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# The Edinburgh Feeding Evaluation in Dementia Scale

Determining how much help people with dementia need at mealtime.



read it watch it try it

**Overview:** The Edinburgh Feeding Evaluation in Dementia scale is an 11-item instrument developed to assess eating and feeding problems in people with late-stage dementia. By looking for certain behaviors—spilling food while eating or turning the head when prompted to eat, for example—a nurse can identify a patient's needs and build an effective care plan. The scale takes as little as five minutes to complete. Watch an online video of nurses demonstrating the use of the scale: http://links.lwww. com/A281.

ighty-nine-year-old Rose Kyle, hospitalized for treatment of urosepsis and dehydration, lives at home with her 87year-old husband of 63 years, Roger, who is her primary caregiver. She had a stroke 10 years ago, which resulted in a partial loss of the use of her left arm and leg and difficulty with fine motor skills in her left hand. Two years ago she was diagnosed with mixed dementia—Alzheimer's disease and cerebrovascular disease—and since then, her eating patterns have changed, and she can transfer from bed to chair only with assistance. Her daily medications are aspirin 81 mg, donepezil (Aricept) 5 mg, lorazepam (Ativan) 0.5 mg, and ranitidine (Zantac) 75 mg, the last three taken at bedtime.

Mr. Kyle's medical history includes dyslipidemia; he has no physical limitations and can help his wife as needed. The couple's son and daughter-in-law, who live nearby, visit them often. The Kyles used to enjoy playing cards with friends, but Ms. Kyle has been increasingly less able to participate in activities requiring such complex cognitive and motor skills. She has become, her husband says, much more isolated. And in recent months, he has had a much harder time managing her cognitive and functional decline.

When passing Ms. Kyle's room at mealtime, the nurse overhears Mr. Kyle shouting at his wife, "Eat! Or you'll never get out of this place!" Later, during dinner, Ms. Kyle's son tells his mother that she might "end up in a nursing home with a tube" if she doesn't eat and drink more. The nurse talks with these family members, who say that they're "fed

### Web Video

Watch a video demonstrating the use of the Edinburgh Feeding Evaluation in Dementia scale at http://links.lww.com/A281.

## A Closer Look

Get more information on why it's important for nurses to screen for nutritional deficits in patients with dementia, as well as why this scale is a good approach for doing so.

## Try This: The Edinburgh Feeding Evaluation in Dementia Questionnaire This is the scale in its original form. See page 51.

up and worried sick" because Ms. Kyle has been "eating like a bird" over the past year. Mr. Kyle says that she's lost 5 lbs. in six months, but on reflection says she must have lost 20 lbs. in the past two years. He says that he hadn't really stopped to think about her weight loss over time and that her physician hadn't seemed too worried, saying that she wanted Ms. Kyle to "keep her weight down."

The nurse discusses these concerns with the interdisciplinary team. The physician orders a laboratory workup to evaluate her serum albumin and prealbumin levels, lymphocyte count, transferrin level, and hemoglobin level and hematocrit. Ms. Kyle's morning weight is 102 lbs. (46.27 kg) and her height is 63 in. (160 cm); the team calculates a body mass index of 18.1 (less than 18.5 is considered underweight). Her ideal body weight is 115 pounds (52.4 kg). The physician orders a dietary consultation to evaluate Ms. Kyle's three-day caloric intake and to make recommendations for greater intake of protein, calories, and fluids. Findings will allow the physician to discuss these recommendations with Mr. Kyle. Realizing that Ms. Kyle's dementia may be contributing to her inability to eat adequately, the nurse administers the Edinburgh Feeding Evaluation in Dementia (EdFED) scale.

#### THE EDINBURGH FEEDING EVALUATION IN DEMENTIA SCALE

The EdFED scale contains 11 items developed to help clinicians look for eating and feeding problems in people with late-stage dementia. Although it is not a screening or diagnostic tool, it can establish a



# Why Check for Eating and Feeding Problems in Older Adults with Dementia?

This population is at particular risk for malnutrition.

I has long been established that problems with eating and feeding occur in the later stages of dementia and are usually the last activities of daily living to be lost.<sup>3</sup> Families and caregivers usually consider the inability to manage meals and to eat and drink enough as a harbinger of failing health or impending death. It can cause a sense of desperation in family caregivers trying to assist with meals. But during this period of decline, the patient deserves to be treated with dignity at meals. By tracking incremental changes a nurse might develop interventions that will strengthen function.

In 2005, 3% of Medicare beneficiaries 65 years old and older required assistance with five to six activities of daily living<sup>4</sup>; most likely required help with eating. During the first quarter of 2008, 10% of the residents of U.S. nursing homes required extensive assistance with eating, and 14% were totally dependent on help while eating.<sup>5</sup> Because this population is at risk for malnutrition, the usual focus is on increasing caloric intake, but caregivers often struggle with accomplishing this task.

The alternative to supportive hand-feeding is tube feeding. Although the studies of tube feeding haven't been particularly strong, the evidence that does exist shows little benefit to tube feeding, in terms of important outcomes such as survival, functional ability, and infections.<sup>6,7</sup> How we eat, with whom we eat, and where we eat are meaningful to all of us, especially older adults living in nursing homes.<sup>8</sup> A patient's social skills may be preserved, even if she or he is in the later stages of dementia; therefore, the observation of rituals may provide cues to eating in people with cognitive impairment.<sup>9, 10</sup>

> baseline of behaviors and define the level of assistance the patient needs. It can take as little as five minutes to complete, and results can be used to predict needs and build a care plan.

> The first 10 items in the scale are questions addressing 10 mealtime behaviors; each is scored according to how often it occurs during a meal. A score of 0 is given if the behavior "never" happens, a 1 if it happens "sometimes," and a 2 if it happens "often." The first four behaviors indicate that assistance is already required or that it might be required:

- needs close supervision
- requires physical help
- spills food

leaves food on plate

The last six behaviors reflect functional or cognitive decline:

- refuses to eat
- turns head away
- refuses to open mouth
- spits out food
- leaves mouth open
- refuses to swallow

The EdFED scale addresses progressive decline; research has suggested that there's "possibly a cumulative, hierarchical pattern" in these behaviors, meaning that the presence of a behavior on the scale increases the likelihood of the presence of the one preceding it.<sup>1</sup> For example, if a patient leaves food on the plate, it's very likely that she or he also spills food and requires help and supervision during meals.

Finally, an 11th item asks the rater to indicate the level of support the patient requires during the meal: supportive–educative assistance (needs cuing or help with plate setup or refocusing), partly compensatory assistance (is involved with meals but requires physical assistance), or wholly compensatory assistance (requires hand-feeding).

Baseline status should be assessed in people with moderate-to-severe dementia who have been losing weight or showing declines in mealtime function. Results will inform interventions. (The Hartford Institute for Geriatric Nursing has published the scale in "Eating and Feeding Issues in Older Adults with Dementia: Part I: Assessment," available on page 51. Part II addresses interventions and can be found on the Hartford Institute Web site: www.hartfordign. org/publications/trythis/issue11\_2.pdf.) After the initial assessment, the scale can be incorporated into routine assessment; for example, if weekly weighings are performed on Mondays, the staff could schedule assessment with the EdFED during Monday morning breakfast. As with most nutritional assessments, administering the scale at the same time of day in the same environment decreases the chance that other variables can influence the observed behaviors.<sup>2</sup> According to Roger Watson, who created the scale, the EdFED has been shown to have the same accuracy when measuring behavior through direct observation and through the caregiver's report (Roger Watson, e-mail communication, May 12, 2008). (To view the section of the online video in which nurses discuss assessment and care planning, go to http:// links.lww.com/A282. (\*)

#### **ADMINISTRATING THE EDFED SCALE**

The EdFED scale can be administered either by watching the patient eat a meal or by asking care-

givers to report mealtime behaviors (the latter is more frequently done in community or primary care settings). Observation should be as unobtrusive as possible. For example, the nurse completing the assessment should not assist with the meal and should avoid conversation with the patient and caregivers, which could distract the observer. To gain better insight into mealtime patterns, the observed meal should take place where the person usually eats.

The observer will note how often (if at all) the specific behaviors occur during the meal. Afterward, the observer talks with the regular caregiver to find out how often and under what circumstances the observed behaviors occur. (Caregiver input is only necessary to complete the baseline assessment.) For example, if the observer notes that the patient turns his head away, the observer might ask, "I noticed that Mr. Smith turned his head away when you lifted up the cup of coffee. Has this ever happened before?" If so, the observer should ask further questions, such as, "Is there anything specific that seems to cause this? Perhaps certain types of food? When does this occur-at the end of the meal when he seems to be tired? Does he ever cough, clear his throat, or need more time to swallow?" With such probing, a more complex picture will emerge.

If the caregiver isn't available at the time of the initial assessment, schedule a phone conversation or invite the person to participate in a team meeting. If the patient comes from another institution, call the nurse or caregiver in that facility for additional input. (For more, see *Why Check for Eating and Feeding Problems in Older Adults with Dementia?* page 48.<sup>3-10</sup>)

**Ms. Kyle** is observed during the evening meal, during which she is supervised by her husband. For the need for close supervision, the nurse gives Ms. Kyle a score of 2. She also requires significant help with tasks such as cutting her food and receives a score of 2 in the physical assistance category. Frequently during the meal she refuses to eat and in the end leaves more than half of the food on her plate; therefore, the nurse assigns a score of 2 for each of these behaviors. She did not spill any food, turn her head away, refuse to open her mouth, spit out food, leave her mouth open and allow food to drop out, or refuse to swallow, therefore earning a score of 0 in each of those categories. Answering the 11th item, the nurse notes that Ms. Kyle requires partial assistance with the meal.

The nurse asks Mr. Kyle to describe mealtimes at home: are the behaviors noted during observation common there as well? "I make all of the food. I try to make her favorites," he replies, "and we usually eat in front of the television." Mealtimes last between 30 to 45 minutes, and she requires constant prompting to focus on her food. "If I don't remind her to eat, she'll only take a few bites." He always cuts her food, and when possible he serves finger foods, such as sandwiches and cheese cubes, that don't require utensils. During meals Ms. Kyle often complains of having no appetite and says she's full after eating a small amount. With constant encouragement, she usually eats about half what's served. Although Mr. Kyle tries to keep her on a low-fat diet because of her history of cerebrovascular disease, he notes that "she always cleans her plate when I serve dessert."

**Challenges that may arise.** Because Watson never quantified the terms "sometimes" or "often" in the EdFED scale, the determination of frequency is somewhat subjective. If deciding to adopt the EdFED scale, an institution or unit should define frequency; for example, "sometimes" could be defined as observed at least once during a meal.

#### **SCORING AND INTERPRETING THE RESULTS**

The rater will assign a score (ranging from 0 to 2) to each of the 10 behaviors according to whether it is observed never, sometimes, or often. These 10 scores are summed, with final scores ranging from 0 to 20. A higher score indicates greater dysfunction. Any behavior that receives a score of 1 or 2 should be addressed in a new plan of care.

**Ms. Kyle** receives a score of 8, which indicates a need for assistance. The nurse and the case manager arrange for her to be transferred to the hospital's acute-care-of-the-elderly (ACE) unit. The results of the EdFED scale are shared with the new team, which generates further assessments. A dental consultation is arranged; improperly fitting dentures, loose or missing teeth, and poor dental hygiene can all diminish a person's ability and desire to eat. The speech–language pathologist verifies that Ms. Kyle is not aspirating her food but recommends a meal-time environment as free of distractions as possible. The occupational therapist provides a lightweight, sturdy covered cup to improve Ms. Kyle's grip and reduce the likelihood of spilled liquids.

The dietician cancels Ms. Kyle's low-fat diet and recommends a dense calorie diet (with a high calorieto-quantity ratio), suggesting more protein and fat and fewer simple carbohydrates. Commercial nutritional drinks are ordered for between-meal snacks. Because Ms. Kyle enjoys dessert, ice cream is added to the nutritional drink. The dietician also orders a three-day calorie count to be conducted while Ms. Kyle is hospitalized.

To provide insight into which of the modifications are helping Ms. Kyle, she is reassessed with the

# Watch It!

try this

How To

G o to http://links.lww.com/A281 to watch a nurse use the Edinburgh Feeding Evaluation in Dementia scale. Then watch the health care team plan preventive strategies. View this video in its entirety and then apply for CE credit at www.nursingcenter.com/AJNolderadults; click on the *How* to Try This series link. All videos are free and in a downloadable format (not streaming video) that requires Windows Media Player.

> EdFED scale during each evening meal. As it's determined which interventions work and which do not, the information is shared with her family.

#### **OTHER CONSIDERATIONS**

A number of studies have been conducted in which the EdFED either was used by people from differing cultural backgrounds or was translated. Although none of the studies specifically examined difficulties the users of the EdFED might have in understanding the scale, no such difficulties were reported. Lin and colleagues did not note any such cultural issues arising in using the Chinese translation of the scale in a Taiwanese population.<sup>11</sup> One of us (EJA) conducted a study in New York City that included 53 caregivers who were certified nursing assistants: 79% were Caribbean Islander, 11% African American, 8% African, and 2% non-Latino white.12 None of these study participants reported any difficulty in understanding the descriptors for the behaviors or level of assistance used in the scale. The EdFED scale was translated into Chinese13 and used in a study of the effectiveness of an educational intervention in North Taiwan; 68 nursing assistants who spoke Mandarin, Taiwanese, or English participated.<sup>14</sup> Although the scale was used to measure the feeding difficulties of the patients (and only revealed the effectiveness of the educational intervention indirectly), the authors of the study did not note any limitations or challenges in the use of the scale. Finally, Watson and Deary included 78 subjects in a longitudinal study in the United Kingdom; neither demographic characteristics nor cultural issues were reported.15

#### **COMMUNICATING THE RESULTS**

Someone who has dementia so severe that she or he needs assistance with eating is best cared for by an interdisciplinary team. In these complex cases the team should include a dietician, a speech–language pathologist, an occupational therapist, a dentist, a nurse,<sup>9</sup> a social worker, and an appropriate clergyperson or cultural interpreter.

Following up with team members about findings is an important nursing role. For example, dietary changes may need to be accommodated by providing the appropriate implements (such as no-spill cups with straws); oral care techniques should be discussed with family members and other health care professionals.

**Ms. Kyle, continued.** The acute care nurse explains the results of the EdFED scale to Mr. and Ms. Kyle and to their son and daughter-in-law, who occasionally help with meals. Clear communication with all caregivers about the kind of assistance a patient needs and the type of behaviors to watch for is ideal: it supports consistency in the interventions used. For example, in this case, the nurse explains that the plan is to encourage Ms. Kyle's independence, but if her caregivers find that she needs more help or her abilities decline, a referral to a member of the team will be necessary.

When his wife is admitted to the ACE unit, Mr. Kyle discusses her care plan with that unit's team. The dietician suggests that Mr. Kyle keep a food diary for three days after discharge, one day being on a weekend to provide a true snapshot of Ms. Kyle's eating patterns. Mr. Kyle also is asked to make an appointment with the family dentist after discharge. At this time, the plan is for Ms. Kyle to return home, with a personal care worker to visit twice weekly to assist with activities of daily living. When she is ready to leave the hospital, the discharge planner will share Ms. Kyle's care plan recommendations with the agency that employs the personal care worker to ensure that they are followed. (To see the portion of the online video in which a nursing expert answers questions on the EdFED scale, go to http://links.lww.com/A283. (\*)

#### **CONSIDER THIS**

The EdFED scale is one of the few instruments for assessing the behavior of people with late-stage dementia. It was designed to circumvent what is often described as the "floor effect" of certain tests—the inability of a tool to detect change in what is being measured because the person's level of functioning is already at a very low level (the "floor"), as occurs in late-stage dementia. In other words, the EdFED scale can detect decrements in eating even when the person's functioning is severely compromised and the usual tools can no longer detect functional deterioration.<sup>16</sup> In fact, it enables clinicians to note changes almost to the last levels of functioning—the ability to hold food in the mouth.

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# Eating and Feeding Issues in Older Adults with Dementia: Part I: Assessment

By: Elaine J. Amella, PhD, APRN, BC, FAAN, Medical University of South Carolina College of Nursing and James F. Lawrence, PhD, APRN, BC, Evercare

WHY: Hospital patients with dementia are at high risk for eating and feeding difficulties and inadequate food and fluid intake. Depending on the severity of their cognitive impairment, they may forget to eat, forget they have eaten, fail to recognize food, or eat things that are not food. They may have difficulty with specific tasks (e.g., removing plate covers and wrappings, knowing what the utensils are for and using them, moving food or fluid to their mouth, chewing, and swallowing). They may have difficulty initiating the eating process, or they may start eating, get distracted, and fail to finish (Amella, 2004).

Eating difficulties may have existed before hospitalization, but they are likely to worsen in the hospital because people with dementia often become more confused in an unfamiliar place. Different mealtime routines and foods add to the problem. Factors that reduce appetite and food and fluid intake in other older patients (e.g., pain, medications, nausea, dental and oral problems, and special diets) also affect patients with dementia who are less able understand and cope with them. Because of their cognitive and related communication impairments, patients with dementia may not be able tell anyone they are hungry or that they need help eating or more time to chew and swallow. When staff members try to help, some patients with dementia resist, push the food away, refuse to open their mouths, or spit food out.

BEST TOOL: Assessment can be challenging because of patients' cognitive and related communication impairments. The Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) (Watson & Dreary, 1997a) is a valid and reliable observational instrument that nurses can use to identify eating and feeding difficulties and determine the level of assistance needed. The EdFED-Q was developed and tested extensively with nurses in psychogeriatric units and nursing homes.

**TARGET POPULATION:** Hospitalized older adults with diagnosed or suspected dementia.

VALIDITY AND RELIABILITY: The EdFED-Q was developed through Mokken scaling of items and factor analysis. Factor analysis of responses in a study of 196 older persons with dementia demonstrated that items could be reduced to three groups of indicators (Watson & Deary, 1997a) and the three groupings were found to be the best fit through Structural Equation Modeling in 345 patients (Watson & Deary, 1997b). These indicators include: patient behavior – obstinacy/aversion and passivity (seven items); nursing interventions (three items); and, an indicator of feeding difficulty (one item). This instrument has been used clinically in nursing home settings and in one community-based study and among 24 pairs of raters was found to have more than acceptable inter-rater (r = .59, p = 0.013) and intra-rater (r = .95, p < .0001) reliability (Watson, McDonald, & McReady, 2001).

STRENGTHS AND LIMITATIONS: The EdFED-Q is not clinically diagnostic, but it allows the assessor to determine the level of impairment as well as evaluate the need for possible psychosocial and clinical interventions, such as referrals for speech therapy, environmental modification, dietary alterations, environmental modification, diet alterations, and communication techniques. Mokken scaling of the seven behavior items forms a hierarchy of mealtime behavior so that behavior can be predicted. The EdFED-Q can be used as both a caregiver report and observational instrument. When observing a caregiver assist a person with dementia at meals, it is possible to also assess the quality of their interaction as construct validity of the EdFED-Q was established with another instrument (Interaction Behavior Measure - IBM). Because eating and feeding is by definition a reciprocal relationship, Amella (2002) showed that both instruments (IBM and EdFED-Q) were measuring the quality of the mealtime interaction even though the EdFED-Q only measures the behavior of the person with dementia.

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# Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q)\*

#### Score answers to questions 1-10: never (0), sometimes (1), often (2)

1. Does the patient require close supervision while feeding?	
2. Does the patient require physical help with feeding?	
3. Is there spillage while feeding?	
4. Does the patient tend to leave food on the plate at the end of the meal?	
5. Does the patient ever refuse to eat?	
6. Does the patient turn his head away while being fed?	
7. Does the patient refuse to open his mouth?	
8. Does the patient spit out his food?	
9. Does the patient leave his mouth open allowing food to drop out?	
10. Does the patient refuse to swallow?	

#### Total Score =

(Total scores range from 0 to 20, with 20 being the most serious. Scores can be used to track change.)

11. Indicate appropriate level of assistance required by patient: supportive-educative; partly compensatory; wholly compensatory

\* Used with permission of author, R. Watson.

## **Other Essential Assessment Guidelines**

<u>Assessing Pre-Hospital Eating and Feeding Behaviors</u>: The nurse should ask the family or other caregivers whether the patient usually feeds him- or herself and what assistance is generally provided. This information is essential to establish a realistic target for maintaining the patient's self-feeding ability.

<u>Swallowing Disorders</u>: People with dementia and eating difficulties may have swallowing disorders that are often unrecognized. These patients are sometimes labeled as combative, uncooperative, and difficult to feed when they try to refuse food they cannot swallow (Kayser-Jones, 1999). If assessment suggests an undiagnosed swallowing disorder, the patient should be referred to a speech pathologist for further evaluation.

#### MORE ON THE TOPIC

Best practice information on care of older adults: www.ConsultGeriRN.org.

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What is the evidence for using the EdFED scale in practice? At this time, the EdFED scale has been used primarily in research, but that research has been conducted in a variety of settings: acute care, long-term care, and the home. In long-term care, the EdFED has been used to measure behaviors in residents, such as resistance at meals, as well as to determine the level of assistance needed.<sup>12, 14</sup>

A strength of this approach is that it has essentially the same results whether the information is gathered by caregiver report or observation, making it helpful in a clinic or home setting where eating cannot be observed; in the same way, a baseline assessment can be made at an institution and followup assessments performed at home, with results

It has essentially the same results whether the information is gathered by caregiver report or observation.

reported over the phone. As changes are made to standards of practice and providers realize that hand-feeding people with late-stage dementia results in no more complications than tube feeding—and perhaps fewer—the ability to properly assess functional strengths and devise care strategies will be needed. The EdFED scale could meet that need.<sup>17</sup>

- **Reliability.** The EdFED scale has moderate-toexcellent reliability when used by either observation or caregiver report. The reliability of the EdFED scale has been established by several researchers with  $\alpha$  coefficients ranging from 0.44 (moderate) to 1.00 (perfect agreement) on all items,<sup>13</sup> a Cronbach  $\alpha$  of 0.87, and intrarater reliability of 0.95.<sup>1,18</sup>
- Validity. The EdFED scale has the ability to discriminate between people with late-stage dementia who resist food and those who accept food, with resistors taking longer to feed but consuming less than those who accept food. In a study by one of us (EJA) "of 53 nursing home residents with late-stage dementia who were assisted at meals," clinically meaningful but statistically insignificant differences in Mini-Mental State Examination scores and in body mass index were found, with the acceptors scoring higher than

For more information on this and other geriatrics assessment tools and best practices go to www.ConsultGeriRN.org—the clinical Web site of the Hartford Institute for Geriatric Nursing, New York University College of Nursing, and the Nurses Improving Care for Healthsystem Elders (NICHE) program. The site presents authoritative clinical products, resources, and continuing education opportunities that support individual nurses and practice settings.

Visit the Hartford Institute site, www.hartfordign.org, and the NICHE site, www.nicheprogram.org, for additional products and resources. Go to www.nursingcenter.com/ AJNolderadults and click on the *How to Try This* link to access all articles and videos in this series.

resistors on both measures.<sup>12</sup> As mentioned above, the EdFED has been translated into Chinese, when it was used in a study of Taiwanese nursing assistants to evaluate their knowledge of and behaviors when feeding persons with dementia.<sup>14</sup> When the consistency of the scores in the English and Chinese versions was examined, the intraclass correlation coefficient for the absolute agreement was found to range from 0.85 to 0.90.<sup>13</sup>

 Sensitivity and specificity. There have been no published reports of the sensitivity and specificity of the EdFED scale. ▼

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Routine use of Try This tools or approaches may require formal review and approval by your employer.

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