

# Invisible Transitions Inside the Labyrinth of Caregiving

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## Rosalynn Carter



- *“There are only four kinds of people in the world:*
  - *Those who have been caregivers,*
  - *Those we are currently caregivers,*
  - *Those who will be caregivers,*
  - *And those who will need caregivers”*



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## Feeling Invisible Caregivers: Unrecognized and Untreated



- *“No one noticed me, no one would listen to me, no one asked what I thought, no one cared how I felt. To all providers, family and friends, **I was invisible**, my husband was the only focus”*



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## Background



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## 42 Month Journey



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## What is a Labyrinth?



- A circular pathway with one way in that leads directly to the endpoint. While winding and disorienting, we are not lost, yet never quite see where we are going.



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## Anatomy of the Labyrinth

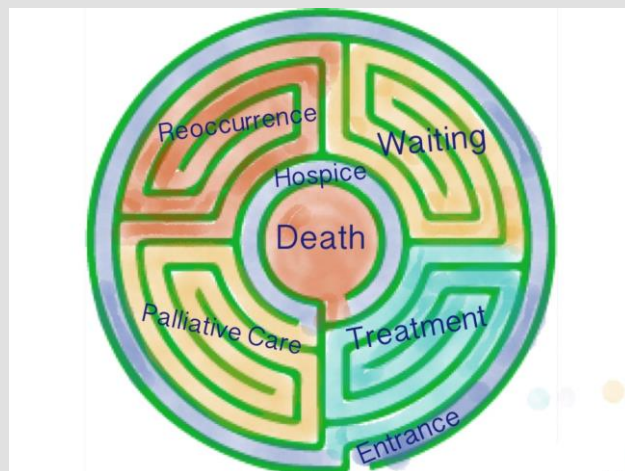


- **7 Circuit's** : Passageways
  - **Transitions**: Changes as you move from one circuit to another
  - **Fork in the Road**: Decision points
  - **Blind Alley**: Unexpected turn, surprises



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## My Labyrinth Path



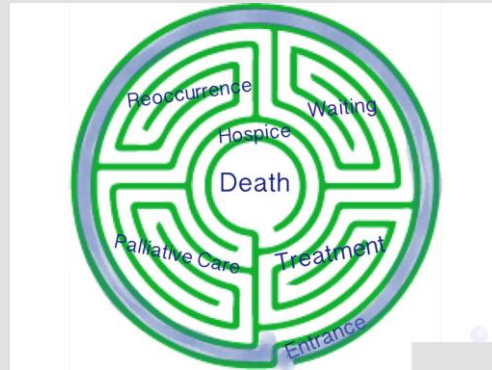
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## Entrance

### Diagnosis And Treatment Consultation



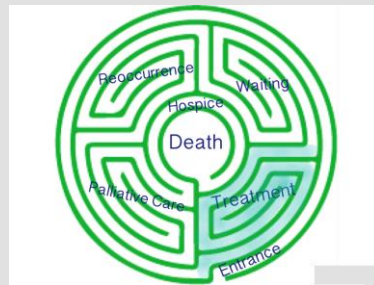
- **Signals of Invisibility**
  - Unknown CG Feelings, Resources, Questions, Fears
  - Impositions to life
  - Nonverbal cues
  - Environment
  - Unknown Caregiver preferences
- **Transitions**
  - Wife to librarian
- **Forks in the Road**
  - Tests, Tests, and more Tests
- **Blind Alleys**
  - No Map
  - Everyone speaks a foreign language



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## Treatment

- **Signals of Invisibility**
  - Unwelcome
  - Environment
  - Patient directed teaching
- **Transition**
  - Enforcer/Mother
- **Forks in the Road**
  - Scans and Symptoms
- **Blind Alleys**
  - Interactional Suffering



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## Waiting

- **Signals of Invisibility**
  - Assumed Responsibility
  - Considered hyper-vigilant
- **Transition**
  - Return to Wife
  - Vigilant observer
- **Forks in the Road**
  - Signs of reoccurrence
- **Blind Alleys**
  - False hope



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## Reoccurrence

- **Signals of Invisibility**
  - No autonomy
- **Transition**
  - Return to caregiving
- **Forks in the Road**
  - So many decisions
- **Blind Alleys**
  - Tricky Language (Cure, survivor, remission)
  - Interactional Suffering returns



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## Palliative Care

- **Signals of Invisibility**
  - Patient focused assessment
- **Transition**
  - Role changes with increased dependency
- **Forks in the Road**
  - What is palliative?
- **Blind Alleys**
  - Anticipatory Grief



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## Hospice

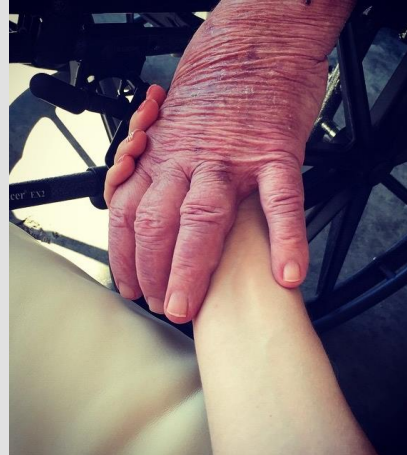
- **Signals of Invisibility**
  - Care based on Patient need
- **Transitions**
  - To nurse, nurse aid, med tech, dietician
  - Losses: private space, privacy, home to hospital
- **Forks in the Road**
  - Emergency room, hospital, physician
- **Blind Alleys**
  - Fear of the end



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## Death

- **Signals of Invisibility**
  - No longer
- **Transitions**
  - Caregiver to widow
- **Forks in the Road**
  - Services
- **Blind Alleys**
  - Alone



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## Family Centered Care

1. **Watch for Signals of Invisibility**
2. **Beware of Interactional Suffering**
3. **Invite and Encourage** caregiver involvement
4. **Routinely interact with caregiver**
5. **Speak privately** with both patient and caregiver
6. **Attend to patient and family preferences for information**
7. **Support and Assign Social Worker as Professional for Family: Examine caseloads and Assessment practices**



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## There are Two Patients Immediately we can



- **Validate Caregiver**
  - Respect knowledge
    - “What problems have you seen”
  - Embrace as a partner
    - “What do you think about this plan”
  - Recognize and hear the emotion
    - “This must be very hard for you on so many levels”

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***. . . To begin depriving death of its greatest advantage over us, let us adopt a way clean contrary to that common one; **let us deprive death of its strangeness**, let us frequent it, let us get used to it. . . We do not know where death awaits us: so let us wait for it everywhere.***

***Michel de Montaigne  
(1533 -1592)***



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