

Appendix J: Strategies for Help Individuals Engage in Decision-making at the End of Life

Patient Engagement in Decision-making

Nurse/patient relationship	Sharing of power and control	Communication and assessment
Promote discussion if families are struggling with conflict (Hsieh, Shannon, & Curtis 2006).	Emphasize the need to consider what information was essential for patients and relatives, use concrete examples and lay language, and provide time for decision-making (Hanna-Mari & Marja-Liisa, 2006).	Offer emotional and existential support through discussion, listening, being present and attending to patients and relatives (Hanna-Mari & Marja-Liisa, 2006).
Raise issues related to end-of-life care early in the course of a life-threatening illness (Thelen, 2005).	Provide resources on how to access reliable trustworthy information (National Advisory Committee: <i>A Guide to End-of-life Care for Seniors, 2000</i>).	Evaluate patients/ and their relatives' competence for decision-making and support them in accepting the medical facts (Hanna-Mari & Marja-Liisa, 2006).
Approach the topic sensitively (National Advisory Committee: <i>A Guide to End-of-life Care for Seniors, 2000</i>).	Be aware of influence providers have in influencing decisions by critically analyzing /reflecting on extent to which they have control over patient/ situation (Hilden & Honlasalo, 2006).	Clarify patients' and relatives' views (Hanna-Mari & Marja-Liisa, 2006).
Be available to listen to concerns and provide uninterrupted time (National Advisory Committee: <i>A Guide to End-of-life Care for Seniors, 2000</i>).	Reframe decisions regarding withholding sustaining treatment as allowing the disease to take its course rather than "not continuing treatments that merely prolong suffering." (Lyness, 2004)	Patient's and their family's need to understand their overall medical condition to plan effectively and how their illness and various treatment options will affect them within the context of their daily lives (Davison & Torgunrud, 2007).
Recognize that each person has unique tolerance for discomfort and a unique drive to live (Loomis, 2009).	Recognized that people may choose to endure physical or emotional distress as part of their spiritual journey (Loomis, 2009).	Facilitate frank assessment of the likelihood of whether withholding or stopping sustaining treatment will be beneficial (Lyness, 2004).

Patient Engagement in Decision-making in the Manner they Prefer

Nurse/patient relationship	Sharing of power and control	Communication and assessment
Encourage family members to spend time at the bedside and talk with them about their perceptions	Identify potential conflicts in advance care planning and effectively manage conflicts	Offer clear, thorough information, rather than requiring family members to ask (Meeker & Jezewski, 2005).
Review the patient's preferences on a regular basis and update documentation – Patient should be reminded that advance directives can be revised at any time (Davison & Torgunrud, 2007; Kass-Bartelmes & Hughes, 2004)	Allow family members time to arrive at consensual decisions (Meeker & Jezewski, 2005).	Assess for conflict within family (Meeker & Jezewski, 2005).
Look at the patient through both their own eyes and the eyes of the patients and family members (Mazanec & Tyler, 2003).	Facilitate the process of substitute decision-making (Meeker & Jezewski, 2005).	Frequently explain and update patient and their substitute decision-maker about the patients' current health status (Gillick, 2006)
Apply the patient's desires to actual circumstances (Davison & Torgunrud, 2007)	Helping achieve consensus among family members and act as an arbitrator between family members (Thelen, 2005).	Engage the patient in prioritizing their goals of care (Gillick, 2006).
Treat the family with compassion and respect (Thelen, 2005)	Conversations about difficult issues may be started by asking the patient open-ended questions and listening attentively to their responses (Griffie, Nelson-Marten, & Muchka, 2004)	Initiate a guided discussion which involves sharing medical knowledge and treatments applicable to a patient's particular situation and find out the patients' preferences for providing or withholding treatments under certain scenario's (Davison & Torgunrud, 2007)