



Family Caregiving

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Who are the caregivers?

“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*



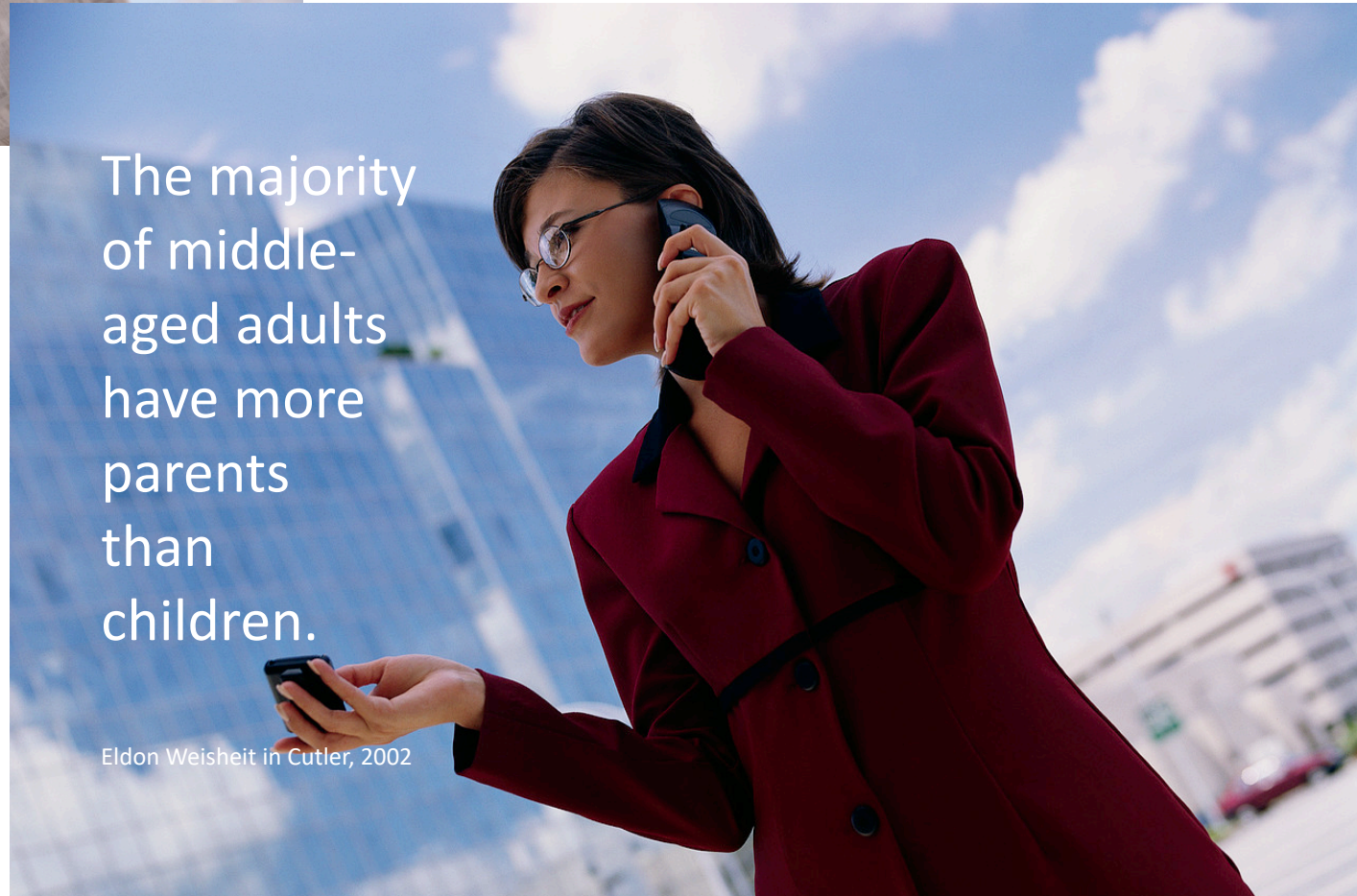


Prototypical Caregiver

51 year old woman (61%) with some college experience is providing 24 hours of care weekly for relative (89%), most often a parent (50%), for whom they felt they had no choice (53%) to provide care for an average of 4.5 years.

Size of CG workforce for older adults in US:

- 63 million
- 24% of adults
- 85% for family
- 76% for 1 and 24% for 2+

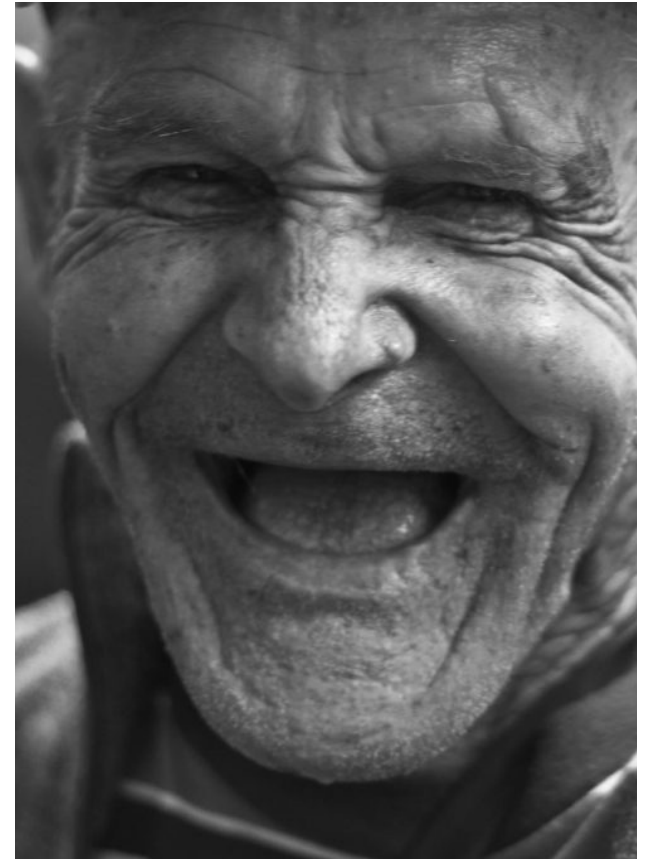


The majority of middle-aged adults have more parents than children.

Eldon Weisheit in Cutler, 2002

Care Recipients

- Living Arrangement
 - 37% live alone
 - 76% live within 20 minutes of caregiver and 74% visit 1x/week or more
 - Culture affects preferences
Asian American (51%), Hispanic (48%), and African American (45%) are more likely than Whites (36%) to live with caregiver [includes all age 18+]
- Conditions that require care (age 65+)
 - 63% have long-term physical condition
 - 34% Memory problem
 - 38% Emotional or mental health or behavioral
 - Multiple conditions are common (45%) with 58% receiving medical/nursing care



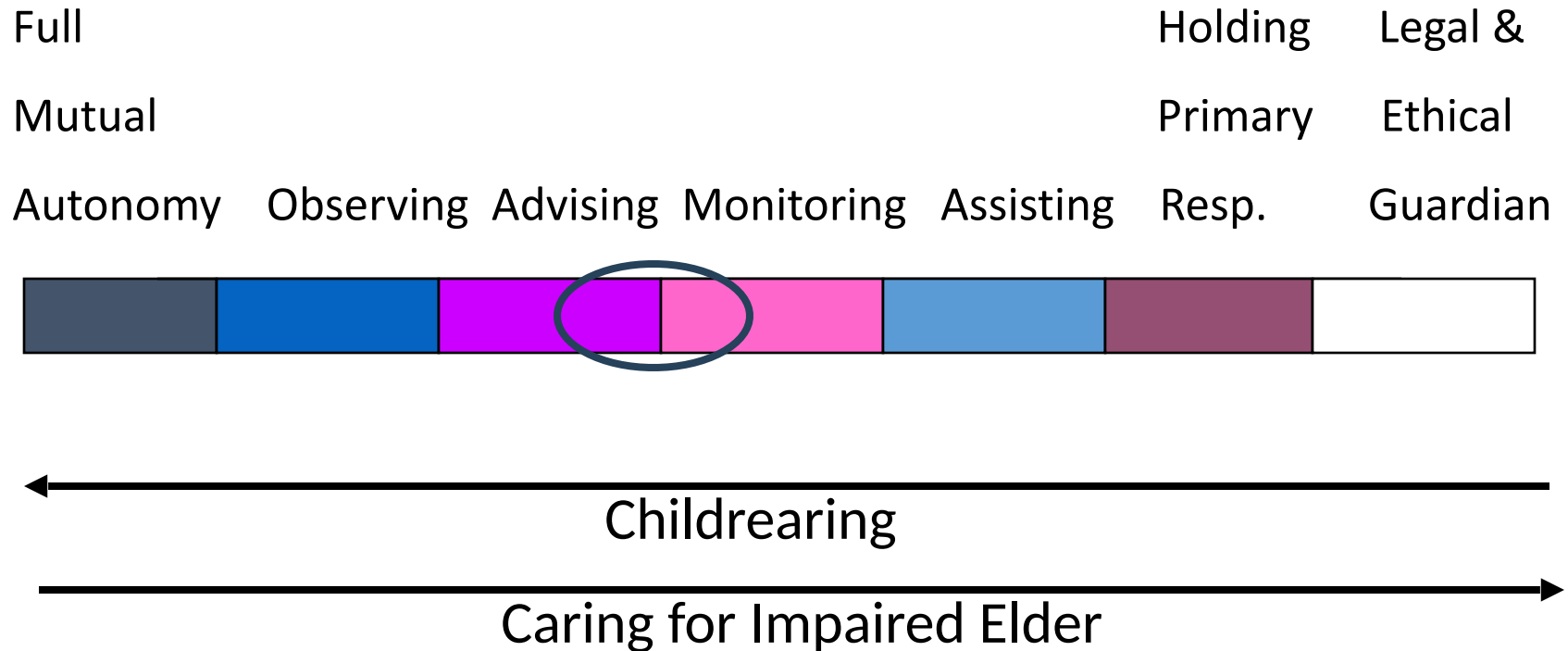


Family is the primary context for caregiving

Family Structures, Dynamics, and History shape the experience

Caregiving is familiar to the family... but in new form

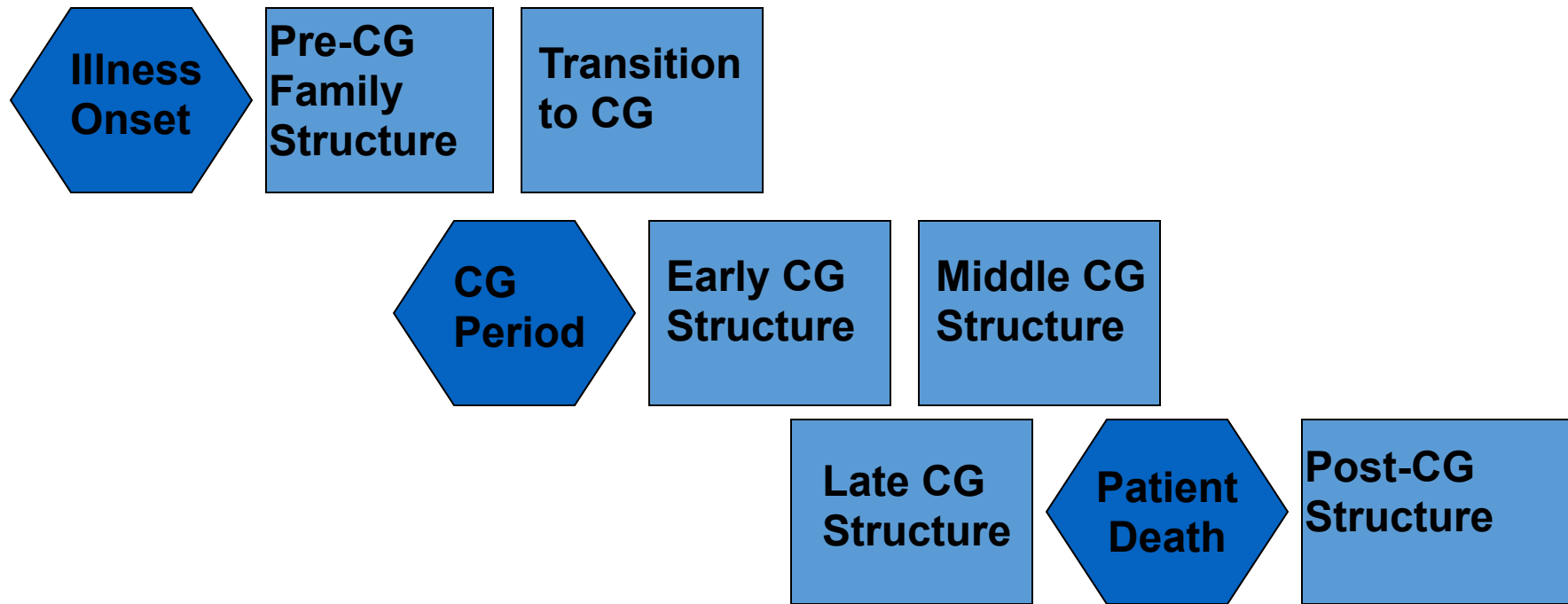
Family Caregiving Transitions





Caregiving Changes Substantially Over Time

The Family CG Career

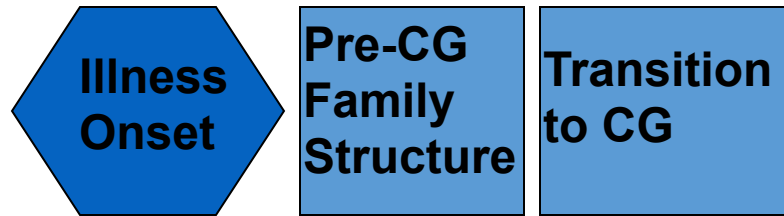


- Stages of the career involve distinct roles
- Roles must be learned, enacted, and given up
- Each stage has distinct, multiple stressors

Throughout the process, families continually wonder, when is it time for ...my role to change?

- Do I insist on an evaluation?
 - What if she won't agree?
 - How do I get him to go if he doesn't want to?
- Will I insult her if I ...
 - drive her?
 - give her directions?
 - help with taxes?
 - lay out her medications?
- How do I learn about her health?
 - Should I be in the exam room?
 - How do I maintain dignity – mine and hers?

Early Caregiving Career



CHANGING REALITY....

- A progressive disease is happening
- His or her world will change
- Our relationship will change as I become CG
- Our family will change

NOW is the
time to

Start
monitoring

Health and
wellness

Environment –
level of demand
and support

Resources used

Support for
well-being

Risks



NOW is the
time to...
Start
investigating

- What is available?
- Who needs to know what?
- What does it take to activate services and resources?
- How can health records be organized and made accessible?
- How can we create a care plan?



Senior Housing

Personal Care

Care Management

**Telephone
Reassurance**

**Legal Assistance
Information Services**

Leisure Services

**Emergency Call Services
Support Groups**

**Home Delivered
Meals**

Information & Assistance

Transportation

Caregiver Support

Adult Day Programs

Respite Care

Caregiver Services

Financial Assistance

Counseling

Services options

Housing

Social services

Legal services

Family supports

Health care

Career Phase I

Now is the time to

- Get evaluation(s) - families and elders *deserve* data as foundation for decisions
- Begin to change role to include monitoring and investigating

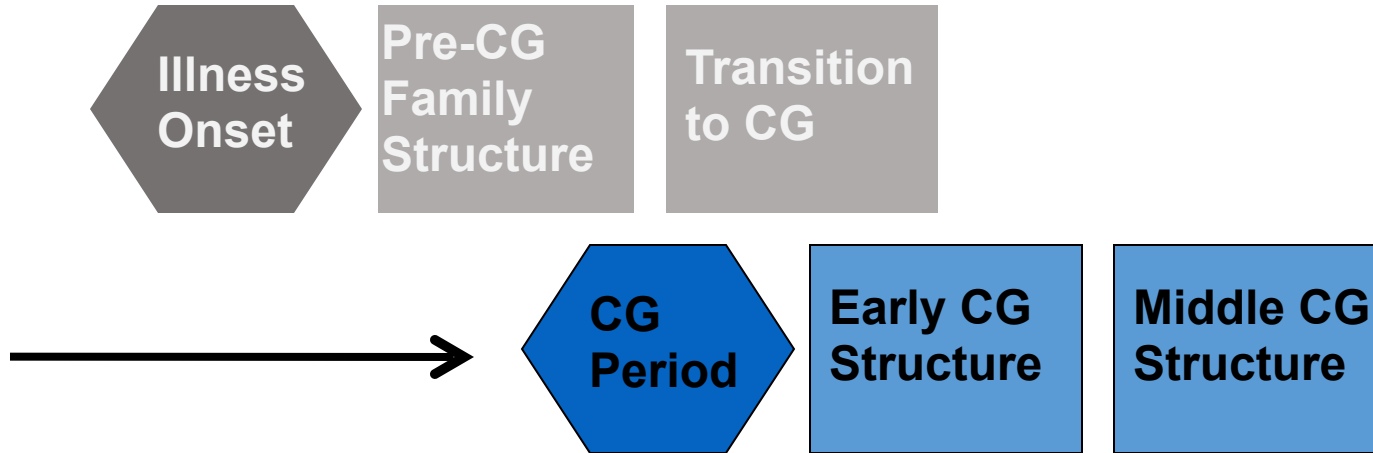


Career Phase I

Now is the time to

- Get evaluation(s) - families and elders *deserve* data as foundation for decisions
 - Begin to change role to include monitoring and investigating
- 

CG Career Phase II

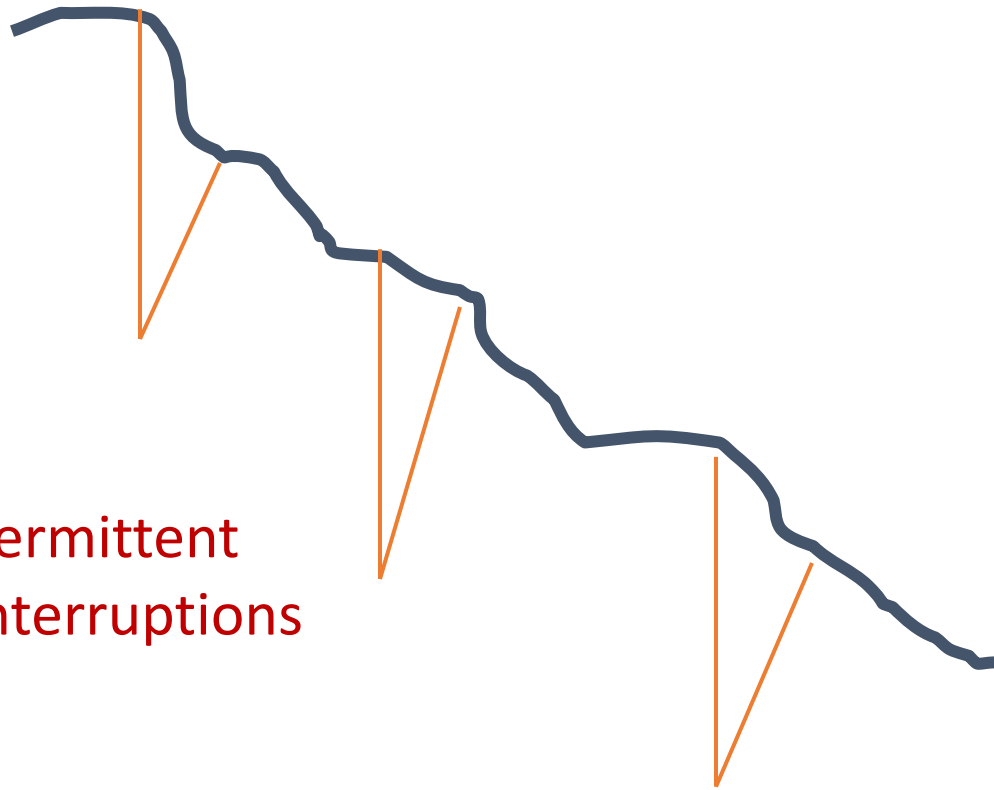


When is it time

- ...to cease driving?**
- ...to assist with finances?**
- ...to help manage medications?**
- ...to have in-home help?**
- ...to move into more supportive housing?**

Chronic disease is filled with shifts in functioning that are

With intermittent
health interruptions



*Middle stage
caregiving leads
into support for
both types of ADL's*

Hands on care

Instrumental Activities of Daily Living

Transportation
Medication monitoring
Shopping
Appointments
Food preparation
Finances

Activities of Daily Living

Bathing
Dressing
Toileting
Transferring
Ambulating

When is it
time for

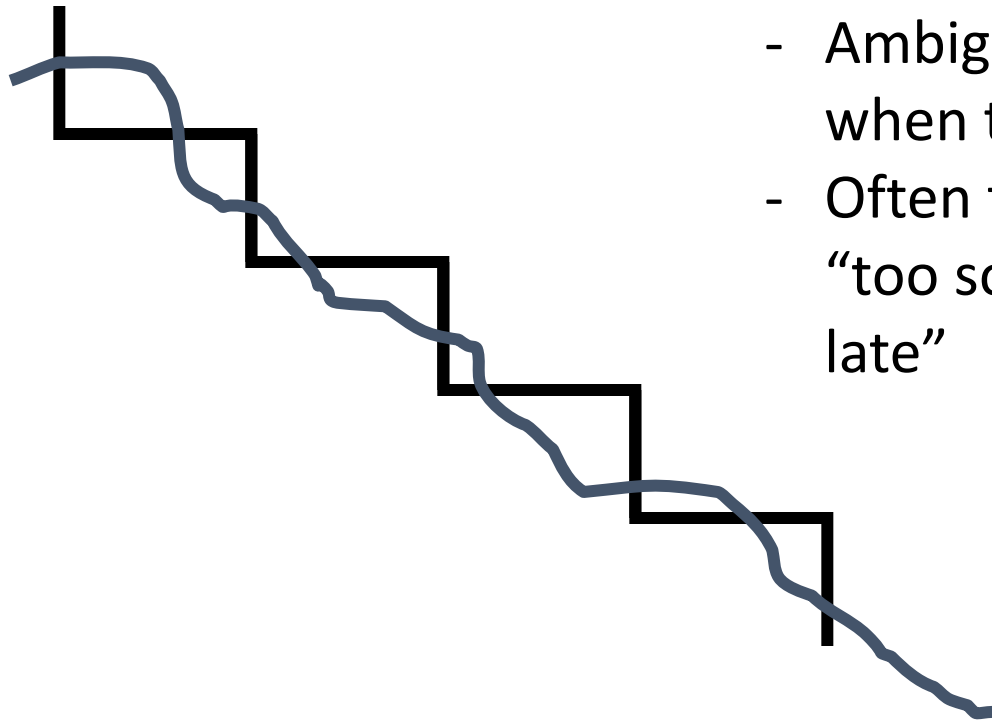
...more
services?

- 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?

Care decisions turn on/off rights and care structures, but decline is incremental...



- Ambiguity about when to change care
- Often feel like it is “too soon” or “too late”

Guiding Principle 1: Person- Environment Fit

Optimal outcomes occur when person's capacities are optimally supported *and* optimally challenged by the environment

- *High competence people are happy in high demand environments*
- *Declining competence²⁴ requires more support in the environment*

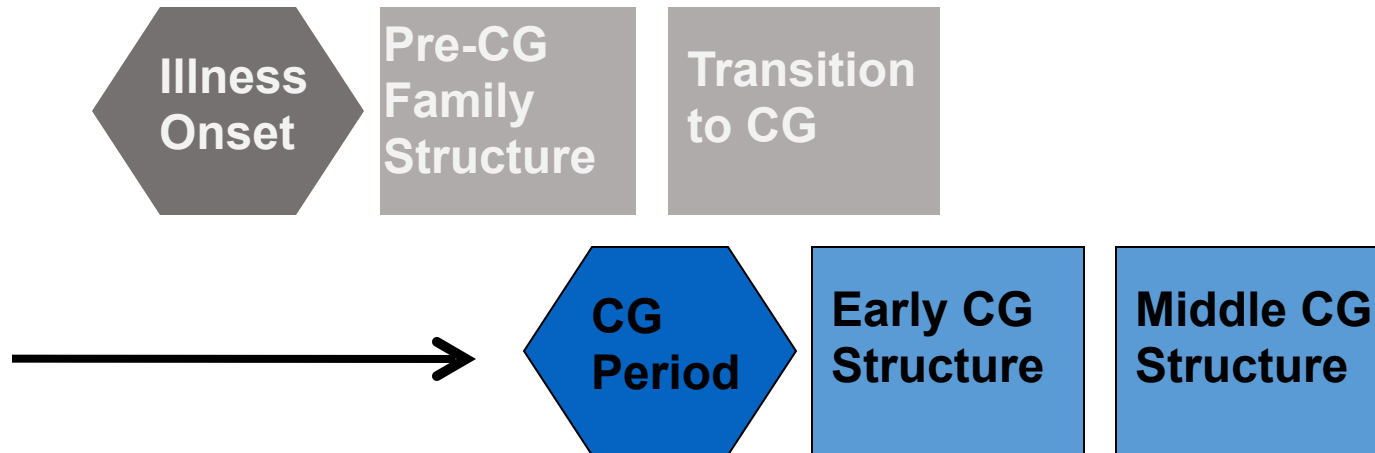
Guiding
Principle 2:
Balance
Autonomy
and Safety

Across the lifespan, caring for family members requires balance of ethical principles

- Autonomy
- Beneficence
- Justice



CG Career Phase II



CHANGING REALITY

- Care needs are demanding more time, effort, and resources
- CG is at risk
- Loss is a dominant theme
- Life satisfaction is more elusive for CR



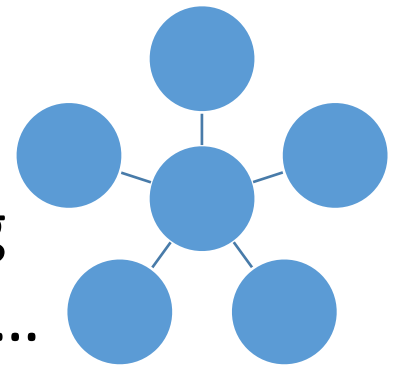
NOW is the time to... Start Partnering

- 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

NOW is time to...

Create a
Decision-Making
Structure among
Family Members

- Clarify CR's involvement
- Families need mechanisms for sharing information, ideas, and opinions
- Clear decision-making structures are helpful... families are rarely a democracy
- Ensure that the lead decision-maker *feels* supported



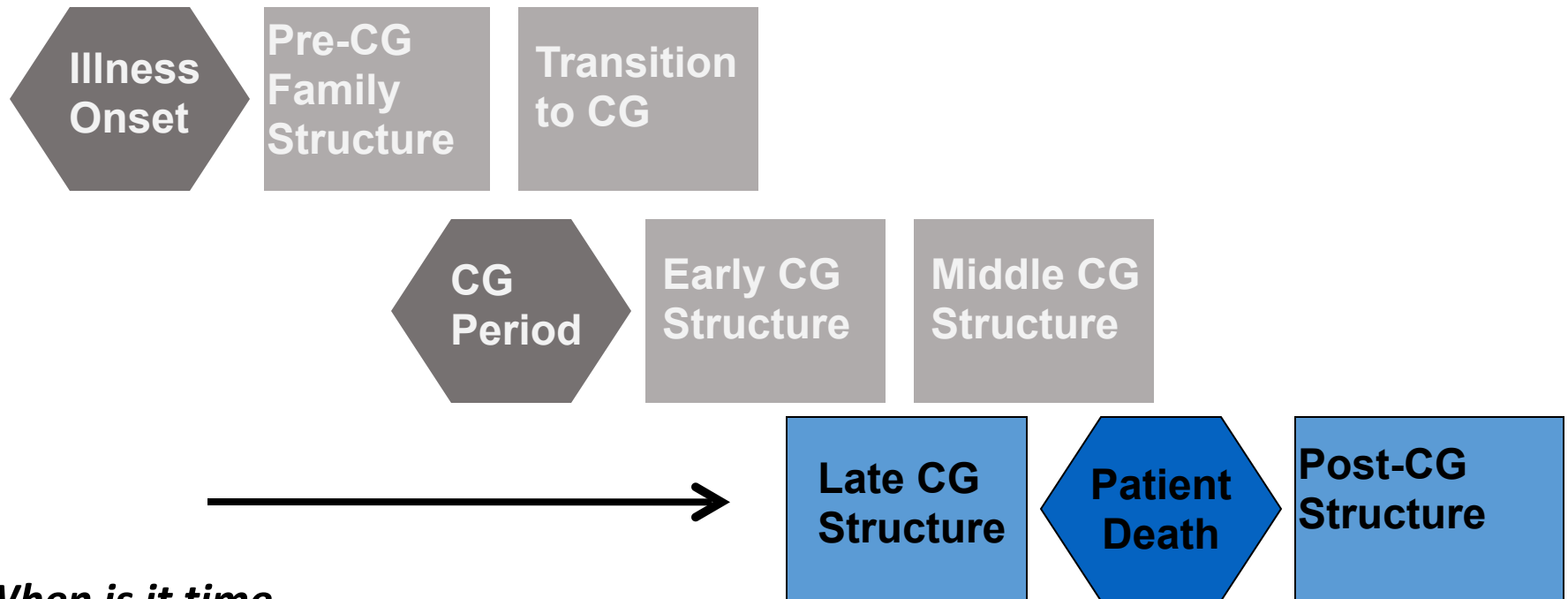


NOW is the
time to...

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

CG Career Phase III



When is it time...

...to prepare for dying?

...to start end-of-life care (hospice or palliative care)?

...to shift focus from *quality of life* to *quality of death*?

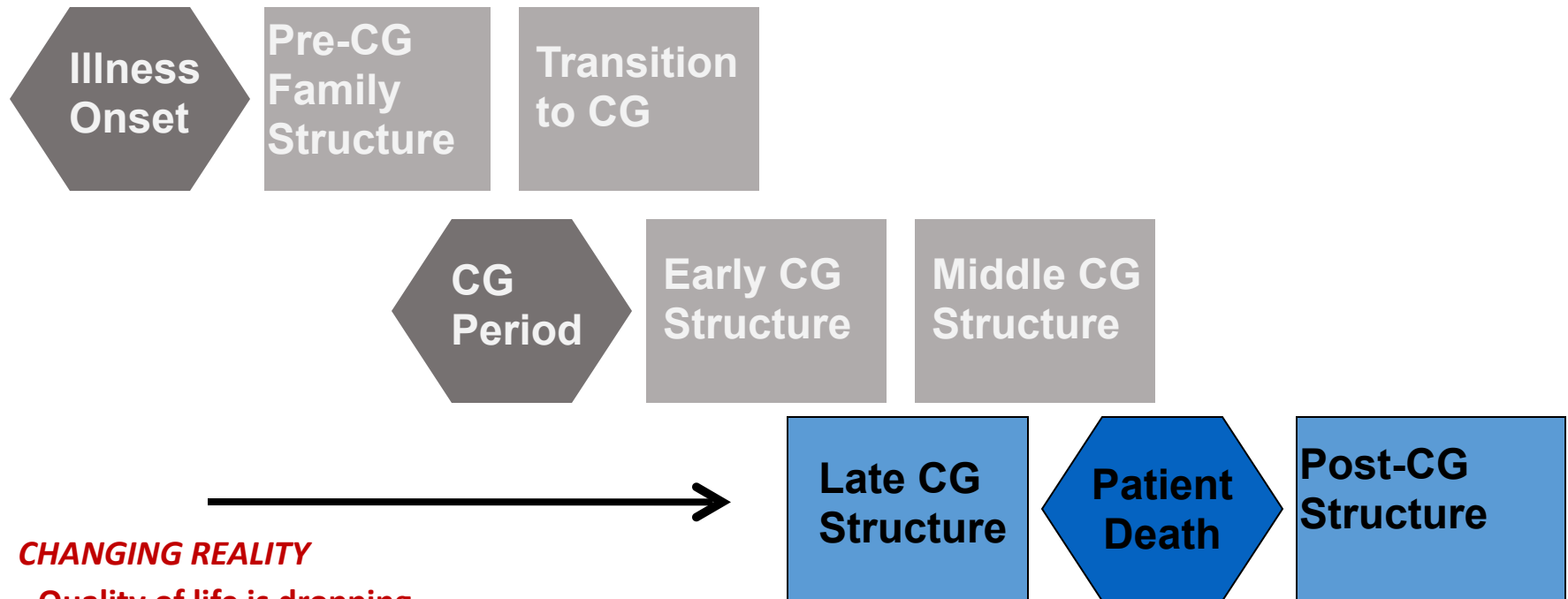
When is it time for ...hospice or palliative care?

- Hospice – start within 6 months of death
 - Choices - how to live and how to die
 - Available in all settings
 - Benefit – extra staff assistance, family support/guidance, expertise in pain management
 - Don't 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

When is it time for ...planning medical end-of-life care and death rituals ?

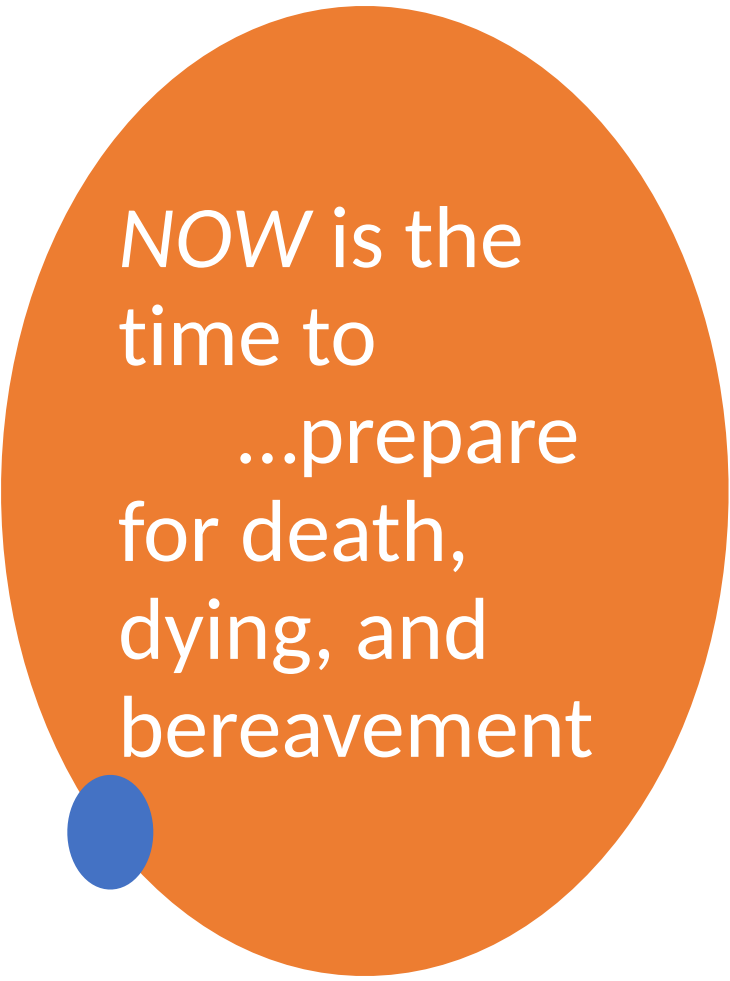
- Values clarification->
What do we want her death to be like?
- Review or establish End-of-life care documents ->
What has she chosen?
 - ✓ Power of attorney (durable or regular)
 - ✓ DNR
- Planning death rituals - What do I/we need for closure?
 - ✓ Who will you inform?
 - ✓ Will you want to gather with others?
 - ✓ What will you do with his/her personal items?

CG Career Phase III



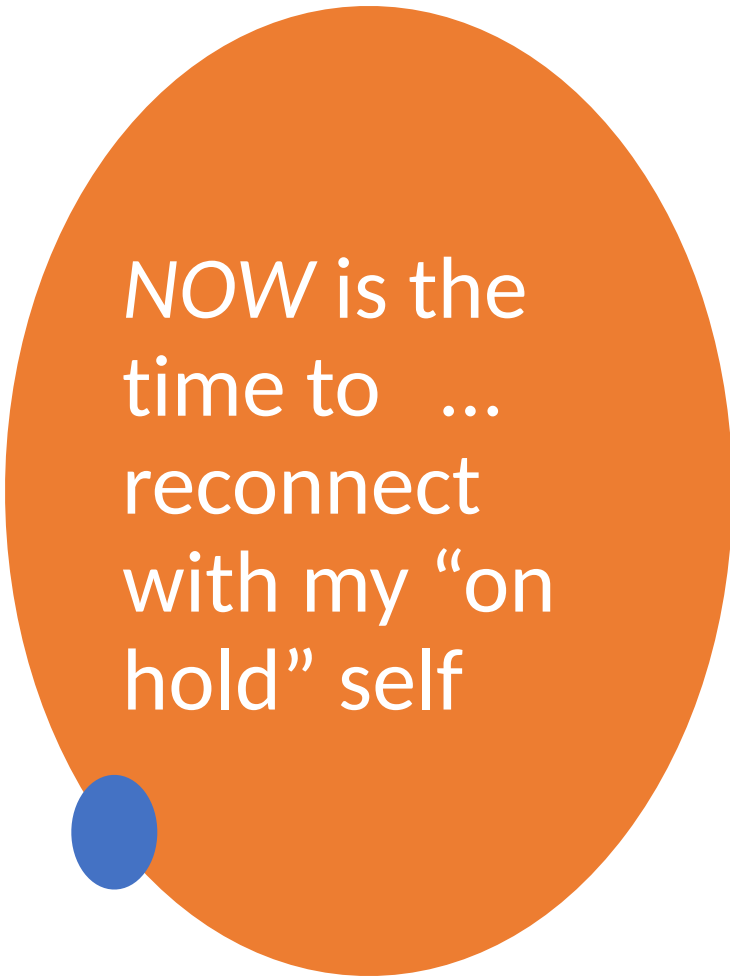
CHANGING REALITY

- Quality of life is dropping
- Repeated acute crises take a toll on CG and CR
- CG anticipates the end of care with mixed feelings
- Overwhelming responsibilities of CG leave a vacuum in life to fill



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

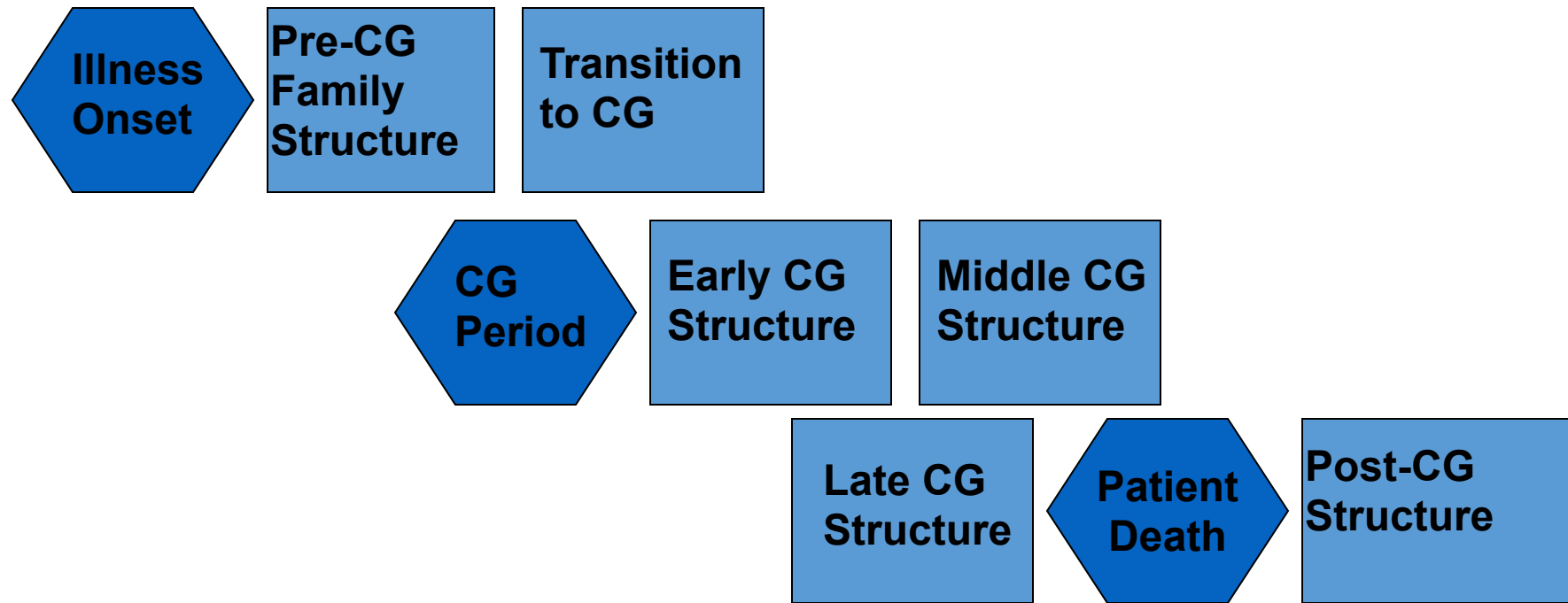
- Reflect on how you want him/her to die
 - > Who, what, when, where, how
 - > How do today's choices shape the dying process?
 - > How do you communicate with him/her about dying?
- Focus on quality of life as it is experienced by CR
- Anticipate death rituals – what do you value/need?
- Consider the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



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...

The Family CG Career – regardless of length of time, an evolving process with much to do

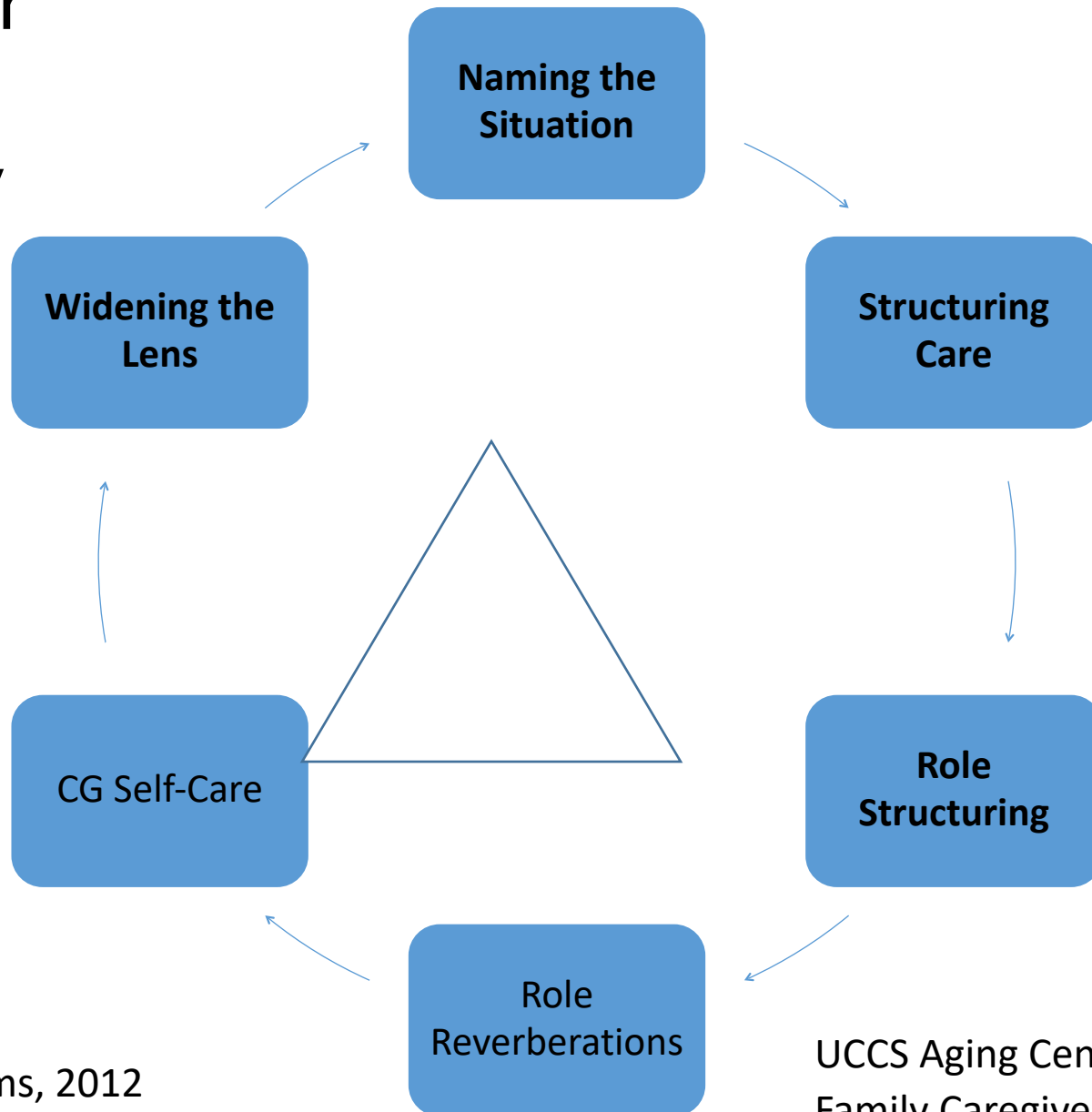


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- Roles must be learned, enacted, and given up
- Each stage has distinct, multiple stressors



***Both normative
and extraordinary,
caregiving requires
of us all significant
investments in
family and friends
throughout our
lifespan.***

Caregiver Family Therapy



Qualls & Williams, 2012

UCCS Aging Center
Family Caregiver Program
719-255-8002

