# KIDNEY DISEASE AND QUALITY OF LIFE SHORT FORM QUESTIONNAIRE $(KDQOL-SF^{TM})$

*Hays, R.D., Kallich, J.D., Mapes, D.L., Coons, S.J., Amin, N., & Carter, W.B. (1995)* Kidney Disease Quality of Life Short Form (KDQOL-SF<sup>TM</sup>), Version 1.3: A Manual for Use and Scoring. *Santa Monica, CA: RAND, P-7994* 

#### INSTRUCTIONS FOR FILLING OUT SURVEY

- 1. This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.
- 2. This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.
- 3. Please answer the questions by circling the appropriate number or by filling in the answer as requested.
- 4. Several items in the survey ask about the effects of kidney disease on your life. Some items will ask about limitations related to your kidney disease, and some items will ask about your well-being. Some questions may look like others, but each one is different. Please answer every question as honesty as possible. If you are unsure about how to answer a question, please give the best answer you can. This will allow us to have an accurate picture of the different experiences of individuals with kidney disease.

# YOUR HEALTH

 1. In general, would you say your health is:

 Unchecked
 Excellent

 Very good
 Good

 Fair
 Poor

- 2. Compared to one year ago, how would you rate your health in general now?
  - Unchecked
  - Much better now than one year ago
  - Somewhat better now than one year ago
  - About the same as one year ago
  - Somewhat worse than one year ago
  - Much worse now than one year ago

3. The following items are about activities you might do during a typical day. **Does your health now limit** you in these activities? If so, how much?

a. **Vigorous activities,** such as running, lifting heavy objects, participating in strenuous sports

Unchecked yes, limited a Lot yes, limited a little No, not limited at all

- b. Moderate activities, such as moving a table, mopping and sweeping Unchecked yes, limited a Lot yes, limited a little No, not limited at all
- c. Lifting or carrying groceries Unchecked yes, limited a Lot yes, limited a little No, not limited at all
- d. Climbing **several** flights of stairs Unchecked yes, limited a Lot yes, limited a little No, not limited at all
- e. Climbing **one** flight of stairs Unchecked yes, limited a Lot yes, limited a little No, not limited at all
- f. Bending, kneeling or stooping Unchecked yes, limited a Lot yes, limited a little No, not limited at all

#### g. Walking more than a kilometer,

Unchecked yes, limited a Lot yes, limited a little No, not limited at all

# h. Walking several blocks

Unchecked yes, limited a Lot yes, limited a little No, not limited at all

- i. Walking **one block** Unchecked yes, limited a Lot yes, limited a little No, not limited at all
- j. Bathing or dressing yourself Unchecked yes, limited a Lot yes, limited a little No, not limited at all

4. During the **past four weeks**, have you had any of the following problems with your work or other regular activities **as a result of your physical health?** 

a. Cut down the amount of time you spend on work on other activities?

	Unchecked Yes No
b.	Accomplished less than you would have liked?
	Unchecked Yes No
c.	Were limited in the <b>kind</b> of work or other activities?
	Unchecked Yes No
d.	Had <b>difficulty</b> performing the work or other activities (for example, it took extra
	effort)?
	Unchecked Yes No

5. During the **past four weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotion problems** (such as feeling depressed or anxious)?

a. Cut down the **amount of time** you spend on work on other activities?

Unchecked Yes No

b. Accomplished less than you would have liked?

Unchecked Yes No

c. Didn't do work or other activities **kind** as carefully as usual? Unchecked Yes No

6. During the <b>past four weeks</b> , to what <b>extent</b> have your <b>physical health or emotion problems</b> interfered with your normal social activities with family, friends, neighbours, or groups?
Unchecked Not at all Slightly Moderately Quite a bit Extremely
7. How much <b>bodily</b> pain have you had during the <b>past four weeks?</b> Unchecked None Very mild Mild Moderate Severe Very severe
8. During the <b>past four weeks</b> , how much did <b>pain</b> interfere with your normal work

(including work outside the home and housework)?								
Unchecked	Not at all	Slightly	Moderately	Quite a bit	Extremely			

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks

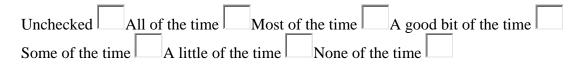
a. Did you feel high spirited?

Unchecked All o	f the time Most of	the time $\Box_{A gc}$	ood bit of the time
Some of the time	A little of the time	None of the time	

b. Have you been a very nervous person?

Unchecked	All of	the time		Most	of th	e time		A goo	od bit	of the	time	
Some of the time	e	A little of	the	time		None of	of the	time				

c. Have you felt so down in the dumps that nothing could cheer you up?



d. Have you felt calm and peaceful?

Unchecked All of the time Most of the time A good bit of the time Some of the time A little of the time None of the time

e.	Did you have a lot of energy?
	Unchecked All of the time Most of the time A good bit of the time
	Some of the time A little of the time None of the time
f.	Have you felt downhearted and blue?
	Unchecked All of the time Most of the time A good bit of the time
	Some of the time A little of the time None of the time
g.	Did you feel worn out?
U	Unchecked All of the time Most of the time A good bit of the time
	Some of the time A little of the time None of the time
h.	Have you been a happy person?
	Unchecked All of the time Most of the time A good bit of the time
	Some of the time A little of the time None of the time
i.	Did you feel tired
	Unchecked All of the time Most of the time A good bit of the time
	Some of the time A little of the time None of the time

10. During past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities?

Unchecked All of the time Most of the time Some of the time A little of the time None of the time

11. Please choose the answer that best describes how TRUE or FALSE each of the following statements is for you.

a. I seem to get sick a little easier than other people
Unchecked Definitely True Mostly True Don't Know Mostly False
b. I am as healthy as anybody I know
Unchecked Definitely True Mostly True Don't Know Mostly False

с.	I expect my health to get worse
	Unchecked Definitely True Mostly True Don't Know Mostly False
	Unchecked Definitely Irue Mostly Irue Don't Know Mostly False
	Always False
	Always False
d.	My health is excellent
	Unchecked Definitely True Mostly True Don't Know Mostly False
	Always False

## YOUR KIDNEY DISEASE

12. How TRUE or FALSE is each of the following statements for you?

a.	My kidney disease interferes too much with my life
	Unchecked Definitely True Mostly True Don't Know Mostly False
	Always False
b.	Too much time is spent dealing with my kidney disease
	Unchecked Definitely True Mostly True Don't Know Mostly False
	Always False
c.	I feel frustrated dealing with my kidney disease
	Unchecked Definitely True Mostly True Don't Know Mostly False
d	I feel like a burden on my family
u.	Unchecked Definitely True Mostly True Don't Know Mostly False

13. These questions are about how you feel and how things have been going during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling? how much of the time

a. Did you	isolate yourself from people around you ?
Unchecked	None of the Time A Little of the Time Some of the Time A
Good	bit of the Time Most of the Time All of the Time
b. Did you	react slowly to things that were said or done?
Unchecked	None of the Time A Little of the Time Some of the Time A

Good bit of the Time Most of the Time All of the Time

c. Did you act irritable toward those around you?
Unchecked None of the Time A Little of the Time Some of the Time A
Good bit of the Time Most of the Time All of the Time
d. Did you have difficulty concentrating or thinking?
Unchecked None of the Time A Little of the Time Some of the Time A
Good bit of the Time Most of the Time All of the Time
e. Did you get along well with other people?
Unchecked None of the Time A Little of the Time Some of the Time A
Good bit of the Time Most of the Time All of the Time
f. Did you become confused?
Unchecked None of the Time A Little of the Time Some of the Time A
Good bit of the Time Most of the Time All of the Time

14. During the past 4 weeks, to what extent were you bothered by each of the following?

a. Soreness in your muscles? Unchecked Not at all bothered Somewhat bothered Moderately bothered Very Much Bothered Extremely Bothered b. Chest pain? Unchecked | Not at all bothered Somewhat bothered Moderately bothered Very Much Bothered Extremely Bothered c. Cramps? Unchecked Not at all bothered Somewhat bothered Moderately bothered Very Much Bothered Extremely Bothered d. Itchy skin? Moderately bothered Unchecked Not at all bothered Somewhat bothered Very Much Bothered Extremely Bothered e. Dry skin? Unchecked Not at all bothered Somewhat bothered Moderately bothered Very Much Bothered Extremely Bothered f. Shortness of breath? Unchecked Not at all bothered Somewhat bothered Moderately bothered Very Much Bothered Extremely Bothered

g. Faintness or dizziness? Somewhat bothered Unchecked Not at all bothered Moderately bothered Very Much Bothered Extremely Bothered h. Lack of appetite? Unchecked Not at all bothered Somewhat bothered Moderately bothered Extremely Bothered Very Much Bothered i. Washed out or drained? Unchecked Not at all bothered Somewhat bothered Moderately bothered Very Much Bothered Extremely Bothered j. Numbness in hands or feet? Unchecked Not at all bothered Somewhat bothered Moderately bothered Very Much Bothered Extremely Bothered k. Nausea or upset stomach? Somewhat bothered Unchecked Not at all bothered Moderately bothered Very Much Bothered Extremely Bothered 1. Problems with your access site (hemo only) ? Not at all bothered Moderately bothered Unchecked Somewhat bothered Very Much Bothered Extremely Bothered

# EFFECTS OF KIDNEY DISEASE ON YOUR DAILY LIFE

15. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

a.	Fluid restrictions?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered
b.	Dietary restrictions?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered
c.	Your ability to work around the house?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered
d.	Your ability to travel?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered
e.	Being dependent on doctors and other medical staff?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered
f.	Stress or worries caused by kidney disease?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered
g.	Your sex life?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered
h.	Your personal appearance?
	Unchecked Not at all bothered Somewhat bothered Moderately bothered
	Very Much Bothered Extremely Bothered

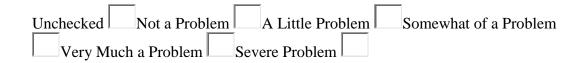
# The next three questions are personal and relate to your sexual activity, but your answers are important in understanding how kidney disease impacts on people's lives.

16. Have yo	u had sex	kual activity	in the pas	t 4 weeks? (	If "No"	Please skip to	Question 30)
Unchecked	Yes						

a. Enjoying sex?

Unchecked Not a Problem A Little Problem Somewhat of a Problem Very Much a Problem Severe Problem

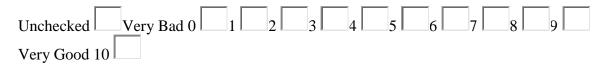
b. Becoming sexually aroused?



For the following question, please rate your sleep using a scale ranging from 0 representing "very bad" to 10 representing "very good".

If you think your sleep is half-way between "very bad" and "very good," please circle 5. If you think your sleep is one level better than 5, circle 6. If you think your sleep is one level worse than 5, circle 4 (and so on)

17. On a scale from **0** to**10**, how would you rate your sleep overall?



18. How often during the past 4 weeks did you

a. Awaken during the night and have trouble falling asleep again? Unchecked None of the Time A Little of the Time Some of the Time

A Good bit of the Time Most of the Time All of the Time

b. Get the amount of sleep you need?

Unchecked None of the Time A Little of the Time Some of the Time A Good bit of the Time Most of the Time All of the Time

c. Have trouble staying awake during the day?

Unchecked	None of the Time	A Little of the Time	Some of the Time
	A Good bit of the Time	Most of the Time	All of the Time

- 19. Concerning your family and friends, how satisfied are you with
  - a. The amount of time you are able to spend with your family and friends? Unchecked Very dissatisfied Somewhat dissatisfied Somewhat satisfied
  - b. The support you receive from your family and friends?
     Unchecked Very dissatisfied Somewhat dissatisfied Somewhat satisfied
     Very satisfied
- 20. During the past 4 weeks, did you work at a paying job?

Unchecked	Yes	No	
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21. Does your health keep you from working at a paying job? Unchecked Yes No

22. Overall, how would you rate your healt						
Worst possible (as bad or worse than being	g dead)	Unchecke	d  1	2	3	4
5 Half-way between worst and best	6 7	8 9	Be	est possił	ole heal	lth 10

# SATISFACTION WITH CARE- FOR PATIENTS ON HAEMODIALYSIS ONLY

23. Think about the care you receive for kidney dialysis. In terms of your satisfaction, how would you rate the friendliness and interest shown in you as a person? Unchecked Very Poor Poor Fair Good Very Good Excellent The Best

24. How TRUE or FALSE is each of the following statements?

a. Dialysis staff encourage me to be as independent as possible Unchecked Definitely True Mostly True Don't Know Mostly False Definitely False

b.	Dialysis staff support me in	n coping with my kidney disea	ase
			Г

Definitely True Unchecked Mostly True Don't Know

Mostly False Definitely False

# BACKGROUND INFORMATION

25. Do you currently take prescription medications regularly (4 or more days a week) that are prescribed by your doctor for a medical condition? Please don't count over the counter medications like antacids or aspirin. If "No" please skip to Question 3.

No: Yes:

1.a. How many different prescription medications do you currently take? Number of Medications:

26. How many days total in the last 6 months did you stay in any hospital overnight or longer?(if none, please write in 0) days

27. How many days total in the last 6 months did you receive care at a hospital, but came home the same day? (if none, please write in 0) days

28. What caused your kidney disease?

Don't know:	Hypertensie	on (High Blood Pressure)	Diabetes
Polycystic Kidne	y Disease	Chronic Glomerulonephritis	Chronic Pyelonephritis
Other (please spe	ecify)		

29. When were you born: \_\_/ \_\_/ \_\_\_\_

30. What is the highest level of school you have completed?
8th grade or less some high school or less High school diploma Vocational school or some college College degree Professional or graduate degree
31. What is your gender?
Male Female

32. Are you currently married

33. During the last 30 days, were you:

 1. working full-time
 2. Working part-time
 3. Unemployed, laid off, or looking for work

 4. Retired
 5. Disabled
 6. In School
 7. Keeping house
 8. None of the above

34. What was your total household income (from all sources) before taxes in the LAST CALENDAR YEAR, including yourself, your partner, and others you regard as family who live in your household?

(Please remember your answers are confidential) MK

35. Did someone help you fill out this survey?

36. What is today's date?: \_\_/\_\_/\_\_\_\_

Time:

37. How long have you been on dialysis? \_\_\_\_\_\_months

THANK YOU.

#### 13.2. KDQOL SF-36 AMMENDMENTS

#### **REMOVED QUESTIONS**

14. During the past 4 weeks, to what extent were you bothered by each of the following? (Peritoneal dialysis only)

m. problems with your catheter site?

m.	Unchecked	Not at al	l bothered	Somewhat bother	red	Moderately bothered
	Very M	uch Bothered	Extrem	ely Bothered		

32.how do you describe yourself?

African Ame	rican or Black	Hispanic	or Latino	Native	American or Ame	rican
Indian	Asian or Pacific is	slander	white	other	(please specify	

35.What kind of health insurance do you have?

### **MODIFIED QUESTIONS**

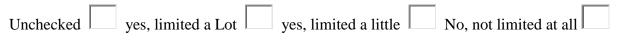
36.What was your total household income (from all sources) before taxes in the LAST CALENDAR YEAR, including yourself, your partner, and others you regard as family who live in your household? (Please remember your answers are confidential)

#### TO

34.What was your total household income (from all sources) before taxes in the LAST CALENDAR YEAR, including yourself, your partner, and others you regard as family who live in your household? (Please remember your answers are confidential)

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf



TO

3. The following items are about activities you might do during a typical day. Does you health now limit you in these activities? If so, how much?

b.**Moderate activities,** such as moving a table, mopping and sweeping Unchecked yes, limited a Lot yes, limited a little No, not limited at all

3. The following items are about activities you might do during a typical day. **Does you** health now limit you in these activities? If so, how much?

g. Walking **more than a mile,** Unchecked yes, limited a Lot yes, limited a little No, not limited at all

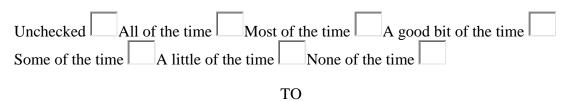
ТО

3. The following items are about activities you might do during a typical day. **Does you health now limit** you in these activities? If so, how much?

g. Walking more than a kilometer, Unchecked yes, limited a Lot yes, limited a little No, not limited at all 9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks

# a. Did you feel full of pep?



9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks

#### a. Did you feel high spirited?

Unchecked	All of	the time	Most o	f the time	A goo	d bit of the	e time
Some of the time	e	A little of	the time	None of	the time		