



Complete Summary

GUIDELINE TITLE

Evidence-based practice guideline. Family preparedness and end of life support before the death of a nursing home resident.

BIBLIOGRAPHIC SOURCE(S)

Davidson KM. Evidence-based practice guideline. Family preparedness and end of life support before the death of a nursing home resident. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center, Research Translation Dissemination Core; 2009 Jan. 22 p. [37 references]

GUIDELINE STATUS

This is the current release of the guideline.

This guideline updates a previous version: Research Dissemination Core. Family bereavement support before and after the death of a nursing home resident. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center; 2002 Oct. 46 p.

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SCOPE

DISEASE/CONDITION(S)

Bereavement

GUIDELINE CATEGORY

Management

CLINICAL SPECIALTY

Family Practice
Geriatrics
Nursing
Psychology

INTENDED USERS

Advanced Practice Nurses
Nurses
Other
Social Workers

GUIDELINE OBJECTIVE(S)

To provide guidelines for end of life support of family members before the death of a nursing home resident

TARGET POPULATION

All family members and significant others with an attachment to a nursing home resident nearing end of life

INTERVENTIONS AND PRACTICES CONSIDERED

1. Educate front line workers
2. Identify nursing home residents who are approaching end of life, using clinical indicators of mortality
3. Ensure ongoing involvement of the nursing home resident's physician in determining approaching end of life and communicating with residents and family members about dying and death
4. Ensure open communication for the course of end of life care and implementation of palliation including incorporation of advance care planning documents
5. Assist the family caregivers to recognize disease progression, dying trajectory, and the dying process
6. Maintain close contact with family caregivers
7. Understand that length of time as a family caregiver does not predict acceptance of the dying process
8. Re-evaluate and possibly discontinue grief support initiatives
9. Coordinate signing and sending a sympathy card to the family
10. Acknowledge that nursing homes are *de facto* hospices

Note: After-death grief support for family members of deceased nursing home residents, and support for nursing home staff members, is beyond the scope of this guideline.

MAJOR OUTCOMES CONSIDERED

Preparedness for death of a loved one

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Databases

Searches were performed using electronic databases CINAHL, Medline, PubMed and Google Scholar. In addition, searches were performed on the citations and reference list of documents that met the inclusion criteria. Searches were performed on the names of authors known to conduct research and publish in the area of interest.

Keywords

The following search terms (keywords) were used individually and in combinations:

- Bereavement + nursing home; grief + nursing home
- Grief support + nursing home; bereavement support + nursing home
- Grief + dementia; bereavement + dementia
- Grief + elderly; bereavement + elderly
- Death + nursing home; end of life + nursing home; palliative care + nursing home
- Family support + dying + nursing home; family preparedness + dying + nursing home
- Evaluation + end of life + nursing home
- Grief + program evaluation; bereavement + program evaluation

Inclusion and Exclusion Criteria

The database searches were limited to documents published in peer-reviewed scholarly journals, published between 2000 – 2008, in English, and pertaining to an adult population. Documents were excluded if they were peripheral to the topic, presented no new discourse, findings or evidence, presented expert opinion only, or cited a majority of references published prior to 2000.

NUMBER OF SOURCE DOCUMENTS

84 documents were identified and 38 documents were used

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Evidence Grading

A1 = Evidence from well-designed meta-analysis or well done systematic review with results that consistently support a specific action (e.g., assessment, intervention, or treatment)

A2 = Evidence from one or more randomized controlled trials with consistent results

B1 = Evidence from a high quality evidence-based practice guideline

B2 = Evidence from one or more quasi-experimental studies with consistent results

C1 = Evidence from observational studies with consistent results (e.g., correlational descriptive studies)

C2 = Inconsistent evidence from observational studies or controlled trials

D = Evidence from expert opinion, multiple case reports, or national consensus reports

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

This guideline was reviewed by experts knowledgeable of research on end of life support guidelines. The reviewers suggested additional evidence for selected actions, inclusion of some additional practice recommendations, and changes in the current guidelines.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

The grades of evidence (A1, A2, B1, B2, C1, C2, D) are defined at the end of the "Major Recommendations" field.

Description of the Practice

Providing clear interventions in the care plan gives front-line nursing home staff confidence and direction to assist family members in an end of life situation where staff often feel stressed and uncertain (Burack & Chichin, 2001. *Evidence Grade = C1*). The registered nurse (RN), who is usually the team leader and most prevalent front line professional, is ideally situated to take accountability for implementing and coordinating family preparedness and end of life support interventions.

1. Staff Development: Successful and consistent implementation of family preparedness and end of life support depends upon the education of front line workers (registered nurses, practical nurses, nurses' aides, social workers, chaplains, and volunteers). The need for training of nursing home staff to improve the standard of end of life care for residents and their family members is widely acknowledged (Avis et al., 1999; Ersek & Wilson, 2003; Katz, Sidell, & Komaromy, 2001; Moss, Braunschweig, & Rubinstein, 2002; Neimeyer, 2004; Oliver, Porock, & Zweig, 2004; Rice et al., 2004. *Evidence Grade = B2*). Staff education topics should include:
 - The dying process, with particular emphasis on recognition of dying trajectory (Forbes, Bern-Klug, & Gessert, 2000; Kehl, 2006. *Evidence Grade = B2*).
 - Communication skills specific to preparing family members for the dying trajectory, death and bereavement (Forbes, Bern-Klug, & Gessert, 2000; Hebert, Dang, & Schultz, 2006; Hebert et al., 2006. *Evidence Grade = B2*).
 - Culturally sensitive end of life care, incorporating explanatory beliefs about illness, dying and death, and religious beliefs and practices (Hebert et al., 2006. *Evidence Grade = B1*).
 - Use of opioid and non-opioid medications for nursing home residents without a cancer diagnosis who require long-term pain management (Parker et al., 2005. *Evidence Grade = C1*).
 - Clinical indicators of dying, as outlined below.
2. Identify nursing home residents who are approaching end of life, using clinical indicators of mortality. "Failure to prognosticate futurity is the most powerful obstacle to effective palliation and end of life plans of care..." in nursing home

residents (Travis et al., 2002). "High quality of life care cannot be achieved if the diagnosis of dying occurs only hours or days before death" (Porock et al., 2005).

Indicators of the trajectory of dying include (Abict-Swenson & Debner, 1999; Flacker & Kiely, 2003; Forbes, Bern-Klug, & Gessert, 2000; Mehr et al., 2001; Porock et al., 2005. *Evidence Grade = A2*):

- Significant deterioration in cognitive status (e.g., poor score on minimum data set [MDS] Cognitive Performance Scale)
 - Decline in ability to communicate
 - Increasing dependence with activities of daily living (ADLs)
 - Incontinence
 - Dysphagia
 - Poor nutritional status: weight loss of 10% of body weight, low body mass index (BMI) ($< 23 \text{ kg/m}^2$), poor appetite (e.g., 25% of food uneaten), dehydration
 - Low total lymphocyte count
 - Lower respiratory infection/pneumonia in past 90 days, shortness of breath
 - Diagnosis of congestive heart failure, chronic renal failure or cancer
 - Recent adverse event (e.g., admission to nursing home)
 - Advanced age
 - Bedfast
 - For nursing homes using the MDS tool, (Porock et al., 2005) a "MDS Mortality Risk Index Point System" has been developed
3. Family members and nursing home residents expect physicians to label the resident as "terminal" when the time comes (Forbes, Bern-Klug, & Gessert, 2000).
- Ensure ongoing involvement of the nursing home resident's physician in determining approaching end of life and communicating with residents and family members about dying and death (Hebert, Dang, & Schulz, 2006. *Evidence Grade = B2*).
 - Give careful consideration to the timing, location, format and language used to communicate to the family that their loved one is approaching end of life (Hebert et al., 2006. *Evidence Grade = B1*).
 - Physicians have expressed difficulty in predicting mortality in the absence of a clear terminal diagnosis. The indicators of mortality as indicated above can be used by physicians to guide resident-specific mortality prediction (Flacker & Kiely, 2003).
 - Family members and nursing home residents often adhere to the "myth of rehabilitation" because the formal message of nursing homes is one of rehabilitation and maintenance of function. False hope in rehabilitation can become a major barrier to advance care planning (Hanson, Henderson, & Menon, 2002; Oliver, Porock, & Oliver, 2006).
4. Lack of communication among decision makers, and failure to agree on a course for end of life care, are two common obstacles to implementing palliation for nursing home residents (Travis et al., 2002. *Evidence Grade = C1*).

- Open discussions about dying, death, and bereavement would likely improve caregiver wellbeing (Hebert, Dang, & Schulz, 2006. *Evidence Grade = B2*).
 - Arrange a family conference with the physician, primary nurse, and other members of the health care team, for open discussion of the resident's approaching end of life. Better communication with physicians would assist family members' preparation for death of a loved one (Hebert, Dang, & Schulz, 2006. *Evidence Grade = B2*).
 - Most people seek to avoid regret in decision making, and in particular "worry about making decisions that in hindsight might prove to be incorrect and that they will regret" (Travis et al., 2002). Such worries make a 'do everything possible' response seem like only a safe decision. Skillful communication with health care professionals, and especially with the resident's physician and RN, are necessary to allay uncertainty about futility and low benefit/high burden of aggressive curative care (Travis et al., 2002. *Evidence Grade = C1*).
 - Ensure that the dying nursing home resident's care plan is updated to incorporate personal, cultural, and spiritual end of life values, beliefs and practices which are important to the resident and the family caregivers (Kehl, 2006. *Evidence Grade = B2*).
 - Ensure that advance care planning documents (e.g., living wills, personal directives) are incorporated into care plans (Hanson, Henderson, & Menon, 2002. *Evidence Grade = C1*).
5. Assist the family caregivers of the nursing home resident to recognize disease progression, dying trajectory, and the dying process. Many family caregivers do not recognize the progressive deterioration of their loved one in a nursing home as signaling end of life (Forbes, Bern-Klug, & Gessert, 2000. *Evidence Grade = C1*).
- Clear communication with health professionals is a major predictor of family preparedness for end of life (Hebert et al., 2006. *Evidence Grade = B1*).
 - Consistent communication with a specific health care provider assists family members to understand the dying trajectory (Forbes, Bern-Klug, & Gessert, 2000. *Evidence Grade = C1*).
 - Conversations with family caregivers about end of life should be in clear, unambiguous language; avoid end of life euphemisms such as "not doing well", "wearing out", or "may not get better" (Hebert et al., 2006. *Evidence Grade = B1*).
6. Maintain close contact with family caregivers.
- Discussions to prepare family members for the death of a nursing home resident should not be static or 'one time only' (Hebert et al., 2006. *Evidence Grade = B1*).
 - Discussions about end of life should occur in stages so family members can absorb and process the implications of the information.
 - If care of a dying resident is not made explicit and communicated clearly to the family members, then when the resident's death occurs family members may believe it was an unexpected and negative outcome of poor care (Oliver, Porock, & Oliver, 2006. *Evidence Grade = C1*).

7. Length of time as a family caregiver does not predict acceptance of the dying process nor preparedness for the death of a loved one (Forbes, Bern-Klug, & Gessert, 2000; Hebert, Dang, & Schulz, 2006. *Evidence Grade = B2*).
 - Providing care for a nursing home resident, sometimes even for years, does not indicate that the family caregiver is aware of, or prepared for, the impending death of the resident (Hebert, Dang, & Schulz, 2006. *Evidence Grade = B2*).
 - Family members may not perceive dementing illnesses as a terminal condition (Forbes, Bern-Klug, & Gessert, 2000. *Evidence Grade = C1*).
 - "Black caregivers, caregivers with less education, those with less income, and those with more depressive symptoms prior to the death were more likely to perceive themselves as 'not at all' prepared" (Hebert, Dang, & Schulz, 2006. *Evidence Grade = B2*).

8. Routine grief support initiatives for family caregivers following the death of a nursing home resident should be carefully re-evaluated and possibly discontinued.
 - Intervening prior to the death is likely to be more beneficial (Hebert, Dang, & Schulz, 2006. *Evidence Grade = B2*).
 - Bereavement support intervention is ineffective and unnecessary for the vast majority of the bereaved (Kissane et al., 2006; Neimeyer, 2004; Schut & Stroebe, 2005; Zhang, El-Jawahri, & Prigerson, 2006. *Evidence Grade = B1*).
 - Inreaching intervention, or grief support and referral for grief counseling given to those who make contact to request it, rather than routinely offering bereavement support, is supported (Schut & Stroebe, 2005. *Evidence Grade = B1*).
 - After the death of a loved one, complicated grief reaction cannot be determined for at least six months (Neimeyer, 2004; Zhang, El-Jawahri, & Prigerson, 2006. *Evidence Grade = B1*).

9. Less than half of nursing homes provide a memorial service (Moss, Braunschweig, & Rubinstein, 2002. *Evidence Grade = B2*). However, receiving a sympathy card was well regarded by bereaved family members (Davidson, 1999; Hutchinson, 1995. *Evidence Grade = C2*).
 - The nursing home administrator should ensure that a supply of religious and secular sympathy cards are available to staff.
 - After the death of a nursing home resident, the unit manager/primary RN should ensure the sympathy card is placed in a visible place where staff members gather.
 - The unit manager/primary RN should encourage staff members to sign the card and include comments and remembrances about the resident.
 - One week after the death, the unit manager/primary RN ensures the card is mailed.

10. Publicly acknowledge that nursing homes are *de facto* hospices, with some 30% of residents dying each year (Philips et al., 2006. *Evidence Grade = C1*).
 - The nursing home industry does not view itself as caring for the dying nor as providing palliative care as a primary service; "the formal message of nursing homes is one of rehabilitation and maintenance of function" (Oliver, Porock, & Oliver, 2006. *Evidence Grade = C1*).

- Funding instruments such as MDS, as well as nursing home regulations and policies, were developed in response to widespread concerns that nursing home residents were dying as a result of poor care. Nursing home funding, regulations and policies are closely tied to rehabilitation and maintenance of function activities (Oliver, Porock, & Oliver, 2006. *Evidence Grade = C1*).
- Nursing home staff and professionals experience dissonance between conducting resident care in such a way as to meet regulatory requirements and achieve optimal funding for the nursing home and wanting to provide optimal palliative care for dying residents which does not include rehabilitation or inappropriate emphasis on maintenance of function. (Porock & Oliver, 2007. *Evidence Grade = C1*).
- The nursing home industry and regulatory bodies need to include palliative care in the primary role of nursing homes, and not mandate that rehabilitation and maintenance of function are achievable or desirable for all nursing home residents (Oliver, Porock, & Oliver, 2006. *Evidence Grade = C1*).

Definitions:

Evidence Grading

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C2 = Inconsistent evidence from observational studies or controlled trials

D = Evidence from expert opinion, multiple case reports, or national consensus reports

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

REFERENCES SUPPORTING THE RECOMMENDATIONS

[References open in a new window](#)

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified and graded for each recommendation (see "Major Recommendations").

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

All family members/significant others with an attachment to a nursing home resident should have the opportunity to be prepared for the death of their loved one and to receive end of life support. Lack of preparedness for the death of a significant other has been clearly linked to complicated grief disorder. Therefore, the nursing home population of bereaved families is likely to benefit from use of this evidence-based guideline.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

This is a general evidence-based practice guideline. Patient care continues to require individualization based on patient needs and requests.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Evaluation of Process and Outcome Factors

Process Indicators

Process Indicators are those interpersonal and environmental factors that can facilitate the use of a guideline.

One process factor that can be assessed with a sample of front line staff, nurses and/or physicians is knowledge about family preparedness and end of life support. The **Family Preparedness and End of Life Support Knowledge Assessment Test** (See Appendix A in the guideline document) should be assessed before and following the education of staff regarding use of this guideline.

The same sample of front line staff, nurses and/or physicians for whom the Knowledge Assessment test was given should also be given the **Process Evaluation Monitor** (See Appendix B in the guideline document) approximately

one month following his/her use of the guideline. The purpose of this monitor is to determine his/her understanding of the guideline and to assess the support for carrying out the guideline.

Outcome Indicators

Outcome indicators are those expected to change or improve from consistent use of the protocol. The major outcome indicators that should be monitored over time are:

1. Reduced or no complaints from family members that they felt unaware of, and unprepared for, the impending death of their loved one in nursing home.
2. Reduced or no complaints from family members that they felt a lack of clear communication about the impending death of their loved one in nursing home.
3. Positive feedback from family members that they had good communication with nursing home staff and the resident's physician, and felt the resident had a good death for which family members were well prepared.

IMPLEMENTATION TOOLS

Staff Training/Competency Material

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Staying Healthy

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Davidson KM. Evidence-based practice guideline. Family preparedness and end of life support before the death of a nursing home resident. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center, Research Translation Dissemination Core; 2009 Jan. 22 p. [37 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2002 Oct (revised 2009 Jan)

GUIDELINE DEVELOPER(S)

University of Iowa Gerontological Nursing Interventions Research Center,
Research Translation and Dissemination Core - Academic Institution

SOURCE(S) OF FUNDING

Developed with the support provided by Grant #P30 NR03979, [PI: Toni Tripp-Reimer, The University of Iowa College of Nursing], National Institute of Nursing Research, NIH.

GUIDELINE COMMITTEE

Not stated

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current release of the guideline.

This guideline updates a previous version: Research Dissemination Core. Family bereavement support before and after the death of a nursing home resident. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center; 2002 Oct. 46 p.

GUIDELINE AVAILABILITY

Electronic copies: Not available at this time.

Print and CD-ROM copies: Available from the University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core, 4118 Westlawn, Iowa City, IA 52242. For more information, please see the [University of Iowa Gerontological Nursing Interventions Research Center Web site](#).

AVAILABILITY OF COMPANION DOCUMENTS

The appendices of the [original guideline document](#) include a family preparedness and end of life support assessment test plus a process evaluation monitor.

PATIENT RESOURCES

None available

NGC STATUS

This NGC summary was completed by ECRI on June 12, 2003. The information was verified by the guideline developer on July 15, 2003. This NGC summary was updated by ECRI Institute on June 12, 2009. The updated information was verified by the guideline developer on July 1, 2009.

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Date Modified: 7/27/2009

