	3	4
	37. Abdominal swelling or bloating	0	1	2	3	4
	38. Bowel problems (diarrhea/constipation)	0	1	2	3	4
__	39. Muscle aches or pains	0	1	2	3	4
	40. Joint aches or pains	0	1	2	3	4
	41. Back pains	0	1	2	3	4
	42. Headaches	0	1	2	3	4
__	43. Difficulty concentrating	0	1	2	3	4
	44. Sleeplessness or insomnia	0	1	2	3	4
	45. Nervousness, anxiety	0	1	2	3	4
	46. Mood swings	0	1	2	3	4
__	47. Feeling depressed, sad or blue	0	1	2	3	4
	48. Trembling or shakiness	0	1	2	3	4
	49. Decreased interest in sex	0	1	2	3	4
	50. Impotence (men only)	0	1	2	3	4
__	51. Poor or blurred vision	0	1	2	3	4
	52. Change in facial appearance	0	1	2	3	4
	53. Bruising or fragile skin	0	1	2	3	4
	54. Warts	0	1	2	3	4
__	55. Itching of skin	0	1	2	3	4
	56. Fluid retention or swelling of ankles	0	1	2	3	4
	57. Jaundice (yellow tinge to eyes)	0	1	2	3	4
	58. Darkening of the urine	0	1	2	3	4

QUALITY OF LIFE FORM: ADULTS
NIDDK Liver Transplantation Database

PATIENT ID _____-
_____

QUALITY OF LIFE FORM: ADULTS
NIDDK Liver Transplantation Database

PATIENT ID _____-_____

E. QUALITY OF LIFE

The following questions are aimed at evaluating your quality of life in general including your satisfaction with your life.

59. Taking all things together, how would you say things are these days? Would you say you're: (check one)

__ 1. Very happy
__ 2. Pretty happy
__ 3. Not too happy

60. All things considered, how satisfied are you with your life as a whole these days? (check one)

__ 1. Completely satisfied
__ 2. Very satisfied
__ 3. Satisfied
__ 4. Neutral
__ 5. Dissatisfied
__ 6. Very dissatisfied
__ 7. Completely dissatisfied

61. All things considered, how satisfied are you with your family life - the time you spend and the things you do with members of your family? (check one)

__ 1. Completely satisfied
__ 2. Very satisfied
__ 3. Satisfied
__ 4. Neutral
__ 5. Dissatisfied
__ 6. Very dissatisfied
__ 7. Completely dissatisfied
__ 8. Doesn't apply, I have no family

62. How satisfied are you with your marriage? (check one)

__ 1. Completely satisfied
__ 2. Very satisfied
__ 3. Satisfied
__ 4. Neutral
__ 5. Dissatisfied
__ 6. Very dissatisfied
__ 7. Completely dissatisfied
__ 8. Doesn't apply, not married

QUALITY OF LIFE FORM: ADULTS
NIDDK Liver Transplantation Database

PATIENT ID _____-
_____

63. Here are some words and phrases which we would like you to use to best describe how you feel about your present life. For example, if you think your present life is very "boring", put an X in the box right next to the word "boring". If you think it is very "interesting", put an X in the box right next to the word "interesting". If you think it is somewhere in between put an X where you think it belongs. Put an X in one box on every line.

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	
63.1 Boring	☐	☐	☐	☐	☐	☐	☐	Interesting
63.2 Enjoyable	☐	☐	☐	☐	☐	☐	☐	erable
63.3 Easy	☐	☐	☐	☐	☐	☐	☐	Hard
63.4 Useless	☐	☐	☐	☐	☐	☐	☐	Worthwhile
63.5 Friendly	☐	☐	☐	☐	☐	☐	☐	Lonely
63.6 Full	☐	☐	☐	☐	☐	☐	☐	Empty
63.7 Discouraging	☐	☐	☐	☐	☐	☐	☐	Hopeful
63.8 Tied Down	☐	☐	☐	☐	☐	☐	☐	Free
63.9 Disappointing	☐	☐	☐	☐	☐	☐	☐	Rewarding
63.10 Brings out the best in me	☐	☐	☐	☐	☐	☐	☐	Doesn't give me much of a chance

Thank you for spending the time to fill out this form.