



Caregiving: From Mystery to Meaning

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“There are only four kinds of people in this world...Those who have been caregivers, those who currently are caregivers, those who will be caregivers, those who will need caregivers.”
*Former First Lady
Rosalyn Carter*





Mystery #1:
What is happening?

Care Recipient's Problem

- Illness
- Functional Challenges

Caregiver's Experience

- Your Current Concern
- Level of Distress
- Meaning and Purpose

Changes in Contexts of Care

- Your Life
- Broader family context
- Care service structures

Metaphors: Career or Journey

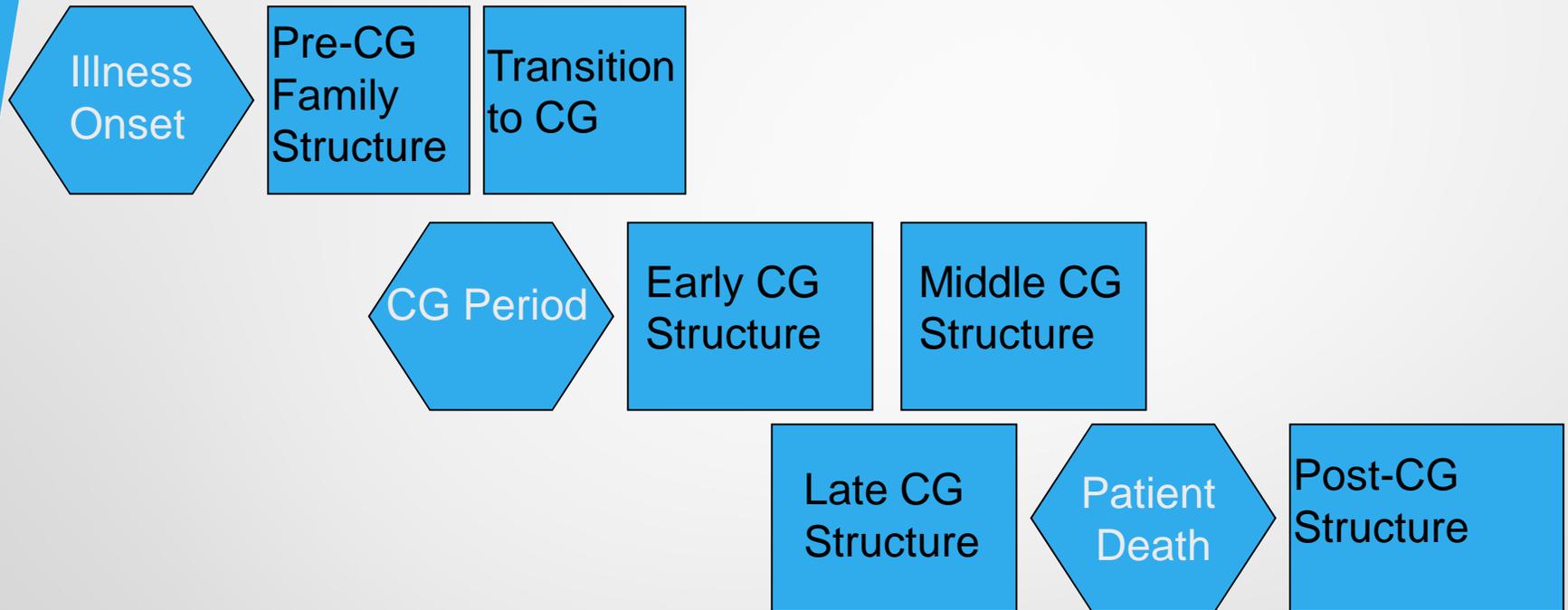
- Caregiving has a temporal dimension that varies with the illness/disability
- Caregiving career has key transition points (e.g., onset of direct care, institutionalization)
- Lifespan context for caregiving - a continuum of care



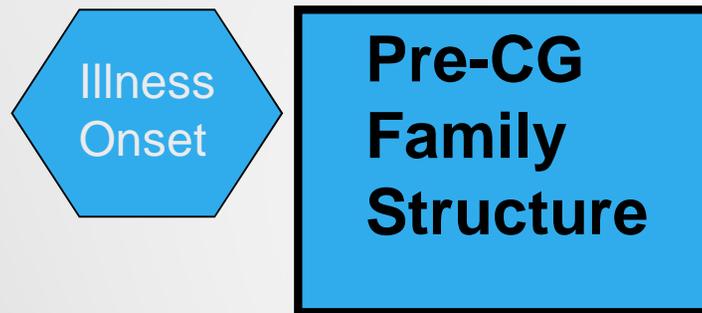
Mystery #2: What do I need to do now?

It depends....

Family CG Stages

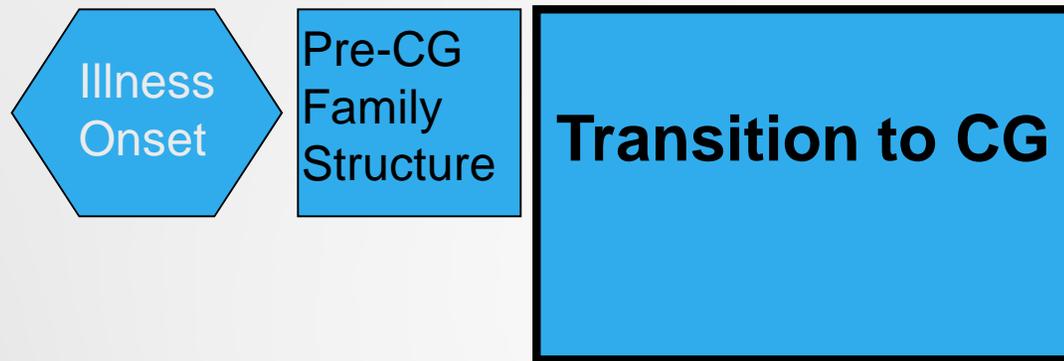


Pre-Caregiving



- Uncertainty about observed changes
- No specific problem has been named

Transition to Caregiving



- Common reference to the “problem”
- Problem may be given a name
- Adjustments in family have not generated any significant role change; operations as usual with more work

Career Phase I

Now is the time to

- Get evaluation
- Start monitoring and investigating

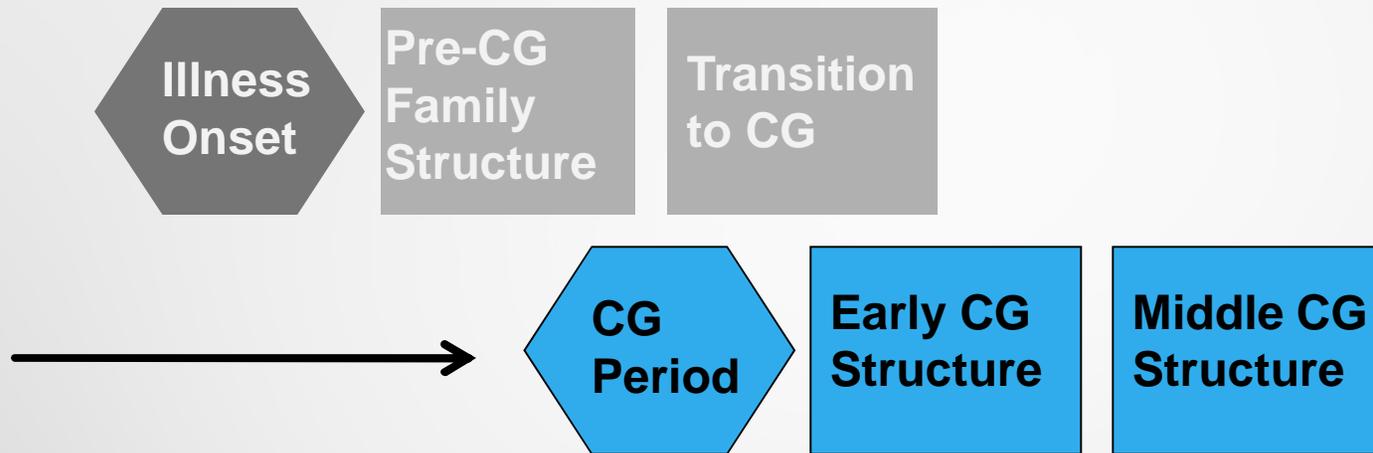




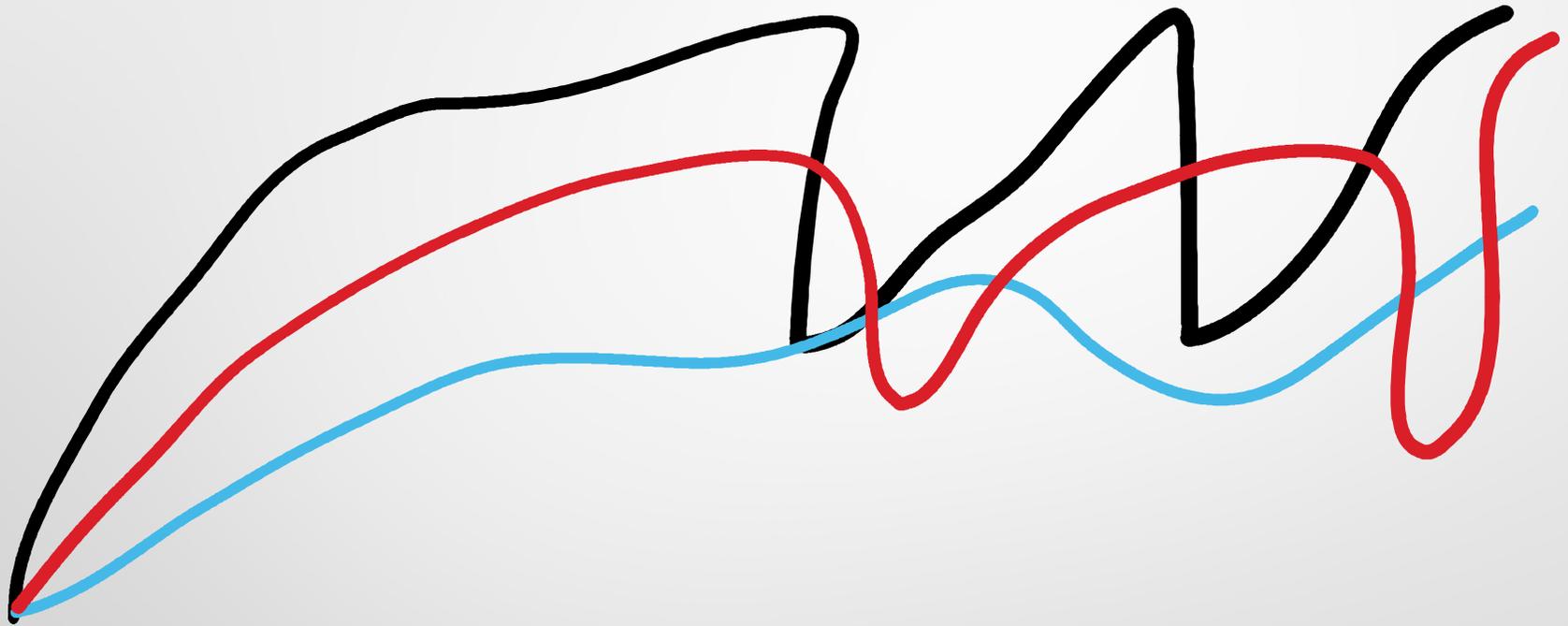
Services Options

- Housing
- Social services
- Legal services
- Family supports
- Health care

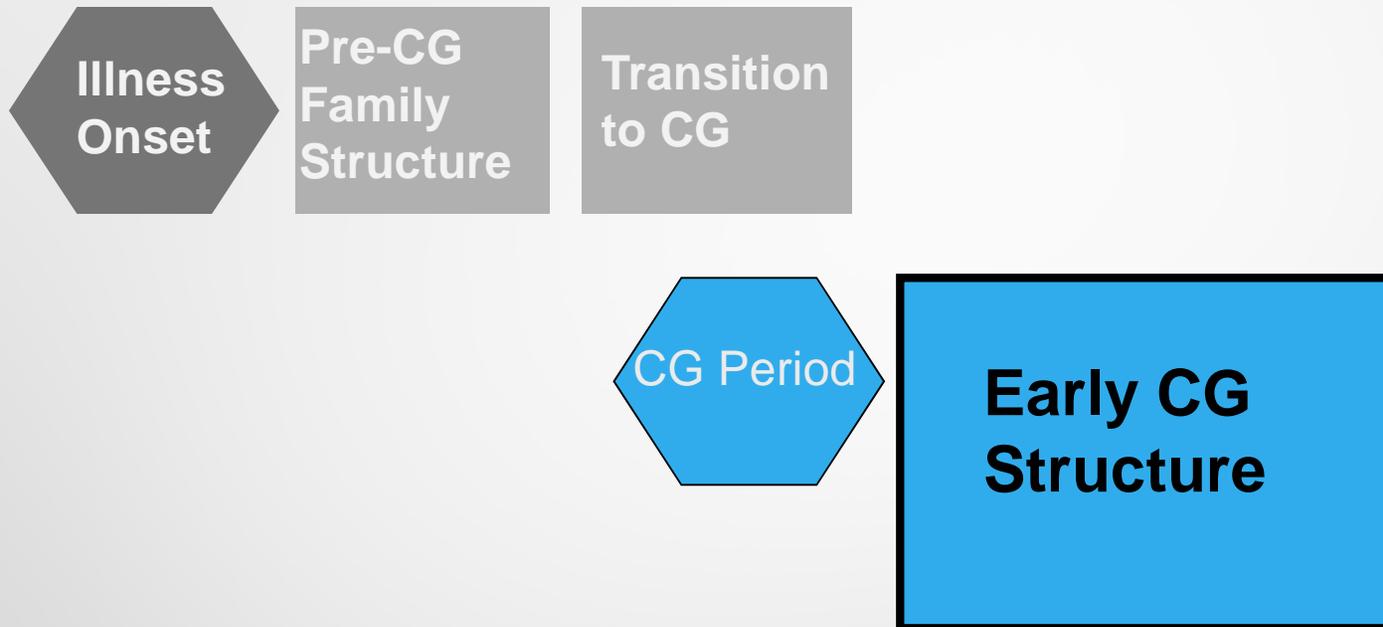
CG Career Phase II



Caregiving is neither linear nor universal



Early CG Structure



Hands on care

IADLs

Transportation
Medication monitoring
Shopping
Appointments
Food preparation
Finances

ADLs

Bathing
Dressing
Toileting
Transferring
Ambulating

When is it time for ...more services?

- How do I know whether he *really* needs help with
 - cleaning the house?
 - managing appointments?
 - transportation?
 - taking medications?
- What do I do if she refuses help but ends up sick because she doesn't take her medicine properly?
- How do I know if she is vulnerable to
 - fraud?
 - financial coercion?

When is it time to ...restrict her independence?

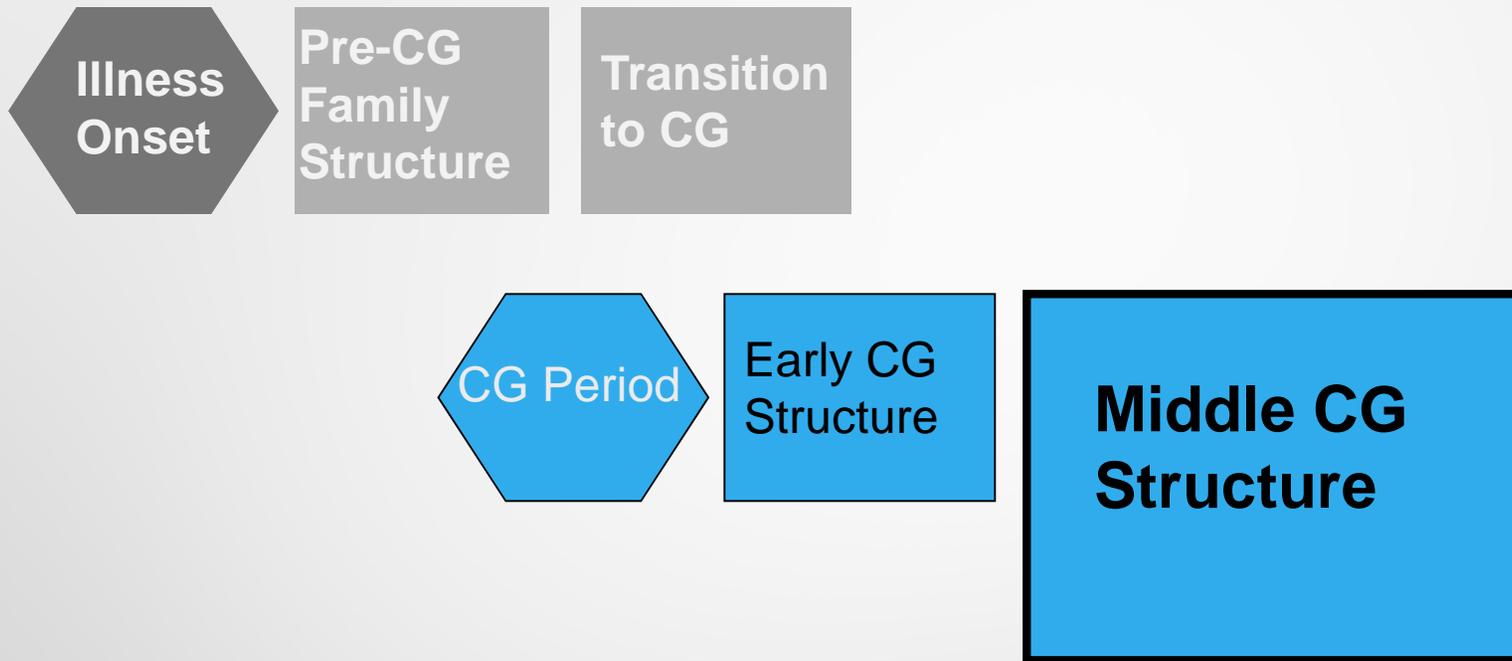
- When does she become a dangerous driver?
 - She's never had an accident.
 - She gets lost all of the time and asks strangers for directions even to familiar places.
- When is it too risky to let him live alone?
 - What if he falls?
 - His neighbors are worried about him, should I be?
 - He won't even discuss moving out of the home even though I find cigarette burns on the furniture and sheets.
- How can I keep her from sending checks to every appeal on TV or in the mail?

NOW is the time to...

Consciously care for self

- CG well-being is critical to both CG *and* CR
- Exercise, nutrition, nurturance
- Use choice to stay free from feeling trapped
- Ask for help

Middle CG Structure



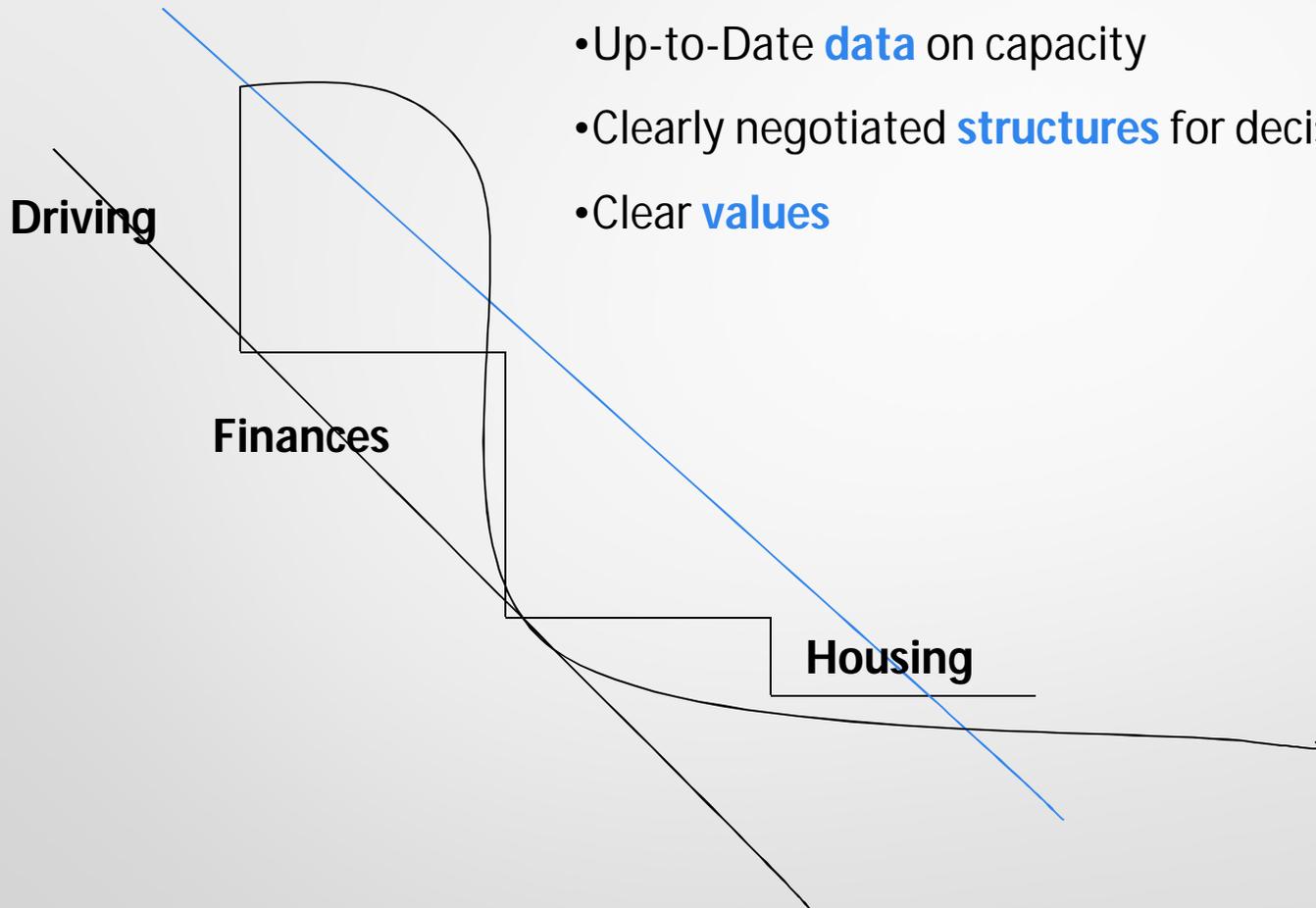
NOW is the time to...
Start Partnering



- Learn about specific elder care services
- Identify financial resources and entitlements
- Make a care plan (short-term, long-term)
 - Use formal as well as informal help
 - Play to your strengths
- Communicate with other family members

Informal Decisions require

- Repeated **conversations** among the key players
- Up-to-Date **data** on capacity
- Clearly negotiated **structures** for decision-making
- Clear **values**

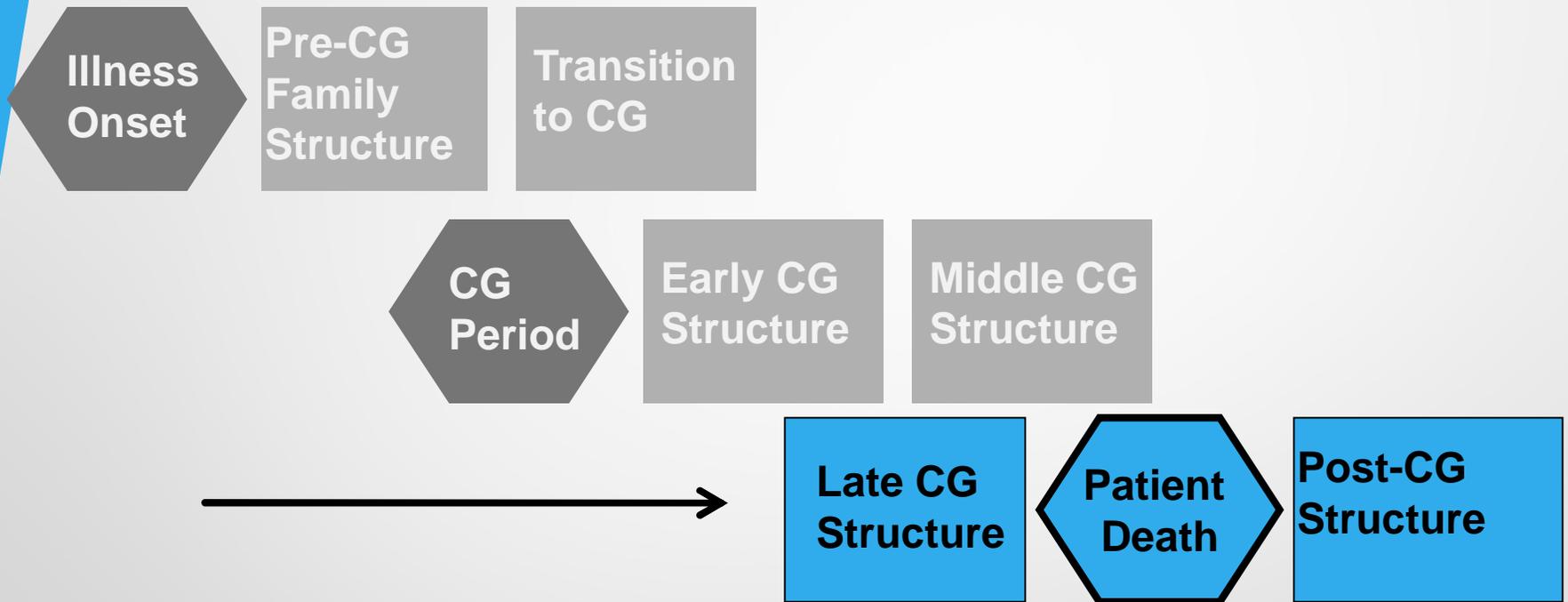


Driving

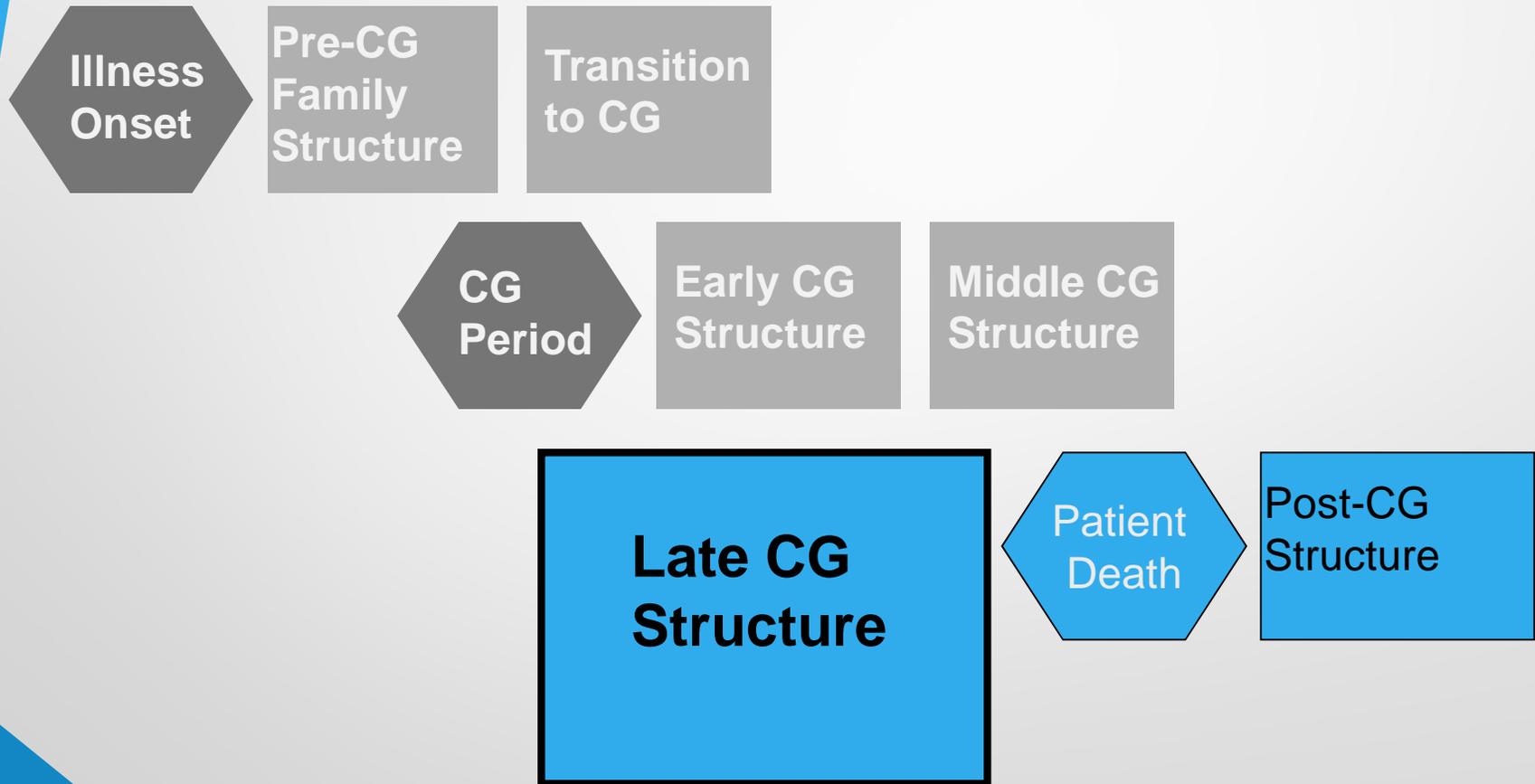
Finances

Housing

CG Career Phase III



Late CG Structure



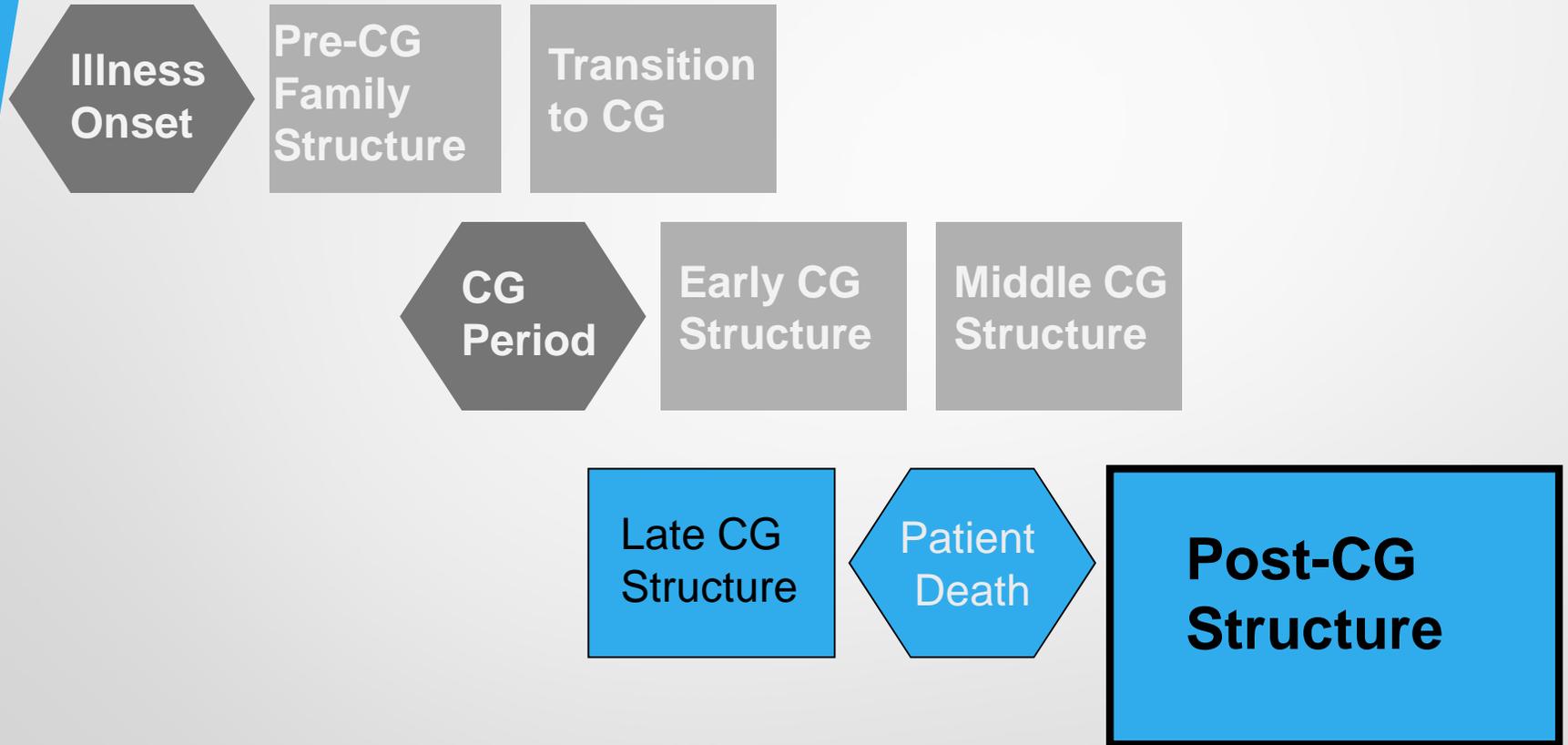
When is it time for ...hospice or palliative care?

- Hospice – start within 6 months of death
 - Focus is on choice about how to live and how to die
 - Available to nursing home residents, at home, or in a residence
 - Benefit – extra staff assistance, family support/guidance, expertise in pain management
 - People wait too long and only get a few days of help
- Palliative care or Comfort care
 - Focus on quality of life rather than length of life
 - Helps craft a dying process that fits your values
 - Can reduce medicalization of end of life care and death, if you want

NOW is the time to ...prepare for death, dying, and bereavement

- Reflect on how you want him/her to die
 - > Who, what, when, where, how
 - > How do today's choices shape the dying process?
 - > How do you communicate with him/her about dying?
- Focus on quality of life as it is experienced by CR
- Anticipate death rituals – what do you value/need?
- Consider the CG's future life after CR death
 - > If possible, build bridges to the future

Post-CG Structure



Family Tasks

- Create closure after death: estate, family dynamics, care arrangements
- Re-create a life structure without formal providers, caregiver-imposed life activities, and emotional demands
- Grieve
- Re-connect with other relationships, rebalancing after imbalance of CG period



NOW is the time to
...reconnect with my “on hold” self

- Inventory my core self – what is depleted, missing, injured, starved?
- Grieve for what has been lost in the relationship and other aspects of life
- Identify sources of joy that can be renewed
- Value the gift of giving care
- Begin to look forward again...



Mystery #3:
What gives the journey meaning?





Connections and Inter-Dependence



Mindfulness

- Engagement in health ... and life
- Support maximal functioning
- Establish benchmarks/milestones that measure facets of life you value
- Anticipate next transitions

Same as at any other point in the
lifespan...we garner hope from -

- Meaning
- Presence
- Connection
- Inter-Dependence



