

Developing and Testing the Dementia Care Management Checklist (DCMC-HT) for Hospice Transitions in Home Healthcare

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The DCMC-HT guides clinicians in discussing hospice care with care partners of people living with dementia by addressing hospice literacy, goals of care, decision-making needs, sociocultural preferences, caregiver support, and available community or bereavement resources.

It also supports a structured referral and documentation process for the care transition by clarifying hospice services, respite options, insurance concerns, legal decision-making, care preferences, and communication with the broader care team.

DEMENTIA CARE MANAGEMENT CHECKLIST FOR HOSPICE TRANSITIONS (DCMC-HT)	
◊ DEMENTIA-RELATED HOSPICE CARE LITERACY	
Offer brief description of hospice and services available; ☐ Emphasize that hospice focuses on comfort and dignity, not prolonging or hastening death ☐ What types of services are available in hospice care and what is not available ☐ Ask "Would you like us to send you more information about hospice?"	Ask about outstanding legal or ethical concerns (especially where the PLWD's wishes are unclear or disputed); ☐ Refer to hospice social worker as needed
Assess the care partner's understanding of hospice in the context of dementia; ☐ "What have you heard about hospice for people with dementia?" ☐ "What are your thoughts about hospice care?"	Review guardianship, conservatorship, or durable power of attorney documentation, if applicable.
Address unmet needs by asking what's needed; "What types of caregiving and decision-making support would be most helpful?" (probes below); ☐ Help with feeding, bathing, mobility, skin care, communication, symptom management ☐ Emotional/psychological support ☐ Spiritual/religious support ☐ Understanding care options as illness progresses	◊ SOCIOCULTURAL NEEDS & RESOURCES
Explain respite care options hospice offers for caregiver relief; ☐ "If caregiving is overwhelming, hospice can offer short-term respite stays. Is this something that would benefit you?"	Address sociocultural needs and/or practices related to death, dying, and dementia care by asking; "Are there cultural or religious practices important to your family that we can honor in the care plan?" "Would any of the following resources be helpful to you?" ☐ Faith leaders, dementia-friendly congregations ☐ Culturally specific community or memory support groups ☐ End-of-life doulas
◊ GOALS OF CARE AND DECISION-MAKING	◊ HOSPICE REFERRAL PROCESS (IF APPLICABLE)
Explore the care partner's values, care preferences, and/or beliefs; ☐ "Are there values, preferences or beliefs that guide your decisions about end-of-life care for your family member?"	Explain the hospice admission process specific to dementia; ☐ RN visit, assessment of stage, focus on comfort care, caregiver support
Discuss dementia-specific wishes (if previously expressed by care recipient); ☐ "Did they ever express how they would want to be cared for if they could no longer speak or recognize others?"	Address concerns about the transition from current setting; ☐ "Do you have any worries about how this transition will affect the person you care for or your family?"
Review and discuss end-of-life care decision-making; ☐ Advance Directives ☐ POLST or MOLST forms ☐ Statements on artificial feeding, hospitalization, antibiotics, or comfort-focused care	Clarify that hospice care can continue wherever the person lives; ☐ Home, nursing facility, assisted living, or inpatient hospice
Confirm legal decision-maker for health care; ☐ "Who is the legal decision-maker if your family member cannot make decisions?"	Address health insurance-related questions and concerns; ☐ Offer assistance in checking benefits related to hospice and/or respite
	◊ DOCUMENTATION AND COMMUNICATION
	☐ Document all care preferences in the care plan ☐ Communicate this information to the broader care team and/or hospice team ☐ Schedule a follow-up visits or care planning as appropriate with medical provider
	◊ CARE PARTNER-CENTERED RESOURCES (OPTIONAL)
	☐ Alzheimer's Association OR Aliviado Dementia Care OR Caring Kind NYC ☐ Refer to anticipatory grief counseling ☐ Share information about bereavement services

Persons with dementia make up one-third of the home healthcare population in the United States.

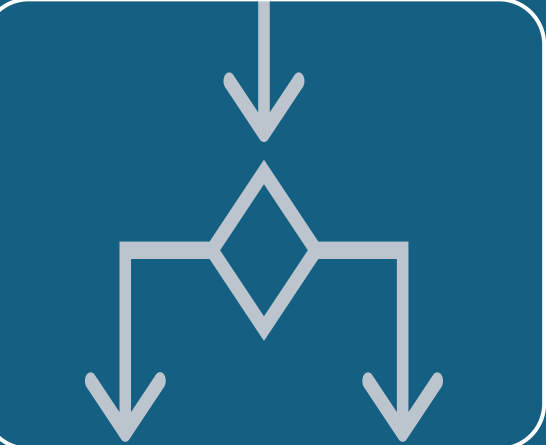
Home healthcare has rapidly become an essential setting for delivering end-of-life care to persons with dementia and their care partners.

Many transitions to hospice occur within this setting.

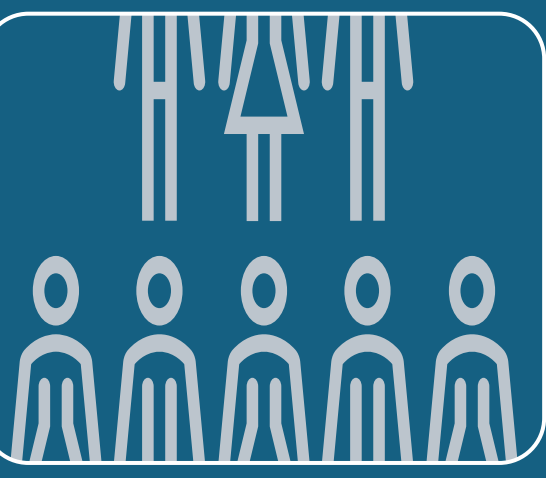
Dementia-tailored care management is critical to improve end-of-life care and decision-making.

We developed the DCMC-HT as a guide for care managers in home healthcare to support hospice-related and end-of-life communication about hospice care with caregivers in home healthcare and potentially prepare for a transition to hospice care.





Guided by the NIH Stage Model, we used an exploratory sequential mixed methods design to develop the DCMC-HT across three phases.



Phase 1 included semi-structured interviews with 20 diverse care partners to identify barriers and facilitators to hospice transitions for PLWD. Phase 1 also included input from 37 healthcare professionals across home and acute care settings to understand workflow and care delivery challenges.



Phase 2 used qualitative findings to develop two investigator-initiated surveys. Surveys were completed by 32 care partners and 43 healthcare professionals to identify essential checklist and intervention components, as well as implementation needs.



Phase 3 integrated qualitative and quantitative findings using a joint display to identify priority checklist domains. Feedback from three study team members guided further checklist refinement.



The checklist was refined through three panel discussions with 18 healthcare professionals to support clinical relevance, workflow fit, and feasibility.

Care Preferences

"No personal experience with hospice care. Um, as far as I understand hospice care, it's not in the home, it's in an institution. I don't know if I'm correct about that...they kind of do everything for the patient...but, unfortunately...it would be strangers doing it"
-Care Partner

Desire for More Information

"If a practice is created where there's a-a lotta different, uh, mediums there, you know, and even have, like, you know, information or workshops about, you know, how this all works, like, that would be helpful too, like forums, like, you know, Zoom things that people could go on and learn, what is an MLTC? What is a waiver program? How do you pick a home health agency? You know, that kinda stuff."
-Care Partner

Dementia Care Coordination Barriers

"I'm the caregiver. You could just speak with me," and they're like, "Oh, no, we need authorization from her [PLWD]." And then we just go on this cycle where it's never gonna be paid because she can't give consent. I wish that there were things on file or they woulda just told them—easier way for things to be organized in the healthcare system- and get some feedback right there, that would be wonderful."
-Care Partner

Understanding Hospice Benefits

"First of all, it's rejection. They reject me. They reject the concept of hospice, but over a period of follow-up calls with them and care managing them, they start to have a little bit of trust...they might become more open to even listening to me and listening to the benefits..."
-Care Manager

Cultural Alignment

"I think with hospice, there's also a patient and caregiver-driven sort of piece, and frankly, like one, you have to be knowledgeable of it. Two, having it be culturally aligned..."
-Physician

Barriers to Access to Hospice

"Unfortunately, lack of education, socioeconomic status, those things are also sometimes barriers as well because they just don't know. They don't know the resources."
-Nurse Practitioner

Hospice Eligibility Criteria

"The barriers that I find are because hospice criteria is based on the physical deterioration, I can find that I feel somebody is failing to thrive, but because they're not medically in that state, they are still not qualified. And that's probably my...biggest barrier that I've found."
-Field Nurse

The iterative development process resulted in a structured care management checklist designed to support communication, education, and shared decision-making with dementia care partners.

Preliminary findings suggest the checklist is appropriate, practical, and usable within routine home healthcare workflows. The DCMC-HT has since progressed to testing in a single-arm feasibility trial.

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