



NIDDK  
Liver Transplantation Database  
**QUALITY OF LIFE FORM: PEDIATRIC**  
04/26/1990

<b>FORM KEYS</b>
Patient ID _____ - _____
Evaluation Timepoint _____
Follow-up Year (0-5) _____

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

COMPLETION LOG

Data Collector ID	_____ - _____
	Center    Initials
	DATE
Data Collection	____/____/____
Data Entry	____/____/____
Sysid	_____
Verification	____/____/____
Cleaned	____/____/____
Transfer	____/____/____
	MM    DD    YY

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PATIENT ID \_\_\_\_\_ - \_\_\_\_\_

I. BACKGROUND INFORMATION

Name of patient: \_\_\_\_\_  
\_\_\_\_\_ (First) (Initial) (Last)

Phone number: ( ) \_\_\_\_\_

1. Today's date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
(month) (day) (year)

2. Date of birth: \_\_\_\_/\_\_\_\_/\_\_\_\_  
(month) (day) (year)

3. Sex (check one)

- \_\_\_ 1. Male
- \_\_\_ 2. Female

4. With whom does patient live? (check one)

- \_\_\_ 1. Mother/Father
- \_\_\_ 2. Mother only
- \_\_\_ 3. Father only
- \_\_\_ 4. Other family member(s)

5. Does patient have siblings? Yes \_\_\_ No \_\_\_

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**II. HOW WELL HAS YOUR CHILD BEEN?**

Here are some statements that mothers have made to describe the children. Please answer them thinking about this child during the last 2 weeks.

Please answer only "B" items for which you chose an asterisked answer in Part "A".

A. During the last 2 weeks, how often did the child (circle one)

B. Was this due to illness? (circle one)

	Never or Rarely (1)	Some of the Time (2)	Almost Always (3)			
1. Eat well	*1	*2	3	Yes	Sometimes	No
2. Sleep well	1	*2	3	Yes	Sometimes	No
3. Seem contented and cheerful	*1	*2	3	Yes	Sometimes	No
4. Act moody	1	*2	*3	Yes	Sometimes	No
5. Communicate what he/she wanted	*1	*2	3	Yes	Sometimes	No
6. Seem to feel sick and tired	1	*2	*3	Yes	Sometimes	No
7. Occupy him/herself	*1	*2	3	Yes	Sometimes	No
8. Seem lively and energetic	*1	*2	3	Yes	Sometimes	No
9. Seem unusually irritable	1	*2	*3	Yes	Sometimes	No
10. Sleep through the night	*1	*2	3	Yes	Sometimes	No
11. Respond to your attention	*1	*2	3	Yes	Sometimes	No
12. Seem unusually difficult	1	*2	*3	Yes	Sometimes	No
13. Seem interested in what was going on around him/her	*1	*2	3	Yes	Sometimes	No
14. React to things by crying	1	*2	*3	Yes	Sometimes	No

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**III. SOCIAL ASSESSMENT**

Choose the appropriate developmental age range for your child and begin answering the questions within that section by placing a check in the appropriate box. Continue to answer questions in the next developmental age category if you feel your child fits into that range of ability.

DEVELOPMENTAL AGE

UP TO AGE 4

- 1. Reaches for a person whom he or she wants.
- 2. Treats at least two people outside the family as friends, different from strangers.
- 3. Imitates actions when asked, such as waving or clapping hands.
- 4. Hands toys or other objects to another person.

Never or Rarely (even if asked)	Does, but not well about 25% of the time (may need to be asked)	Does fairly well about 75% of the time (may need to be asked)	Does very well or almost always (without being asked)

AGE 4 TO 9

- 5. Rolls a ball or plays simple games with another person.
- 6. Takes part in simple group games and social activities (e.g. tag, hide-and-seek, follow-the-leader).
- 7. Says "please" and "thank you" when appropriate.
- 8. Waits at least two minutes for turn in a group activity (e.g. taking turns at batting a ball or getting a drink of water).


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**SOCIAL ASSESSMENT**

DEVELOPMENTAL AGE (continued)

AGE 10 TO 16

- 9. Offers help to other people (e.g. holds a door open for one whose arms are full or picks up an object dropped by someone else).
- 10. Acts appropriately without drawing negative attention while in public places with friends (e.g. a movie theater or library).
- 11. Says "hello" or shakes hands when being introduced.
- 12. Locates or remembers telephone numbers and calls friends on the telephone.

Never or Rarely (even if asked)	Does, but not well about 25% of the time (may need to be asked)	Does fairly well about 75% of the time (may need to be asked)	Does very well or almost always (without being asked)

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**IV. GROSS MOTOR ASSESSMENT**

Choose the appropriate developmental age range for your child and begin answering the questions within that section by placing a check in the appropriate box. Continue to answer questions in the next developmental age category if you feel your child fits into that range of ability.

DEVELOPMENTAL AGE

Never or Rarely (even if asked)	Does, but not well about 25% of the time (may need to be asked)	Does fairly well about 75% of the time (may need to be asked)	Does very well always or almost always (without being asked)
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BELOW AGE 4

- 1. Sits alone for thirty seconds with head and back held straight and steady (without support).
- 2. Stands for at least five seconds by holding onto furniture or other objects.
- 3. Pulls self into a standing position.
- 4. Stands alone and walks for at least 6 weeks.


AGE 4 TO 5

- 5. Kicks a ball or object that is not moving without falling.
- 6. Walks up and down stairs by alternating feet from step to step (may hold handrail).


AGE 6 TO 7

- 7. Climbs a six-foot ladder (e.g. to a slide).
- 8. Uses pedals to ride a tricycle or other three-wheeled toy.
- 9. Picks up and carries a full bag of groceries at least 20 feet and sets it down.


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**GROSS MOTOR ASSESSMENT**

DEVELOPMENTAL AGE (continued)

AGE 8 TO 16

10. Walks on a narrow surface (a curb, railroad track or line) for at least 10 feet without stepping off.

11. Catches a bounced tennis-size ball with two hands. (Ball is not caught against the body.)

12. Rides a bicycle (without training wheels) for at least 20 feet.

13. Jumps rope at least ten times without missing.

14. Takes part in physical exercise on a regular basis (e.g. routine exercises or calisthenics, tennis, jogging, swimming, volleyball, biking).

15. Catches tennis-size ball with only one hand.

16. Does at least six push-ups.

17. Takes part in strenuous physical activities on a regular basis that require strength or endurance (e.g. weight-lifting, running at least 3 miles, or swimming at least 1/2 mile).

Never or Rarely (even if asked)	Does, but not well about 25% of the time (may need to be asked)	Does fairly well about 75% of the time (may need to be asked)	Does very well or almost always (without being asked)

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V. YOUR CHILD'S HEALTH

1. In general, would you say this child's health is excellent, good, fair or poor? (check one)

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

2. During the last 3 months, how much have you worried about the child's health? (check one)

- 1. A great deal
- 2. Somewhat
- 3. A little
- 4. Not at all

3. During the last 3 months, how much pain or distress has this child's health caused him or her? (check one)

- 1. A great deal
- 2. Somewhat
- 3. A little
- 4. Not at all

4. Please read each of the following statements, and then circle one of the numbers on each line to indicate whether the statement is true or false for this child. There are no right or wrong answers.

Some of the statements may look or seem like others. But each statement is different, and should be rated by itself.

Circle one:

	<u>Definitely True</u>	<u>Mostly True</u>	<u>Don't Know</u>	<u>Mostly False</u>	<u>Definitely False</u>
4.1 This child's health is excellent.	5	4	3	2	1
4.2 This child seems to resist illness very well.	5	4	3	2	1
4.3 This child seems to be less healthy than other children I know.	5	4	3	2	1
4.4 When there is something going around, this child usually catches it.	5	4	3	2	1



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**VI. SELF-REPORT KARNOFSKY SCALE**

At this time, how would you rate your child's health (check one):

- 1. Normal; no complaints, no evidence of disease.
- 2. Able to carry on normal activity; minor signs and symptoms of disease.
- 3. Able to carry on normal activity (appropriate for age) with effort; some signs and symptoms of disease.
- 4. Able to care for himself/herself (appropriate for age) but unable to carry on normal activity or do active work.
- 5. Requiring occasional assistance but able to care for most of his/her own needs (appropriate for age).
- 6. Requiring considerable assistance and frequent medical care.
- 7. Disabled; requiring special care and assistance.
- 8. Worse off than any of these statements suggest.

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VII. ACADEMIC ASSESSMENT

1. Current Education Level (check one)

- 1. Pre-School/Nursery School
- 2. Kindergarten
- 3. Grade (circle one) 1 2 3 4 5 6 7 8 9 10 11 12

2. Is your child attending school?

- 2.1 Yes IF YES, check one
 

<input type="checkbox"/> 2.1.1 Full-time
<input type="checkbox"/> 2.1.2 Part-time

- 2.2 No IF NO, check one
 

Reason: <input type="checkbox"/> 2.2.1 Age
<input type="checkbox"/> 2.2.2 Health
<input type="checkbox"/> 2.2.3 Other (explain)
_____

3. Is your child being tutored at home?

- 3.1 Yes IF YES,
- 3.2 No

4. Does your child attend special education classes or receive tutoring in school? Yes \_\_\_ No \_\_\_

IF YES

<input type="checkbox"/>	4.1 Type of Special Education Program (check all that apply)						
	<p>IF YES</p> <table border="1" style="margin-left: 20px;"> <tr><td><input type="checkbox"/> 4.1.1 Learning disabilities</td></tr> <tr><td><input type="checkbox"/> 4.1.2 Emotional disability</td></tr> <tr><td><input type="checkbox"/> 4.1.3 Mental retardation</td></tr> <tr><td><input type="checkbox"/> 4.1.4 Physical disability</td></tr> <tr><td><input type="checkbox"/> 4.1.5 Other _____</td></tr> <tr><td style="text-align: center;">specify</td></tr> </table>	<input type="checkbox"/> 4.1.1 Learning disabilities	<input type="checkbox"/> 4.1.2 Emotional disability	<input type="checkbox"/> 4.1.3 Mental retardation	<input type="checkbox"/> 4.1.4 Physical disability	<input type="checkbox"/> 4.1.5 Other _____	specify
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<input type="checkbox"/> 4.1.4 Physical disability							
<input type="checkbox"/> 4.1.5 Other _____							
specify							
<input type="checkbox"/>	4.2 Tutoring: IF YES						
	<table border="1" style="margin-left: 20px;"> <tr><td>4.2.1 Hours per week _____</td></tr> <tr><td>4.2.2 Subjects _____</td></tr> </table>	4.2.1 Hours per week _____	4.2.2 Subjects _____				
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**ACADEMIC ASSESSMENT (continued)**

5. Number of school days missed during the last year: \_\_\_\_\_

6. 6.1 Grade child was in before transplant \_\_\_\_\_

6.2 Grade child is currently in \_\_\_\_\_

7. Grade failure:                      Yes \_\_\_                      No \_\_\_

IF YES, 

Was it due to illness?    Yes ___                      No ___
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