## Measure Description

Percentage of patients with dementia whose caregiver(s)* were provided with education** on dementia disease management and health behavior changes AND were referred to additional resources*** for support in the last 12 months.

### Measure Components

**Numerator Statement**

Patients with dementia whose caregiver(s) were provided with education on dementia disease management and health behavior changes AND were referred to additional resources** for support in the last 12 months.

* “Caregiver” is broadly defined and the Work Group adopted the definition utilized by the National Quality Forum and Feinberg.(1) Caregiver refers to any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older adult or an adult with chronic or disabling conditions.(1)

** “Education” requires learning and processing information about disease management and health behavior changes. This should also include advising the caregiver that, as a caregiver, he or she is at “increased risk of serious illness (including circulatory and heart conditions and respiratory disease and hypertension), increased physician visits and use of prescription medications, emotional strain, anxiety, and depression.”(2) Providers are encouraged to review state specific guidelines to ensure education is being provided as required.

*** “Additional Resources” are defined as situation-specific, tailored programs to assist the caregiver; these included national organizations such as the Alzheimer’s Association, but also include local resources, such as community, senior center and religion-based support groups.

**Denominator Statement**

All patients with dementia (Diagnostic codes listed in Appendix A)

### Denominator Exceptions

- Patient does not have a caregiver.
- Caregiver is trained and certified in dementia care.
- Patient/caregiver dyad referred to appropriate resources and connection to those resources confirmed.

### Exception Justification

- Exception created for patients who do not have caregivers, as it would be impossible to provide in this situation.
- An exception was also created for trained and certified caregivers, as education would be redundant.
- An exception was created for patient/caregiver dyads that are known to be connected with existing supports as education would be redundant.

### Supporting Guideline & Other References

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:

- “Important aspects of psychiatric management include educating patients and families about the illness, its treatment, and sources of additional care and support (e.g., support groups, respite care, nursing homes, and other long-term-care facilities) and advising patients and their families of the
need for financial and legal planning due to the patient’s eventual incapacity (e.g., power of attorney for medical and financial decisions, an up-to-date will, and the cost of long-term care) (Category I)… The family should be educated regarding basic principles of care, including

1. recognizing declines in capacity and adjusting expectations appropriately,
2. bringing sudden declines in function and the emergence of new symptoms to professional attention,
3. keeping requests and demands relatively simple,
4. deferring requests if the patient becomes overly upset or angered,
5. avoiding overly complex tasks that may lead to frustration,
6. not confronting patients about their deficits,
7. remaining calm, firm, and supportive and providing redirection if the patient becomes upset,
8. being consistent and avoiding unnecessary change, and
9. providing frequent reminders, explanations, and orientation cues…

In addition to providing families with information on support groups, there are a number of benefits of referral to the local chapter or national office of the Alzheimer’s Association (1-800-272-3900; http://www.alz.org), the Alzheimer’s Disease Education and Referral Center (ADEAR) (1-800-438-4380; http://www.nia.nih.gov/Alzheimers/), and other support organizations.” (3)

- “Short-term programs directed toward educating family caregivers about AD should be offered to improve caregiver satisfaction” (4).
- “Intensive long-term education and support services (when available) should be offered to caregivers of patients with AD to delay time to nursing home placement” (4).
- “Staff of long-term care facilities should receive education about AD to reduce the use of unnecessary antipsychotics” (4)
- "Support programs for caregivers and patients with dementia significantly decreased the odds of institutionalization and improved caregiver well-being." (5)
- “A dementia diagnosis mandates an inquiry to the community for available public health care support programmes (Good Practice Point). Counselling and case/care management amongst caring family members have positive effects on burden and satisfaction for caregivers of people with dementia (Good Practice Point).” (6)
- “Following a diagnosis of dementia, health and social care professionals should, unless the person with dementia clearly indicates to the contrary, provide, them and their family with written information about
  1. The signs and symptoms of dementia
  2. The course and prognosis of the condition
  3. Treatments
  4. Local care and support services
  5. Support groups
  6. Sources of financial and legal advice, and advocacy
7. Medico-legal issues, including driving
8. Local information sources, including libraries and voluntary organisations.” (7)
- “…emphasise that professional support should have a wide focus that includes helping family and friends to support the person with dementia, rather than being limited to an exclusive and direct focus on the person with dementia.” (8)

<table>
<thead>
<tr>
<th>Relationship to Desired Outcome</th>
<th>By providing education as well as resources to caregivers it is anticipated that caregiver will act on information received connecting to support networks and gain a greater understanding of dementia. As a result, caregiver burden will decrease, caregiver and patient Quality of Life will improve, and caregiver and patient physical health will improve.</th>
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<tr>
<td>Opportunity for Improvement</td>
<td>There is evidence that dementia-related needs for care, services and support for patients with dementia in the community and their caregivers are unmet. (9) Caregiver stress is the unequal exchange of assistance among people who stand in close relationship to one another, often resulting in physical and emotional distress in the caregiver. (10) The patient and the caregiver will inevitably face challenges related to cognitive and behavioral decline. All healthcare providers have a wealth of expertise that can be shared with caregivers of patient with dementia who often lack the time and resources to identify appropriate referrals for their needs. Helping to guide the patient and the caregiver through these challenges is an essential aspect of providing good clinical care.</td>
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| National Quality Strategy Domains | ☒ Patient and Family Engagement  
☐ Patient Safety  
☐ Care Coordination  
☐ Population/Public Health  
☐ Efficient Use of Healthcare Resources  
☐ Clinical Process/Effectiveness |
| Harmonization with Existing Measures | Harmonization with existing measures was not applicable to this measure. |
| Measure Purpose (Check all that apply) | ☒ Quality improvement  
☒ Accountability |
| Type of Measure (Check all that apply) | ☒ Process  
☐ Outcome  
☐ Structure |
| Level of Measurement (Check all that apply) | ☒ Individual Provider  
☒ Practice  
☒ System |
| Care Setting (Check all that apply) | ☒ Outpatient  
☐ Inpatient  
☐ Emergency Departments and Urgent Care  
☒ Post-Acute Care (i.e., Long Term Care Hospitals, Skilled Nursing Facilities, Inpatient Rehabilitation Facilities, and Home Health Agencies) |
### Data Source

(Check all that apply)

- ☒ Electronic health record (EHR) data
- ☐ Administrative Data/Claims
- ☐ Chart Review
- ☒ Registry

### References