

# Serious Illness Learning Community: Summary of Key Themes

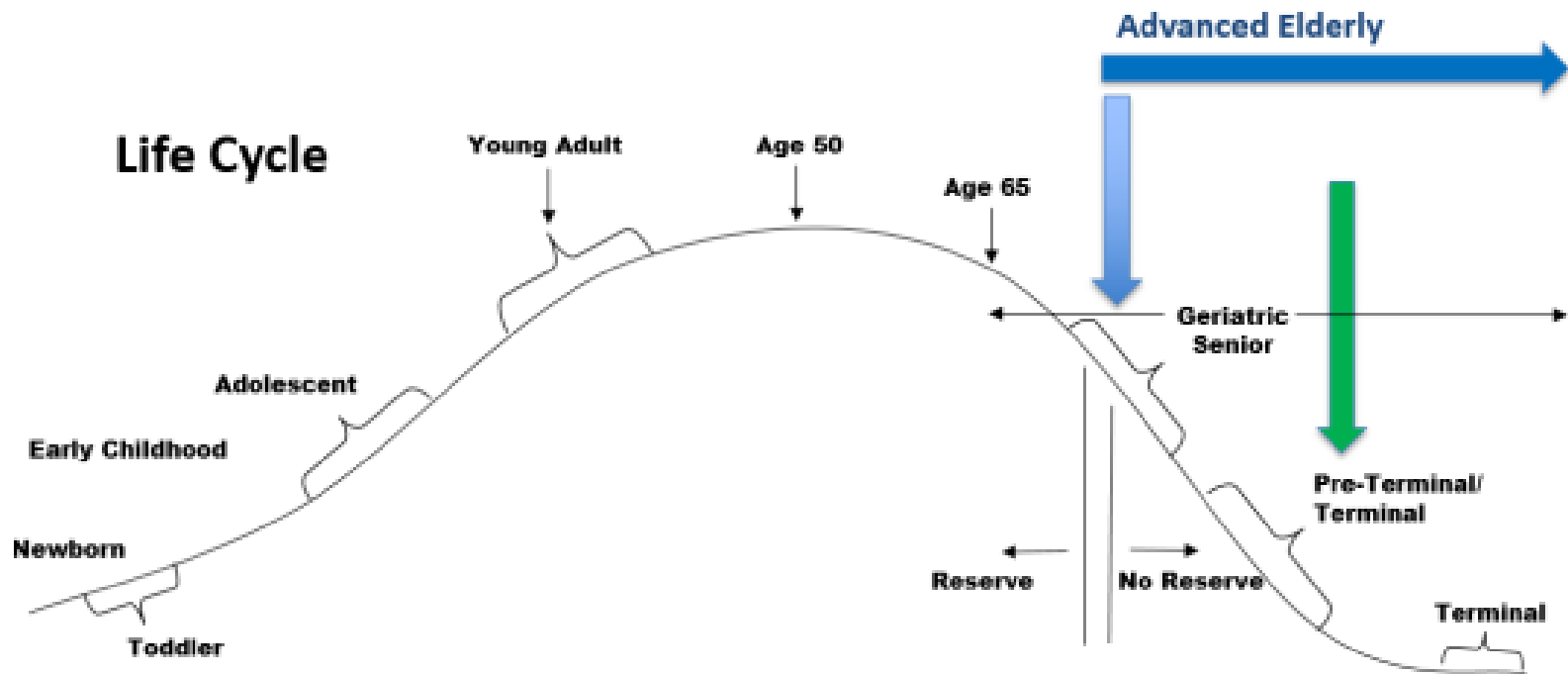
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# Responding to Themes from the Interviews

- Finding participants at the beginning of decline
- Timing of advance care planning and goals-of-care conversations
- Understanding burdens and needs
- Varying staff comfort levels in “end of life conversations”
- Creative use of hospice providers

# EARLY IDENTIFICATION OF THOSE IN DECLINE/TIMING /ADDRESSING NEEDS

# Identifying Those on the Decline



*Hoefler, Daniel, M.D.*

# Evidence-based Predictors

- LACE Index – risk of hospital re-admission and death based on hospital experience
- Charlson Co-Morbidity Index – risk of death based on conditions and severity
- Walter Index – risk of death based on ADLs and specific DX and labs

*Clinical opinion has not been shown in the literature to be a reliable means to predict decline*

# Looking for Frailty

- Loss of Strength
- Weight Loss (unintended)
- Low Activity Level/Increased Sleeping
- Poor Endurance/Easily Fatigued
- Slowed or Unsteady Gait
  - Timed Get Up and Go Test (>15s)

# Increased Illness Burden and Lack of Clarity – Predictors of NEED

- Pain and other symptom distress
- Caregiver stress and burn-out
- Misunderstanding of prognosis
- Unarticulated values and goals
- Existential worry
- Disagreement within family

# Key Assessments of Need

## → Symptom Burden

- Edmonton Symptom Assessment System (ESAS-r)

## → Functional Decline

- Karnofsky Performance Status Scale (or PPS)

## → Caregiver Burden

- Zarit Burden Interview

## → Spiritual Distress

- Beck Hopelessness Scale

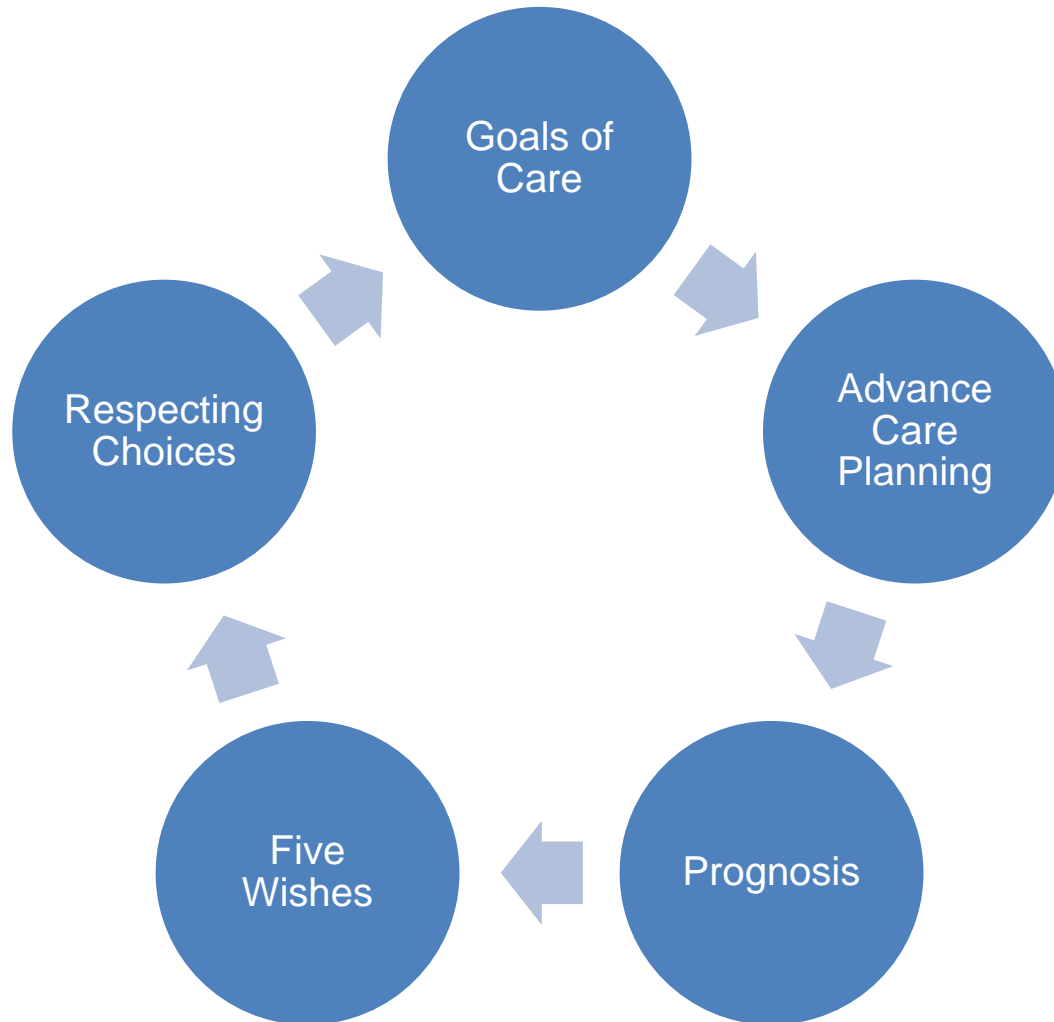


# Ideas From the Interviews

- Assess and hold initial conversations during intake
  - Part of comprehensive question-and-answer process
- Incorporate symptom distress assessment into formal 6-month re-assessment process
- Remember to use physical therapy as a means to manage pain
  - CDC Guidelines for Prescribing Opioids for Chronic Pain, 2016

# CLARIFYING GOALS-OF-CARE AND ADVANCE CARE PLANNING

# What conversations are needed? When?



# Try a Different Frame



- Prognosis  
Understanding
- Fears
- Goals
- Trade-Offs

Many professionals find this conversation easier to start, and can more naturally lead to questions around medical interventions

# Speaking with Participants: Some Best Practices

- Make sure that they know their condition(s) and what to expect from it. Do not proceed unless they do.
- Start by finding out what is important to them at this time in their life, and if time were to run short
- Allow for silence

# Advance Directives – Health Care Decisions

- Start with identification of a surrogate decision-maker/health care proxy
  - Upon admission is best
- POLST/MOLST – advance medical decisions
  - See VitalTalk and Compassionate Coalition of California Scripts and Videos

# Communication Skills Training – CAPC Courses

- Delivering serious news
- Discussing prognosis – ALL STAFF
- Clarifying goals-of-care – ALL STAFF
- Conducting a family meeting
- Advance care planning conversations
- ACP courses from Respecting Choices

# Ideas from the Interviews

- Social Work taking more responsibility for goals-of-care and advance care planning
- MOLST/POLST conversation part of formal 6-month re-assessments
- Special palliative care team for those nearing the end-of-life
  - Completely revisit the care plan
  - Enables continuing planning conversations
  - (expert symptom management as well)



# CREATIVE USE OF HOSPICE

# Most Programs Prefer to Manage End-of-Life Care

- Keep a familiar care team/minimize hand-offs
- Hospice not as able to provide extensive home health aide services
- Hospice expense
- Disenrollment required

# However, Hospices bring certain advantages

- Inpatient facility
  - Caregiver respite
- Expertise with opioids
- Family bereavement support

# Ideas from the Interviews

- Contract with Hospice(s) for inpatient care only
- Professional training arrangement with hospice
  - Medication management
  - Communication skills
- Contract with Hospices(s) for bereavement support
  - For participant family members
  - For PACE staff