

**Frequent Hemodialysis Network**  
**COUSINEAU SELF-PERCEIVED BURDEN SCALE - FORM #222**

**Instructions:** This form is completed by Central Interview.

**Schedule:** Daily: Baseline, F-4 and F-12.

Nocturnal v3.0: Baseline, F-4 and F-12. (*Nocturnal v2.1: Baseline, F-5 and F-14*).

Diagram illustrating the layout of the data table with 10 columns:

- 1. Participant ID # (5 columns)
- 2. Alpha Code (2 columns)
- 3a. Visit Type (1 column)
- 3b. Visit Number (2 columns)
- 4a. Date of Questionnaire: dd/mon/yyyy (5 columns)

4b. Time of interview? (hh:mm:ss)..... : :

We are interested in how you feel about the relationship that you have with the person (or people) who helps you out with your day-to-day activities. You may need a little bit or a lot of help with things like driving, carrying groceries, preparing meals and getting dressed or bathed. The person who helps you may be a friend, neighbor, or a member of your family – someone who is NOT paid to help you. We will refer to this person as your caregiver.

Please rate each statement on a scale of how often you feel this way, from “none of the time” to “all of the time”.

For Questions 5 - 14, use the following codes: 1=None of the time, 2=A little of the time  
3=Some of the time, 4=Most of the time, 5=All of the time

5. I worry that the health of my caregiver could suffer as a result of caring for me.....
6. I worry that my caregiver is overextending him/herself in helping me .....
7. I am concerned that it costs my caregiver a lot of money to care for me .....
8. I feel guilty about the demands that I make on my caregiver .....
9. I am concerned that my caregiver is helping me beyond their capacity.....
10. I am concerned that I am “too much trouble” to my caregiver.....
11. I am concerned that because of my illness, my caregiver is trying to do too many things at once .....
12. I am confident that my caregiver can handle the demands of caring for me .....
13. I think that I make things hard on my caregiver .....
14. I feel that I am a burden to my caregiver .....

For items 5-14, possible responses may include: 7=Does not have unpaid caregiver, 8=Don't know, 9=Refused to answer (these responses will be considered as missing data.)

**QOL Center Only**

100. Language used to complete this form? (1=English, 2=Spanish) \_\_\_\_\_

101. Setting where this form was completed? \_\_\_\_\_

1=Telephoned person at home (or patient returned QOL phone call shortly after)

2=Telephoned person when he or she was at the dialysis unit

3=Telephoned person at another location

4=Patient phone in at his/her convenience

102. Identify reason this QOL instrument was not completed? \_\_\_\_\_

0=N/A, instrument was completed

1=Not completed due to patient logistics (phone disconnected, on vacation)

2=Attempted but unable to be completed - patient too sick

3=Attempted but unable to be completed - patient in hospital

4=Unable. Patient withdrew consent.

5=Study Staff logistics

6=Patient does not have an unpaid caregiver

201. Username of person completing interview \_\_\_\_\_