

## Directions for Use of the Symptom Management at the End Of Life in Dementia Scale (SM-EOLD) (SM-EOLD page 1 of 2)

**Procedure:** SM-EOLD should be completed by a person familiar with the condition of the person with dementia during the last month of his or her life. The respondent could be a family member who visited frequently or a staff member who was responsible for the care of the person with dementia. Instruct the respondent to complete the scale by circling the number that corresponds to his or her agreement with each included statement. Responses should reflect the respondent's experiences during the last month of the person's life. If he or she is unsure of how to answer a statement, refer him or her to the Item Definitions on the second page of the scale. Completing the scale should not take more than 5 minutes.

**Scoring:** Scores have a normal distribution and can be used to compare quality of care in different institutions or changes in quality of care after the introduction of a new program. The scale has two subscales that evaluate two different areas of symptoms.

## Symptom Management at the End Of Life in Dementia (SM-EOLD)

|  |             |              |                     |             |                     |           |       |                  |
|--|-------------|--------------|---------------------|-------------|---------------------|-----------|-------|------------------|
| Patient ID/PIN:  |             |              | Date:               |             |                     |           |       |                  |
| Instructions: Please circle the number that corresponds to your agreement with each statement below. Responses should reflect your experiences during the last month of the person's life. If you are unsure of how to answer a statement, please refer to the Item Definitions on page 2. |             |              |                     |             |                     |           |       |                  |
|  | Frequencies |              |                     |             |                     |           |       |                  |
| Item   | Never       | Once a month | 2 or 3 days a month | Once a week | Several days a week | Every day | Score | Sub-scale scores |
| Pain   | 5           | 4            | 3                   | 2           | 1                   | 0         |       | Physical         |
| Shortness of breath  | 5           | 4            | 3                   | 2           | 1                   | 0         |       |                  |
| Skin breakdown   | 5           | 4            | 3                   | 2           | 1                   | 0         |       |                  |
| Calm*  | 0           | 1            | 2                   | 3           | 4                   | 5         |       | Psychological    |
| Depression   | 5           | 4            | 3                   | 2           | 1                   | 0         |       |                  |
| Fear   | 5           | 4            | 3                   | 2           | 1                   | 0         |       |                  |
| Anxiety  | 5           | 4            | 3                   | 2           | 1                   | 0         |       |                  |
| Agitation  | 5           | 4            | 3                   | 2           | 1                   | 0         |       |                  |
| Resistiveness to care  | 5           | 4            | 3                   | 2           | 1                   | 0         |       |                  |
| Total score  |             |              |                     |             |                     |           |       |                  |

\*Reverse coded for calculation of total score.

From Volicer, Hurley, & Blasi (2001). Scales for evaluation of end-of-life care in dementia. *Alzheimer Disease and Associated Disorders*, 15(4), 194-200.

**Item Definitions:**

*Pain* = The person with dementia exhibited behavior indicating that he or she was in pain. Presence of pain could be based on informal observation or on one of the pain scales (e.g., PAINAD).

*Shortness of breath* = Shortness of breath could be manifested by increased respiratory rate or heart rate, restlessness, accessory muscle use, grunting at end-expiration, nasal flaring, and fearful facial expression (The Respiratory Distress Observation Scale [RDOS]; Campbell, 2008).

*Skin breakdown* = Presence of grade 2 or higher disruption of skin integrity.

*Calm* = The person with dementia is not agitated.

*Depression* = The person with dementia exhibits three or more of the following symptoms: negative statements, anger, expression of what appear to be unrealistic fears, repetitive health complaints, repetitive anxious complaints or concerns, sadness, and crying (Burrows, Morris, Simon, Hirdes, & Phillips, 2000).

*Fear* = The person with dementia has a fearful facial expression.

*Anxiety* = The person with dementia exhibits the following: worry, apprehension and vigilance, motor tension, and autonomic hypersensitivity (for detailed scale, see Shankar, Walker, Frost, & Orrell, 1999).

*Agitation* = The person with dementia has periods of restlessness, repetitive physical movements, wandering, and socially inappropriate/disruptive behavior (Gerritsen et al., 2008).

*Resistiveness to care* = The person with dementia does not cooperate with care and rejects staff members' attempts to provide care; person may become combative if staff insist on providing care.