

Supporting the Emotional Needs of Renal Patients

Patient Questionnaire

We are inviting you to take part in this study on supporting the emotional needs of renal patients. We are interested in your views. The information collected will help improve future renal support services.

If you agree to take part, please fill-in this questionnaire.
The answers you provide will be kept strictly confidential.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If you need help to complete the questionnaire, the answers should be given from **your** point of view – not the point of view of the person helping you to fill it in.

Completing the questionnaire

Please use a black or blue pen to complete the questionnaire. For each question where there are circle/s to fill in, please fill in the circle that is closest to your views.

Please fill in circles like this: ● Not like this: ⊗ or ⊙

Don't worry if you make a mistake: simply cross out the mistake and fill in the correct circle.

Many of the questions relate to *distress*. By *distress* we mean the unpleasant feelings or emotions that may interfere with your ability to cope with kidney failure, its physical symptoms and its treatment. Distress covers a wide range of feelings including anger, frustration, sadness, fear, depression, guilt and anxiety.

We encourage you to answer all the questions. However, if there is a question you do not want to answer, you can choose to leave it blank, and just go onto the next question.

Questions or help?

If you have any queries about the questionnaire, or need support, please call one of the telephone numbers given in the letter enclosed with this questionnaire.

**These first questions are about your feelings and emotions,
and what influences them.**

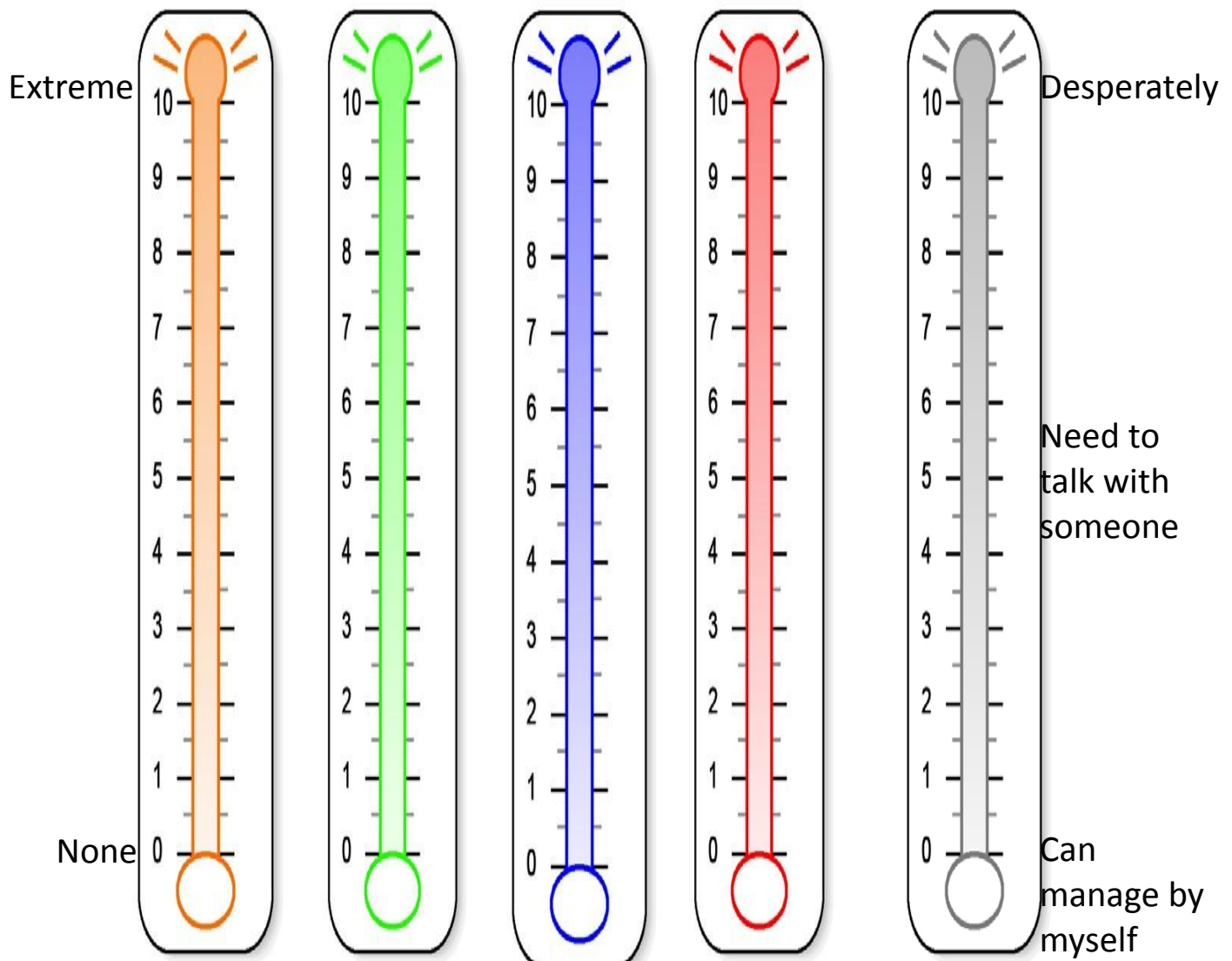
Q. 1.

Instructions

*In the first four columns, please **circle the number** (0-10) that best describes how much emotional upset you have been experiencing in the past week, including today.*

In the last column, please indicate how much help you need for these concerns.

1. Distress 2. Anxiety 3. Depression 4. Anger 5. Need



Q.2. Please indicate if any of the following has been a problem for you in the past week including today. Be sure to fill in **YES** or **NO** for each.

Please fill in circles like this: ● Not like this: ⊗ or ☑

Practical problems

YES NO

- Child care
- Housing
- Insurance/ financial
- Transportation
- Work/ school

Family problems

YES NO

- Dealing with children
- Dealing with partner
- Dealing with close friend/
relative

Emotional problems

YES NO

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual
activities

Spiritual/religious concerns

YES NO

- Any spiritual /religious
concerns

Physical problems

YES NO

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhoea
- Eating
- Fatigue
- Feeling swollen
- Fevers
- Getting around
- Indigestion
- Memory/
concentration
- Mouth sores
- Nausea
- Nose dry/ congested
- Pain
- Sexual
- Skin dry/ itchy
- Sleep
- Tingling in hands/ feet

Other problems

Q.3. *This scale consists of a number of words that describe different feelings and emotions. Read each item and then fill in the circle from 1 to 5 to indicate to what extent you have felt this way during the past week.*

Please fill in circles like this: ● Not like this: ⊗ or ☒

1 Very slightly or not at all **2** A little **3** Moderately **4** Quite a bit **5** Extremely

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1. Interested
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2. Distressed
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3. Excited
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4. Upset
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5. Strong
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6. Guilty
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7. Scared
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8. Hostile
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9. Enthusiastic
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	10. Proud
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	11. Irritable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	12. Alert
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	13. Ashamed
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	14. Inspired
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	15. Nervous
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	16. Determined
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	17. Attentive
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	18. Jittery
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	19. Active
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	20. Afraid

Q.4. Below are some events renal patients have said made them feel distressed. Please indicate whether any of the events listed have caused you distress in the last week, and in the last 2 months.

Please fill circles like this: ● Not like this: ⊗ or ☑

	In the last week	In the last two months
Being diagnosed with kidney failure	<input type="radio"/>	<input type="radio"/>
Being given a poor prognosis	<input type="radio"/>	<input type="radio"/>
Making a decision about choice of dialysis treatment	<input type="radio"/>	<input type="radio"/>
Adjusting to being on dialysis	<input type="radio"/>	<input type="radio"/>
Having dietary restrictions/change in dietary restrictions	<input type="radio"/>	<input type="radio"/>
Adjusting to having a transplant	<input type="radio"/>	<input type="radio"/>
Death of another renal patient	<input type="radio"/>	<input type="radio"/>
A failing transplant	<input type="radio"/>	<input type="radio"/>
Crisis in home/work life	<input type="radio"/>	<input type="radio"/>
Change to a different type of dialysis	<input type="radio"/>	<input type="radio"/>
Problems with dialysis e.g. fistula failure, difficulties with my line, machine problems	<input type="radio"/>	<input type="radio"/>
Decision to stop being on dialysis	<input type="radio"/>	<input type="radio"/>
Loss of employment/ fear of loss of employment	<input type="radio"/>	<input type="radio"/>

Please write in any other events that have caused you distress

<p>In the last week</p>

<p>In the last two months</p>

Q.7. Below are some things that other patients have said about the support they get from renal staff. For each statement, please mark ● how strongly you agree or disagree.

	Strongly disagree							Strongly agree			
	0	1	2	3	4	5	6	7	8	9	10
I can discuss any worries or fears with renal staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sometimes I feel like I'm treated as a set of kidney disease symptoms rather than a whole person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Renal staff tell me about different types of support available, such as talking with other patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The renal staff do not have time to listen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel the renal staff really care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't need the support of renal staff as I get good support from family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It's very comforting the way renal staff treat me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'd like to talk to one of the renal staff, but I don't know who to talk to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q.8. *Thinking now about how you have been coping with your illness and treatment, please mark ● how strongly you agree or disagree with the following statements.*

	Strongly disagree											Strongly agree
	0	1	2	3	4	5	6	7	8	9	10	
I have no problems or difficulties coping with my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry that my condition will get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I manage to keep any bad feelings about my illness and treatment under control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty accepting my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to think positively about my illness and treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel nervous about what will happen in the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm satisfied with how I'm coping with my illness and treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry I might become more distressed in the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident I can handle anything upsetting about my illness and treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q.9. Below are listed different types of support that some renal units provide for patients. For each type of support, please mark ● how **helpful** you think you would find this support.

	Not at all helpful							Extremely helpful			
	0	1	2	3	4	5	6	7	8	9	10
Time to discuss emotional feelings during nurse-run clinics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time to discuss emotional feelings during consultations with a doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training in how to handle any negative thoughts and feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking about my distress with a psychologist/counsellor who knows about renal disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A friendly one-to-one chat with another renal patient organised by my renal unit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An online training course in how to manage my feelings and moods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marking on a sheet given to me by the staff, the issues I want to discuss in my clinic/consultation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A personal physical activity programme designed by renal staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Joining an art or drawing group arranged by my renal unit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
While I'm dialysing, talking with a nurse about my distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An online support group with other renal patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please write in any other types of support that you would like your renal unit to provide.

Now some questions about you.

If you are helping someone to complete this questionnaire, please make sure this information is the patient's, not your own.

Q.10. *Your age: in what year were you born? (Please write in)*

Q.11. *Are you male or female? (Please mark ●)*

Male

Female

Q.12. *How long has it been since you were diagnosed with end-stage renal disease (chronic kidney disease stage 5)? (please mark ●)*

Less than 6 months ago

Between 6 months 12 months ago

1+ year to 2 years ago

2+ years to 3 years ago

3+ years to 5 years ago

5+ years to 10 years ago

10+ years to 15 years ago

More than 15 years ago

Q.13. *At what stage is your treatment for end-stage renal disease?
(please mark ●)*

Not yet started renal replacement treatment

On dialysis for less than 2 years, and not on the transplant waiting list

On dialysis for 2 or more years, and not on the transplant list

On dialysis and on the transplant list

With a transplant

On dialysis after a failed transplant

On conservative management/ chosen not to be on dialysis

Other (please write in) _____

***If you are on dialysis, please answer Q.14.
If you are not on dialysis, please go to Q.15.***

Q.14. *What type of dialysis are you on? (please mark ●)*

Haemodialysis (HD) in a hospital

Haemodialysis (HD) in a satellite unit

Home haemodialysis (HHD)

Continuous ambulatory peritoneal dialysis (CAPD)

Automated peritoneal dialysis (APD)

Q.15. *What is your ethnic group? Please mark ● the one option below that best describes your ethnic group or background.*

White

- English/Welsh/Scottish/
Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other White background

Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background

Mixed/Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/Multiple
ethnic background

**Black/African/Caribbean/
Black British**

- African
- Caribbean
- Any other Black/ African/
Caribbean background

Other ethnic group

- Arab
- Any other ethnic group

Q.16. *What are your current living arrangements? Please mark ● the one option below that best describes your living arrangements.*

I live on my own

I live with a partner or family member(s)

Other (please describe)

Q.17. *Has anyone helped you fill-in this questionnaire? Please mark ● for either yes or no*

Yes

No

Q.18. *Finally, would you be willing to help us with further research on these issues, by taking part in a 35-45 minute telephone or face-to-face interview, with a researcher from the University of Birmingham, sometime over the next two months? (We can provide over-the-phone interpreting for anyone that would like this).*

Please mark ● if willing to help us with further research by taking part in an interview

Yes, I would be willing to take part in a 35-45 minute interview

Please provide your contact details:

Phone number/Email _____

