

Dementia Roadmap Conversation Guide

1. What has changed?

Dressing/grooming, toileting, walking, talking, eating

How fast?

2. Where are we now?

Early/ Middle/ Late Dementia/ Actively Dying

Use the roadmap to name signposts

3. What's coming next?

How fast?

year(s)/ months/ weeks/ days

4. Prepare for decisions

Early: MOST Advance Care Planning, Substitute decision maker or representative agreements, joint accounts and Enduring Power of Attorney, Will and estate planning, dementia education, caregiver support, day programs, homecare, and placement options

Middle, once in longterm care: avoid hospitalization (falls and hip fracture, heart attack, stroke, pneumonia, bladder or skin infections), feeding problems and choking, behavioural challenges

Late: Infections due to decreased immunity (pneumonia, bladder, skin), feeding problems and choking, weight loss, dehydration and feeding tubes, skin breakdown

Signs of approaching actively dying (sleeping more, eating less, bedbound, refusing food or fluids)

Actively Dying call the family early, focus on comfort and symptom control, stop the pills (trouble swallowing)

5. Reinforce comfort care and quality of life (right in the facility)