QUALITY OF LIFE IN LATE-STAGE DEMENTIA (QUALID) SCALE ©

Name (L, F, MI)	Date (M/D/Y)

The QUALID is administered in interview format to an informant following the instructions below.

Informants may be either a family member or professional caregiver who by having regular contact is familiar with the subject's general behavior. Informants must, in addition to being familiar with the subject, have spent a significant portion of at least 3 days out of the last 7 days with the subject, in order to accurately rate the items on the scale. The scale is scored by summing the responses. The possible scores range from 11 to 55, with 11 representing the highest quality of life

The final items on the scale require that the interviewer make a judgement about the validity of the interview. Provide both a rating of the overall quality of the interview, which includes the informant's ability to understand the items and responses and the effort the informant put forth in answering questions, and the familiarity of the informant with the subject. These items are not included in the score, but offer information about the validity and usefulness of the ratings for that subject.

Informants are handed a blank copy of the scale so that they may look at the items as they are read aloud, and the following instructions are given:

I want to ask you some questions about <u>name's</u> quality of life. I want you to rate his/her behaviors using the responses under each question on this page. (point to the responses on the first question) There is no one right or wrong answer, I just want to know how you would rate his/her behavior from your observations.

Specifically, I want to know about his/her behavior over the past week only, not how he/she previously behaved. Remember that your answers should reflect his/her behavior over the past seven days. If you are not sure what the question means, you can ask me about it. If you have difficulty choosing a rating for an item, just make your best guess. Again, indicate your observation about his/her behavior over the past week.

Which response best describes _____ over the past week...

A. [S] smiles

- 1. spontaneously once or more each day
- 2. spontaneously less than once each day
- 3. only in response to external stimuli; at least once each day
- 4. only in response to external stimuli; less than once each day
- 5. rarely, if at all

B. [S] appears sad

- 1. rarely or never
- 2. only in response to external stimuli; less than once each day
- 3. only in response to external stimuli; at least once each day
- 4. for no apparent reason less than once each day
- 5. for no apparent reason once or more each day

C. [S] cries

- 1. rarely or never
- 2. only in response to external stimuli; less than once each day
- 3. only in response to external stimuli; at least once each day
- 4. for no apparent reason less than once each day
- 5. for no apparent reason once each day or more

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Name (L, F, MI)	Date (M/D/Y)

- D. [S] has a facial expression of discomfort appears unhappy or in pain (looks worried, grimaces, furrowed or turned down brow)
 - rarely or never
 - 2. less than once each day
 - 3. at least once each day
 - 4. nearly half of each day
 - 5. most of each day
- E. [S] appears physically uncomfortable -he/she squirms, writhes, frequently changes position
 - 1. rarely or never
 - 2. less than once each day
 - 3. at least once each day
 - 4. nearly half of each day
 - 5. most of each day
- F. [S] makes statements or sounds that suggest discontent, unhappiness or discomfort (complains, groans, screams)
 - rarely or never
 - 2. only in response to external stimuli; less than once each
 - 3. only in response to external stimuli; at least once each day
 - 4. without cause less than once each day
 - 5. without cause once or more each day
- G. [S] is irritable or aggressive (becomes angry, curses, pushes or attempts to hurt others)
 - 1. rarely or never
 - 2. only in response to external stimuli; less than once each day
 - 3. only in response to external stimuli; at least once each day
 - 4. without cause less than once each day
 - 5. without cause once or more each day
- H. [S] enjoys eating
 - 1. at most meals and snacks
 - 2. twice a day
 - 3. at least once a day
 - 4. less than once each day
 - 5. rarely or never
- I. [S] enjoys touching/being touched
 - almost always; almost always initiates touching
 - 2. more than half the time; sometimes initiates touching
 - 3. half the time; never initiates touching, but doesn't resist touching
 - 4. less than half the time; often or frequently resists touching/being touched
 - 5. rarely or never; almost always resists touching/being touched

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- J. [S] enjoys interacting or being with others
 - 1. almost always; almost always initiates interaction with others
 - 2. more than half the time; sometimes initiates interaction with others
 - 3. half the time; never initiates interaction, but doesn't resist interaction with others
 - 4. less than half the time; often or frequently resists interacting with others
 - 5. rarely or never; almost always resists interacting with others
- K. [S] appears emotionally calm and comfortable
 - 1. most of each day
 - 2. more than half of each day
 - 3. half of each day
 - 4. less than half of each day
 - 5. rarely or never

_____Total Score (sum of all items; scores range from 11 to 55 with lower scores representing higher quality of life)

Quality of Interview

(Administrator's judgement): 0 Interview appeared valid

1 Some questions about interview, but probably acceptable

2 Information from interview of doubtful validity

Knowledge/familiarity

of caregiver with subject: 0 Very familiar; provides daily care

1 Somewhat familiar; often provides some care

2 Not very familiar; only dispenses meds, minimal contact

Which response best describes ______ over the past week...

- A. [S] smiles
 - 1. spontaneously once or more each day
 - 2. spontaneously less than once each day
 - 3. only in response to external stimuli; at least once each day
 - 4. only in response to external stimuli; less than once each day
 - 5. rarely, if at all
- B. [S] appears sad
 - 1. rarely or never
 - 2. only in response to external stimuli; less than once each day
 - 3. only in response to external stimuli; at least once each day
 - 4. for no apparent reason less than once each day
 - 5. for no apparent reason once or more each day
- C. [S] cries
 - 1. rarely or never
 - 2. only in response to external stimuli; less than once each day
 - 3. only in response to external stimuli; at least once each day
 - 4. for no apparent reason less than once each day
 - 5. for no apparent reason once each day or more
- D. [S] has a facial expression of discomfort appears unhappy or in pain (looks worried, grimaces, furrowed or turned down brow)
 - 1. rarely or never
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 - 4. nearly half of each day
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- F. [S] makes statements or sounds that suggest discontent, unhappiness or discomfort (complains, groans, screams)
 - 1. rarely or never
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 - 3. only in response to external stimuli; at least once each day
 - 4. without cause less than once each day
 - 5. without cause once or more each day
- G. [S] is irritable or aggressive (becomes angry, curses, pushes or attempts to hurt others)
 - 1. rarely or never
 - 2. only in response to external stimuli; less than once each day
 - 3. only in response to external stimuli; at least once each day
 - 4. without cause less than once each day
 - 5. without cause once or more each day

- H. [S] enjoys eating
 - 1. at most meals and snacks
 - 2. twice a day
 - 3. at least once a day
 - 4. less than once each day
 - 5. rarely or never
- I. [S] enjoys touching/being touched
 - 1. almost always; almost always initiates touching
 - 2. more than half the time; sometimes initiates touching
 - 3. half the time; never initiates touching, but doesn't resist touching
 - 4. less than half the time; often or frequently resists touching/being touched
 - 5. rarely or never; almost always resists touching/being touched
- J. [S] enjoys interacting or being with others
 - 1. almost always; almost always initiates interaction with others
 - 2. more than half the time; sometimes initiates interaction with others
 - 3. half the time; never initiates interaction, but doesn't resist interaction with others
 - 4. less than half the time; often or frequently resists interacting with others
 - 5. rarely or never; almost always resists interacting with others
- K. [S] appears emotionally calm and comfortable
 - 1. most of each day
 - 2. more than half of each day
 - 3. half of each day
 - 4. less than half of each day
 - 5. rarely or never