

For Office Use: ____ / ____
Respondent ID

April, 2002

Study of Dialysis Patients: Health and Well-Being

Dear Patient,

We are interested in understanding what helps patients have satisfying lives on dialysis. We are interested in learning more about your feelings and your relationships with others. With this information, we hope to improve the dialysis services that are provided to patients.

We would like to emphasize that your participation is completely **voluntary** and you may skip any question you may not want to answer. Your answers will be kept completely **confidential** to the maximum extent allowable under federal and state laws.

When you have finished with the questionnaire, please seal it in the enclosed envelope, and it will be delivered to our research staff.

If you have any questions or comments regarding the study please contact Erica Perry at the National Kidney Foundation at (800) 482-1455 or Dr. Richard Swartz.

Sincerely,

Erica Perry, M. S. W.

A1. Write down today's date / /
MONTH DAY YEAR

A2. What is your birth date? / /
MONTH DAY YEAR

A3. What is your sex? *Circle one number* 1. Male 5. Female

A4. The following are questions about your ethnic or racial background.

a. Are you of Hispanic origin? 1. Yes 5. No

b. How would you describe your ethnic or racial background?

*Circle **all** that apply*

- 1. White/Caucasian
- 2. Black/African American
- 3. American Indian, Eskimo or Aleut
- 4. Asian or Pacific Islander
- 5. Other, specify _____

A5. What is your educational background?

Circle the best answer

- 1. Some high school
- 2. High school diploma
- 3. Some college
- 4. College degree
- 5. Master's degree
- 6. Professional degree (law, M.D., Ph.D)

A6. In general, how important are religious or spiritual beliefs in your day-to-day life?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

A7. When you have decisions to make in your everyday life, how often do you ask yourself what God or a higher power would want you to do?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

A8. When you have problems or difficulties in your family, work, or personal life, how often do you seek spiritual comfort or support?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

A9. In general, how often do you pray?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

B1. Following is a list of problems or complaints that people have. Please indicate how much each has **bothered** or **distressed** you in the last **two weeks**, including today.

In the last two weeks , how much were you bothered or distressed by...	<u>Not at All</u>	<u>A Little Bit</u>	<u>Moderately</u>	<u>Quite a Bit</u>	<u>Extremely</u>
a. ...crying easily?	1	2	3	4	5
b. ...blaming yourself for things?	1	2	3	4	5
c. ...feeling lonely?	1	2	3	4	5
d. ...feeling no interest in things?	1	2	3	4	5
e. ...feeling blue?	1	2	3	4	5

In the last two weeks , how much were you bothered or distressed by...	<u>Not at All</u>	<u>A Little Bit</u>	<u>Moderately</u>	<u>Quite a Bit</u>	<u>Extremely</u>
f. ...thoughts of ending your life?.....	1	2	3	4	5
g. ...feeling hopeless about the future?.....	1	2	3	4	5
h. ...a feeling of being trapped or caught?	1	2	3	4	5
i. ...worrying or stewing about things?	1	2	3	4	5

B2. In general, would you say your health is excellent, good, fair or poor?

<u>Excellent</u>	<u>Good</u>	<u>Fair</u>	<u>Poor</u>
1	2	3	4

Some questions about how you feel about your illness

B3. To what extent do you blame yourself for your kidney failure?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

B4. To what extent do you feel that your illness was caused by circumstances beyond your control?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

B5. To what extent do you feel that your illness affects everything else that you do?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

B6. To what extent do you feel that you can overcome some of the problems caused by your illness?

<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
1	2	3	4	5

Some questions concerning your feeling about life

C1. How much do you agree or disagree with the following statements?

<i>Circle one number</i>	<u>Strongly Disagree</u>	<u>Somewhat Disagree</u>	<u>Neither Disagree nor Agree</u>	<u>Somewhat Agree</u>	<u>Strongly Agree</u>
a. In most ways my life is close to my ideal.....	1	2	3	4	5
b. The conditions of my life are excellent.....	1	2	3	4	5
c. I am satisfied with my life.	1	2	3	4	5
d. So far I have gotten the important things I want in life....	1	2	3	4	5
e. If I could live my life over, I would change almost nothing...	1	2	3	4	5
f. Death is simply part of the process of life.....	1	2	3	4	5
g. I don't see any point in worrying about death.....	1	2	3	4	5
h. I would neither fear death nor welcome it.....	1	2	3	4	5
i. I am resigned to the fact that we all have to die.....	1	2	3	4	5
j. People die when it's their time to die and nothing can change that	1	2	3	4	5

Some questions about how you feel about advance directives

D1. Have you filled out an advance directive? 1. Yes 5. No

D2. Have you discussed with anyone on your renal team, in a face-to-face discussion, the kinds of treatment you would want if you became too sick to speak for yourself?

1. Yes 5. No

Some questions about your knowledge of advance directives

Circle one choice:

- D3. What is an advance directive?
- A) End of life wishes
 - B) A document that speaks for you should you not be able to
 - C) Helps family know your final wishes
 - D) Names who will speak for you should you not be able to
 - E) All of the above
- D4. Do you need a lawyer to fill out an advance directive?
- A) Yes, to make sure it's legal
 - B) No, it is not necessary
- D5. Can you change your advance directive?
- A) Yes, anytime you wish
 - B) No, only your advocate can do that
 - C) No, once written, it is permanent
- D6. Can your family or medical staff witness your advance directive?
- A) Yes, because it's convenient
 - B) No, you will need someone outside the family and staff
- D7. Will you be asked if you have an advance directive each time you're admitted into the hospital?
- A) Yes, because they are required to under law
 - B) No. You will never be asked upon admission
 - C) No, not if you already have one
- D8. Will only chronically ill people be asked to fill out an advance directive?
- A) Yes, because their life span is shorter
 - B) No, all patients over the age of 18 will be asked to fill out an advance directive, including women who are pregnant.
- D9. Must all patients fill out an advance directive by law?
- A) Yes, with no exceptions
 - B) No, only if you wish

E1 . Please answer the following to tell us your feelings about your renal team:

<i>Circle one number</i>	No	Probably Yes	Definitely Yes
a. Do you think your renal team knows the kinds of treatment you would want if you got too sick to speak for yourself?	1	2	3
b. When you are talking with your renal team about the kinds of treatment you want if you get very sick, do you feel that your doctor cares about you as a person?	1	2	3
c. When you are talking with your renal team about the kinds of treatment you want if you get very sick, do you feel that your doctor listens to what you say?	1	2	3
d. When you are talking with your renal team about the kinds of treatment you want if you get very sick, do you feel that your team member gives you enough of his or her attention?	1	2	3

E2. Over the past 12 months, how would you rate the quality of renal care you have received?

<u>Excellent</u>	<u>Good</u>	<u>Fair</u>	<u>Poor</u>
1	2	3	4

Some questions about your relationships with others

F1. Do you have a peer counselor?

1. Yes 5. No → **Go to G1**

F2. How much do you...

<i>Circle one number</i>	<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
a. ...think that you will feel connected to your peer counselor no matter what he or she does?	1	2	3	4	5
b. ...think that your relationship with your peer counselor is mutual?.....	1	2	3	4	5
c. ...feel that your peer counselor needs you as much as you need him or her?...	1	2	3	4	5
d. ...feel dependent on your peer counselor?.....	1	2	3	4	5
e. ...feel that your peer counselor depends on you?.....	1	2	3	4	5
f. ...think that your peer counselor will be important to you in the future?...	1	2	3	4	5
g. ...feel that you help your peer counselor?.....	1	2	3	4	5
h. ...feel important to your peer counselor?....	1	2	3	4	5
i. ...feel valued by your peer counselor?.....	1	2	3	4	5
j. ... feel like you would do as much as you could for your peer counselor, even if they could never return the help?	1	2	3	4	5
k. ...feel that you make an important contribution to your peer counselor?.....	1	2	3	4	5
l. ...feel that you are a burden to your peer counselor?.	1	2	3	4	5

H2. How much does your family...	<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
c. ...understand the way you think and feel about things?.....	1	2	3	4	5

H2. How much do <u>you</u> ...	<u>Not at All</u>	<u>A Little</u>	<u>Some</u>	<u>Pretty Much</u>	<u>A Great Deal</u>
a. ...show that you care about your family?	1	2	3	4	5
b. ...listen to your family when they need to talk about things that are important to them?.....	1	2	3	4	5
c. ...understand the way your family thinks and feels about things?	1	2	3	4	5

H3. How much do you...

<i>Circle one number</i>	<u>Not at All</u>	<u>A Little Bit</u>	<u>Somewhat</u>	<u>Quite a Bit</u>	<u>A Great Deal</u>
a. ...feel like a burden to your family?	1	2	3	4	5
b. ...feel like a financial burden to your family?	1	2	3	4	5
c. ...feel like an emotional burden to your family?.....	1	2	3	4	5
d. ...feel that you make an important contribution to your family?.....	1	2	3	4	5
e. ...feel that your family needs you?.....	1	2	3	4	5
f. ... feel valued by your family?.....	1	2	3	4	5

When you have finished with the questionnaire, please place it in the envelope provided.

**Thank you very much for taking the time to fill out this questionnaire.
We greatly appreciate your help.**