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May 24, 2018

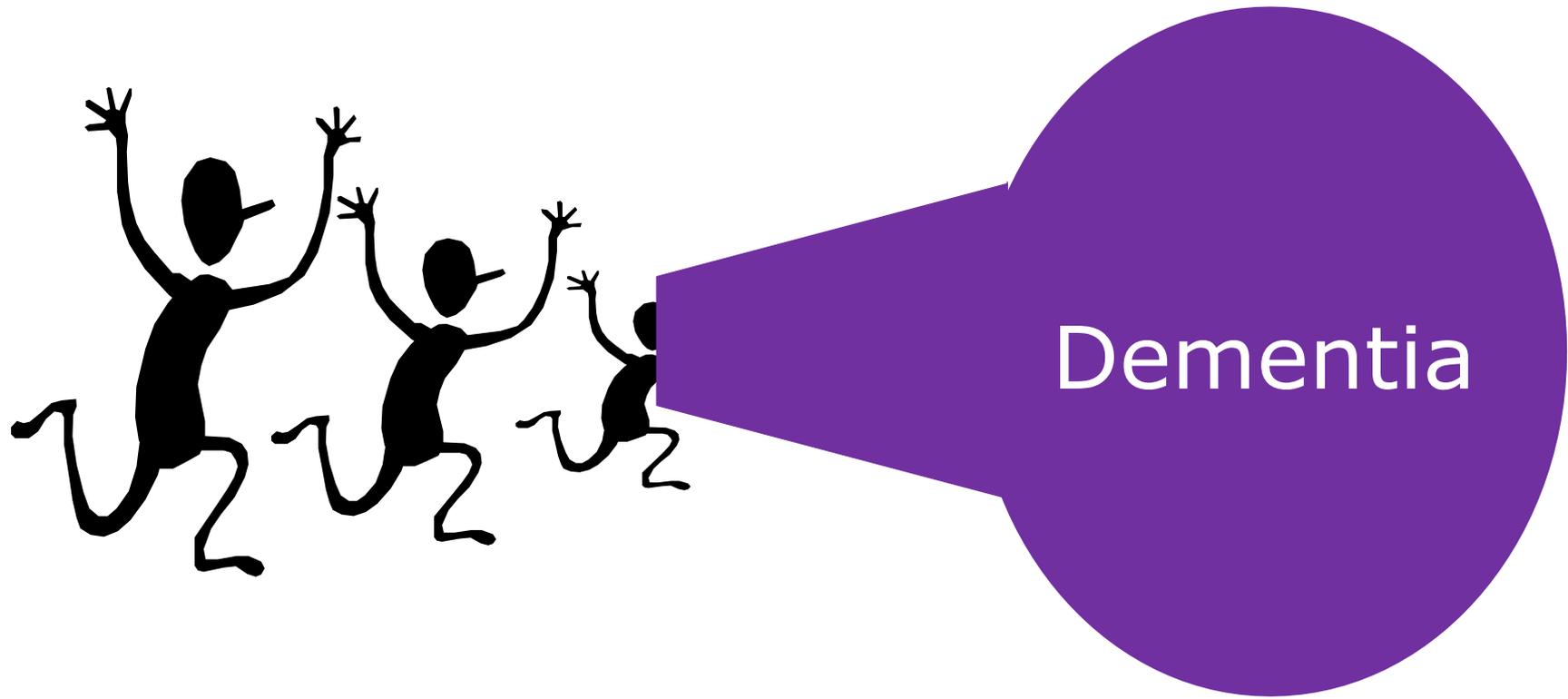
Family Responses to Dementia: Managing Emotions

Goals for today

- Through this session participants will be able to:
 - Identify ways in which families respond to the experience of illness and the feelings illness often evokes in family members
 - Describe the value of a comprehensive family assessment in understanding emotions in families with dementia
 - Reflect on their own responses to family emotions
 - Identify at least 2 skills to increase their comfort level working with families in emotional distress

FAMILY RESPONSES TO ILLNESS







"The Dementia Bubble"

What happens in the “Dementia Bubble”?

Those with the diagnosis and their families often...

- Experience shock and disbelief
- Grieve losses
- Begin to think about how to make sense of the illness
- Develop coping strategies
- Grapple with how they will live with uncertainties
- Have important conversations
- Put some medical, legal, and financial plans in place
- Decide whom to tell and what the message will be

Shock and disbelief

- How could this happen to me/us?
- Why me?
- Could the doctors be wrong?
- What about a second opinion?
- Time spent looking for alternative explanations/finding excuses for behaviors/symptoms

Grief and loss

- Loss of
 - Former self
 - Previously held roles
 - Previous use of financial resources
 - Previous relationship qualities
 - Future as it was planned

Sentiments about grief & loss

- *I feel like her doctor has given up on her. He has stopped looking for other causes for her medical symptoms.*
- *This is not how we planned to spend our retirement years.*
- *I want to feel better about the future. Nothing I do seems to be as it used to be. (PWD)*
- *I feel isolated. I never planned to retire. (PWD)*
- *We just want to get normalcy back.*
- *I miss having a career. (CG)*

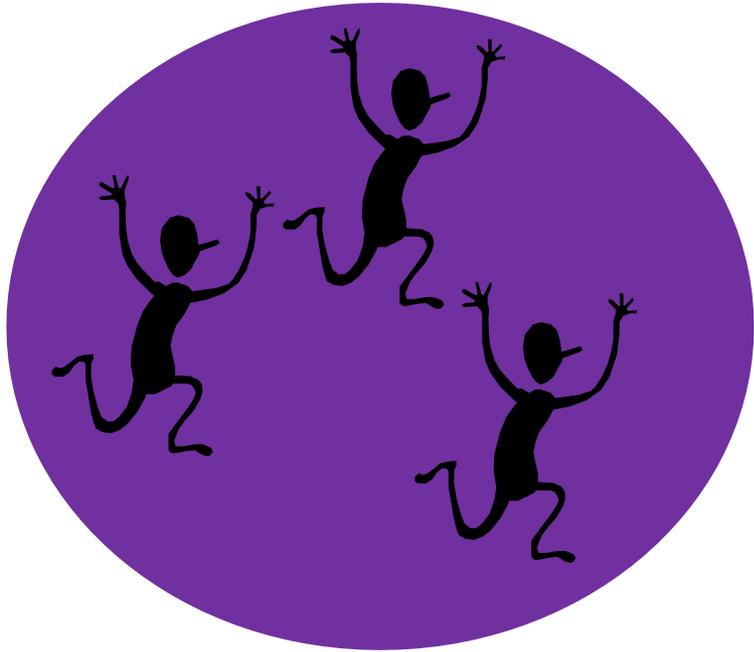
Some common reactions

- **General feelings:**
- This must be trying for my family.
- I am letting my wife/husband down.
- I hate being dependent.
- My family babies me.
- **Around the time of the diagnosis:**
- Everybody was here, then they went away.
- There are things I am uncomfortable saying to my family.
- I am scared, angry and embarrassed.

Making sense of the illness

A process

- For the person with the diagnosis
- For family members
- For the couple





Escaping "The Bubble"

Reflections from PWCI on Adjustment

- **HOPE**
 - Central to the adjustment process
 - Restoring and maintaining a sense of normalcy
 - Developing cognitive, social, and behavioral strategies to improve confidence
- **Maintaining hope, helping others, and living within a supportive social network** can positively influence adaptation to daily living and to the preservation of self-concept.
- **Positive outlook**
 - Made sense of and accepted illness
 - Received understanding and support from family and friends
 - Were respected
 - Felt heard
- **Social Connections**

Feelings related to memory loss

- Other considerations
 - Time since CI was first noticed
 - Time since diagnosis
 - Time since family member became a CG

HOW MUCH DO YOU NEED TO KNOW ABOUT A FAMILY BEFORE YOU REALLY "GET THEM"?

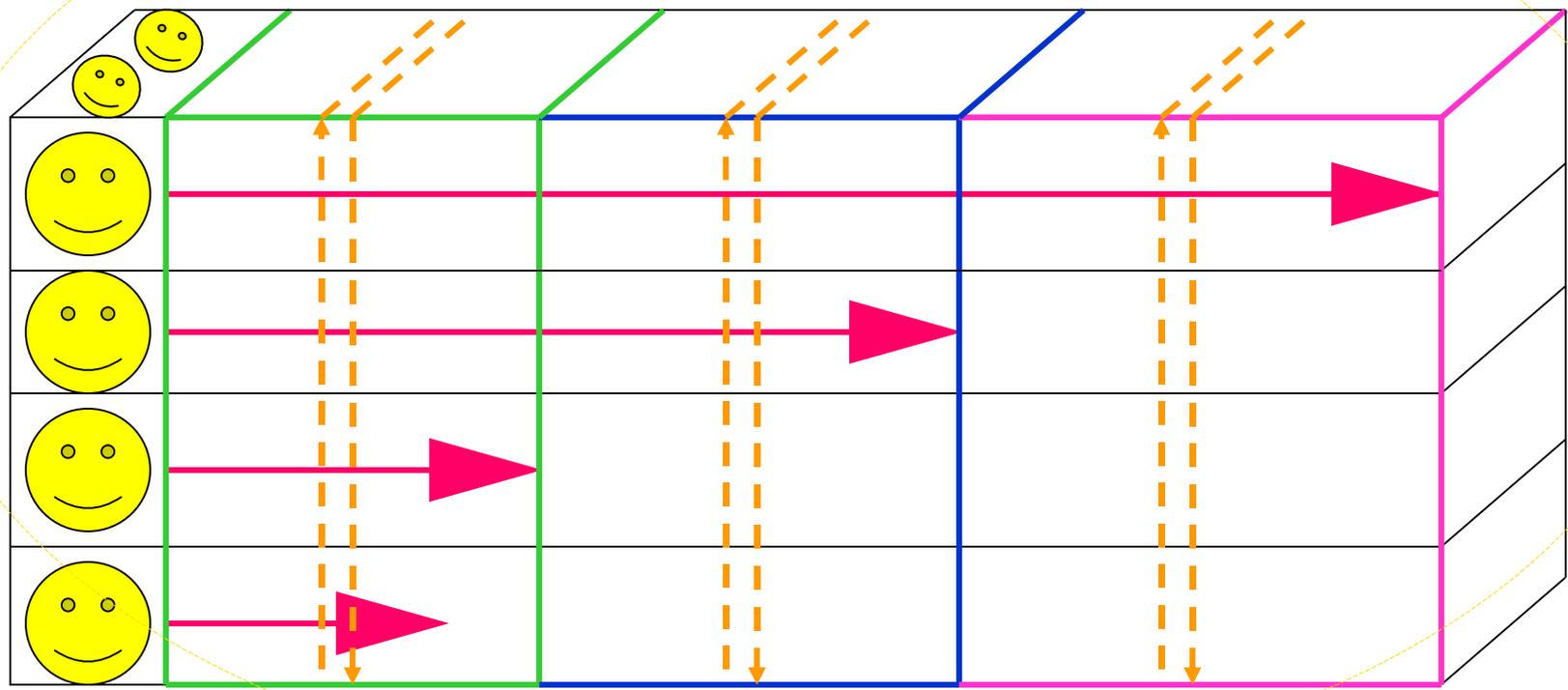


Dimensions of family assessment

- Developmental issues
- Structure and organization
- Family life cycle
- Family of origin issues
- Family rules, roles, and responsibilities
- Personality traits
- Attachment, problem solving and communication patterns
- Coping styles
- Meaning

Environment

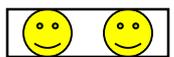
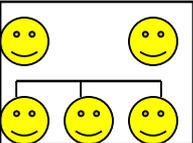
Family Members



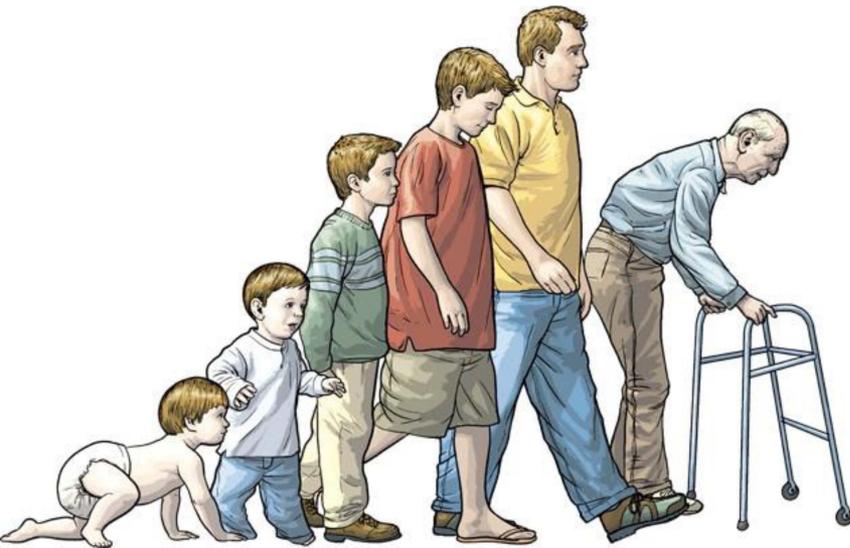
Young Adulthood

Mid-Life

Late Life

	Family Relationships		Developmental Stage
	Family Systems		Family Life Cycle Stage
			Intergenerational Patterns

Stages of human development

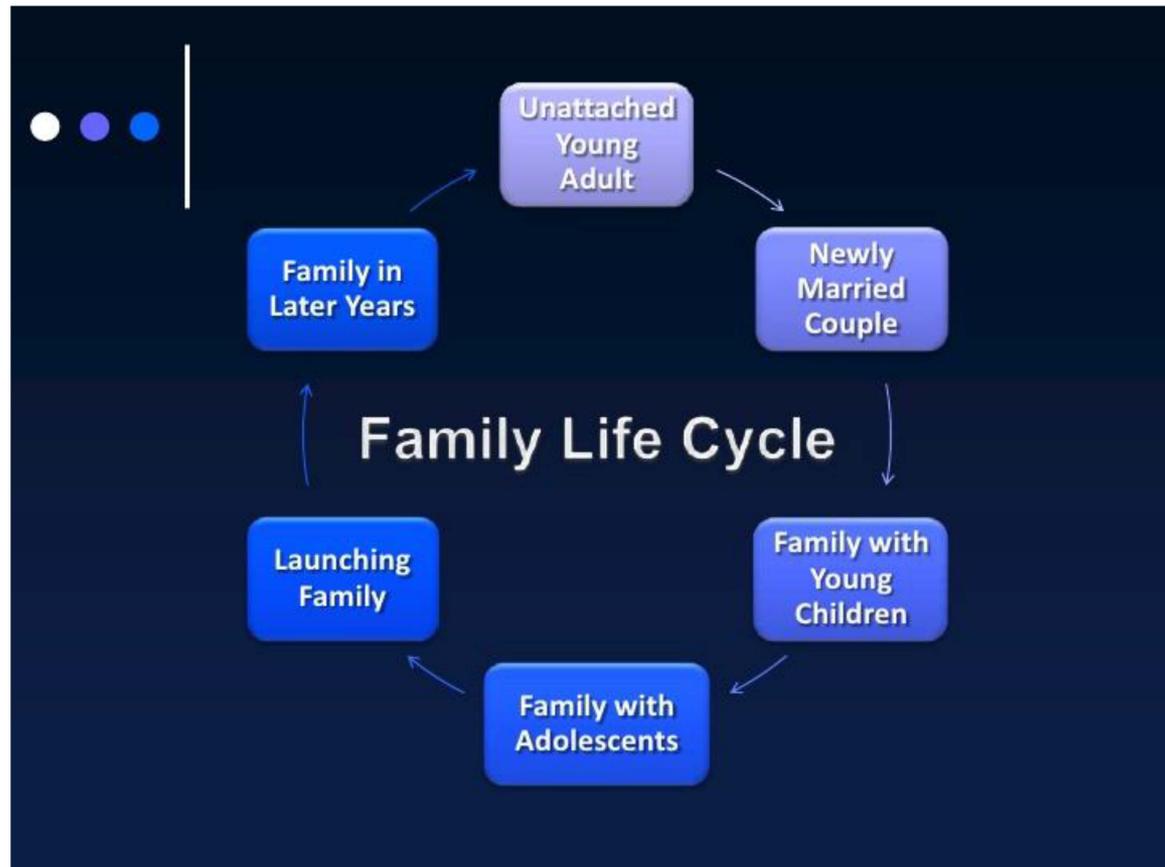


Stages of human development

Development throughout life-span (8 Stages)

- **Prenatal (from conception to birth)**
- **Infancy (birth to age 2)**
- **Early Childhood (2-7)**
- **Middle Childhood (7-11)**
- **Adolescence (11-20)**
- **Young Adulthood (20's to 40's)**
- **Middle Adulthood (40's to 60's)**
- **Late Adulthood (60's onwards)**

Family life cycle



Family life cycle

- Mid-Adulthood (Glick, et al., 2000)
 - Defined as ages 40 to 50 years
 - Those between 40 and 50 constitute “the command generation”
 - Caring for children and/or aging parents
 - Re-evaluating life goals, work, relationships
 - Forgive self for sins of omission and commission
 - Those between 50 and 60:
 - Settle into the life one chose in the 40s
 - Accept who one has become
 - Deal with grandparenthood
 - Deal with issues of aging and mortality

Status transitions in family

NORMATIVE

- Socially acceptable
- Expected to occur at a given time
- Examples
 - Children will leave home and become independent
 - Children will marry and have children
 - Parents retire

NON-NORMATIVE

- Out of sync with norms
- Examples
 - Child drops out of school
 - Child goes to prison
 - Parents or child divorce
 - Parent or child can't keep a job
 - Adult child moves back home

Intergenerational patterns

- The past often shapes the future
 - Attitudes
 - Rules for “how things are done”
 - Past experiences
 - Family’s experience of illness and caregiving
- The role of culture

Relationships matter

- Factors to assess
 - Closeness, affection, amount of contact
 - Strengths in family or relationship
 - Are expectations clear and reasonable
 - Have parent/child transitions been normative
 - Stressful life events
 - Motivation for caring
 - The *demilitarized zone* – what's off limits

Coping style

- Planful problem solving
- Self-control
- Confrontative
- Distancing
- Seeking social support
- Positive appraisal
- Accepting responsibility
- Escape/Avoidance

The value of family stories

- What is the meaning behind the thoughts and behaviors of the family members?



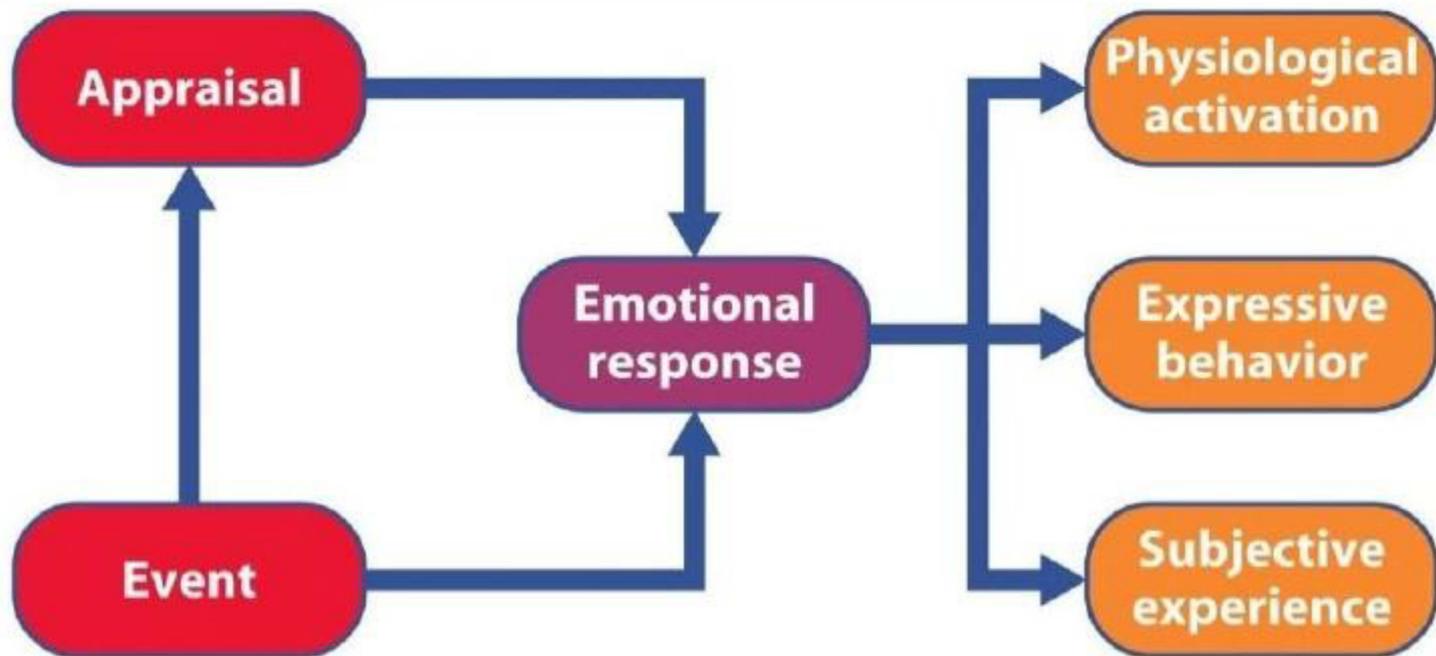
Assessing the caregiver

- CG's roles and responsibilities
- Caregiving difficulties
- CG's preparedness
- Quality of care
- CG's physical and mental health & self-care activities
- Existence and involvement of family and social supports
- Relationship between CG and CR
- Family's cultural background

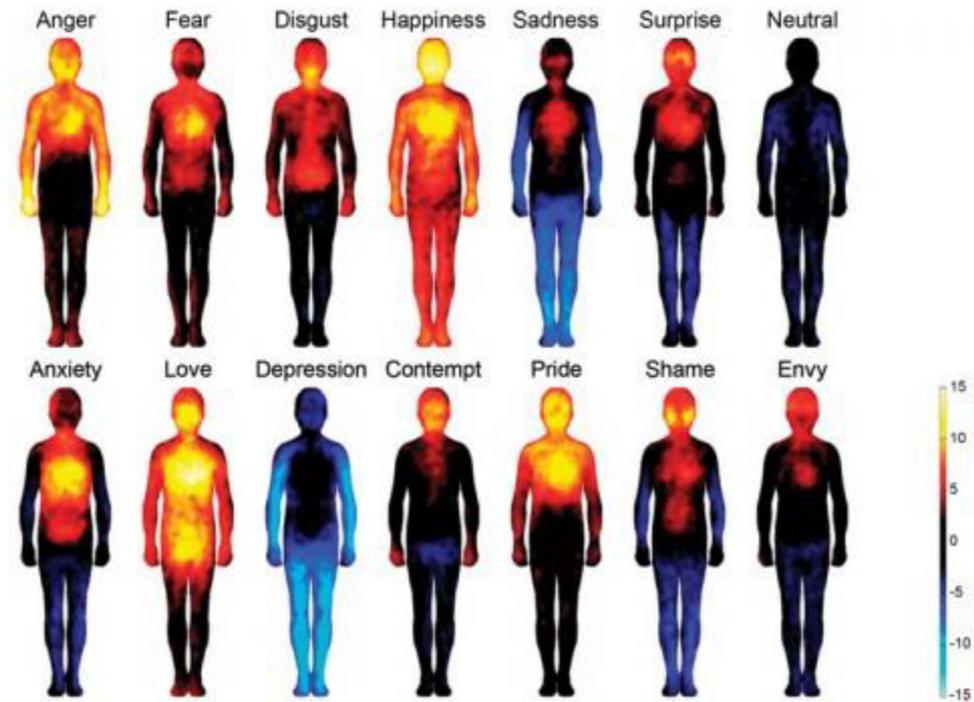
OUR RESPONSES TO OTHERS' EMOTIONS



Paths to Emotional Responses



PHYSIOLOGICAL RESPONSES TO EMOTIONS



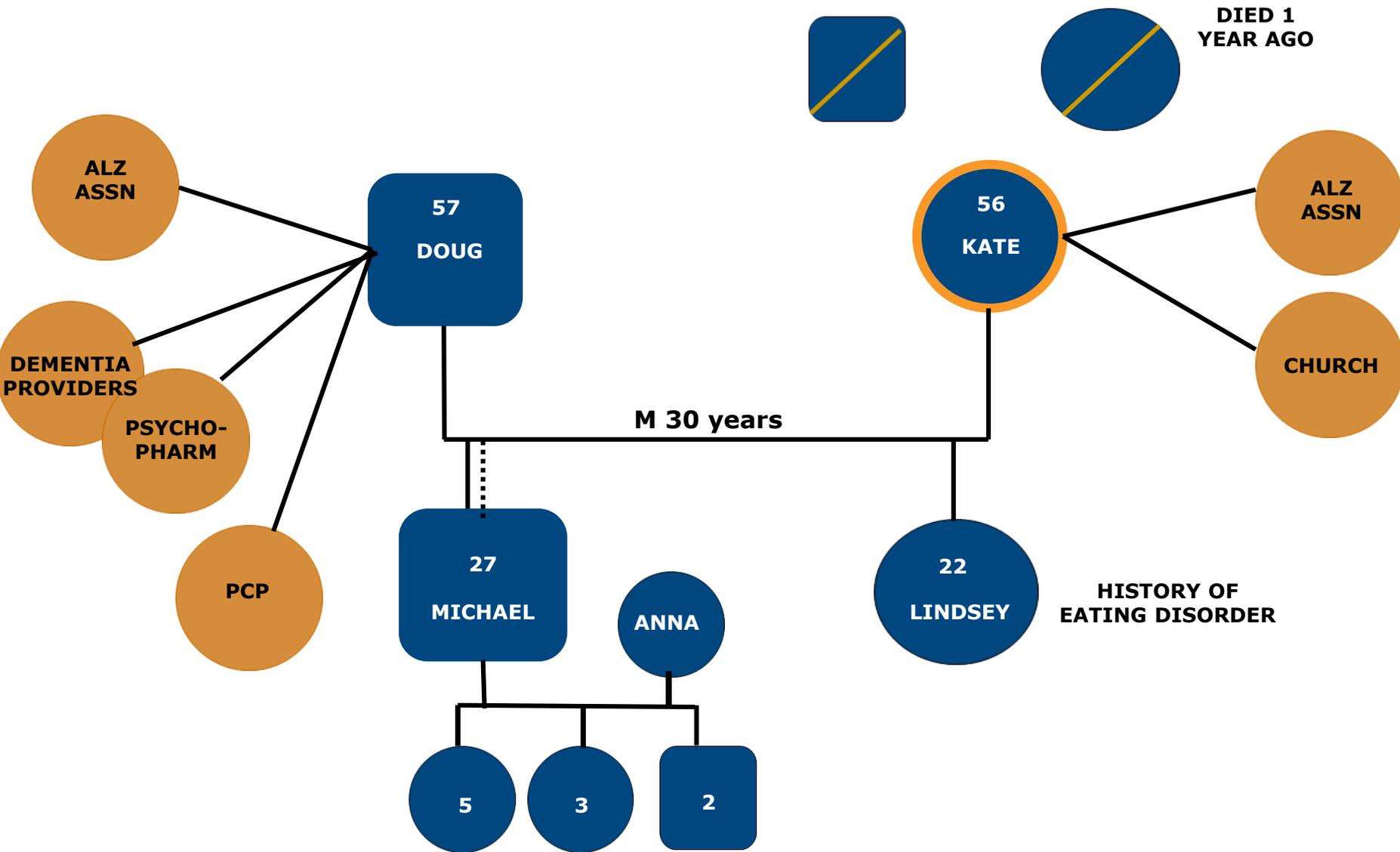
THE SPENCER FAMILY



Volunteers?



- Doug
- Kate
- Michael
- Lindsey
- Anna



Doug and Kate: Social History/Background

Met in college; married post graduation

D: accomplished music teacher/songwriter/performer -- K: ESL teacher

K: Provided in-home care to mother who died recently from cancer

Embraced role of grandparents

L: 5 year hx of anorexia nervosa/depression—college on hold

D: dx of early AD 2 yrs ago; depression

K: re-entered workforce as receptionist/clerk in medical office

M: adopted from China: sees family as “medicalized”; studied Eastern medicine in college; embraces homeopathic medicine

Doug & Kate: Health

DOUG

- History of depression (since 14)
- Painful musculoskeletal disorder
- Self-medicated (etoh/pain meds by age 16)
- Opioid tx at age 45; remission

KATE

- Ulcerative colitis for 5 years
- Focused on healthy lifestyle
- “Tremendous pressure” to stay well for her family
- Residual grief (loss of mother)

Doug & Kate: Assessments

- PHQ-9: D (17-moderate)/K (8-mild)
- GAD-7: D (12-moderate)/K (16-severe)
- Zarit CGB: K (8-high burden)
- FAD: Problem areas:
 - Communication (often miss emotions others are trying to convey)
 - Problem-solving (unable to decide on course of action)

Doug & Kate: Diagnoses

D: Mild neurocognitive D/O due to AD, with behavioral disturbance, mild

Major depressive disorder, recurrent, moderate

Opioid use disorder in remission

Back pain

Relationship distress with spouse or intimate partner

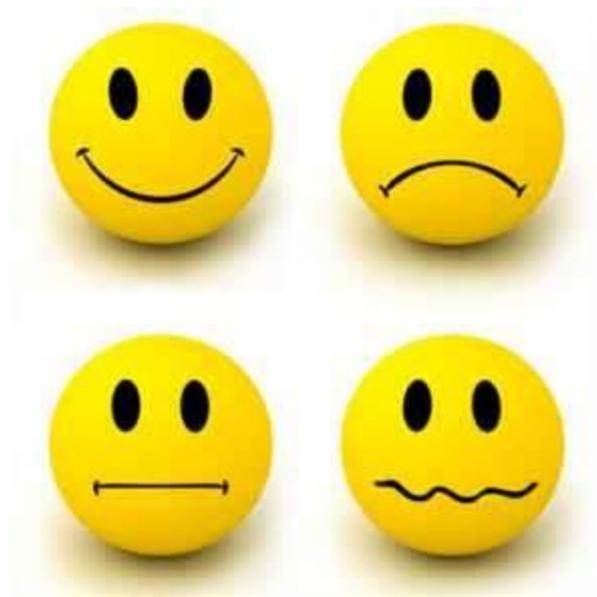
Phase of life problem

K: Adjustment Disorder with mixed anxiety and depressed mood

Relationship Distress with spouse or intimate partner

FEELING INVENTORY

- Doug
- Kate
- Michael
- Lindsey
- Anna
- Others affected?



FEELINGS RELATED TO MEMORY LOSS

- Feelings for the person with CI
- Caregiver's feelings
- Feelings about the relationship between PWCI and CG
- Feelings about its impact on family & friends
- Other feelings

FEELINGS RELATED TO FAMILY FACTORS

- Themes in the Spencer family?
 - Addiction
 - “Sick role”
 - Culture
 - Others?

WORKING WITH FEELINGS



STAY MINDFUL OF YOUR ROLE

- What is your role in the case?
- What are the goals?
- What is within your scope of practice?
- What are your options when the need falls outside your scope of practice?

Reflect on the Spencers

- How would you feel working with this family?
- What did their story bring up for you?

Working with emotions

- Connect with the family in meaningful ways
- Get “permission” to speak the family’s language
- Learn the art of validating emotions

WHAT IS GRIEF?

- A multifaceted response to loss to which a bond or affection was formed
 - Death or separation from a loved one
 - Loss of a job
 - Death or loss of a beloved pet
 - Divorce, becoming an "empty nester," or retirement
- Responses to loss can be:
 - Emotional
 - Physical
 - Cognitive
 - Behavioral
 - Social
 - Spiritual
 - Philosophical

Grief responses

- The *order and timing of these phases may vary* from person to person:
 - Accepting the reality of the loss
 - Allowing oneself to experience the pain of loss
 - Adjusting to a new reality

Signs of complicated grief

- Intense sorrow and pain at the thought of the loved one
- Focus on little else but the diagnosis/PWCI
- Extreme focus on reminders of the loved one or excessive avoidance of reminders
- Intense and persistent longing or pining for the past
- Problems accepting the diagnosis or progression
- Numbness or detachment
- Bitterness about the loss(es)
- Feeling that life holds no meaning or purpose
- Irritability or agitation
- Lack of trust in others
- Inability to enjoy life or think back on positive experiences with loved one

When to refer the client

- When a client feels such profound disbelief or hopelessness that it inhibits function in daily life
- If intense grief doesn't improve over time
- If person continues to:
 - Have trouble carrying out normal routines
 - Withdraw from social activities
 - Experience depression or deep sadness
 - Have thoughts of guilt or self-blame
 - Believe that s/he did something wrong or could have prevented the illness or illness experience
 - Have lost his/her sense of purpose in life
 - Feel life isn't worth living

Grief: what helps?

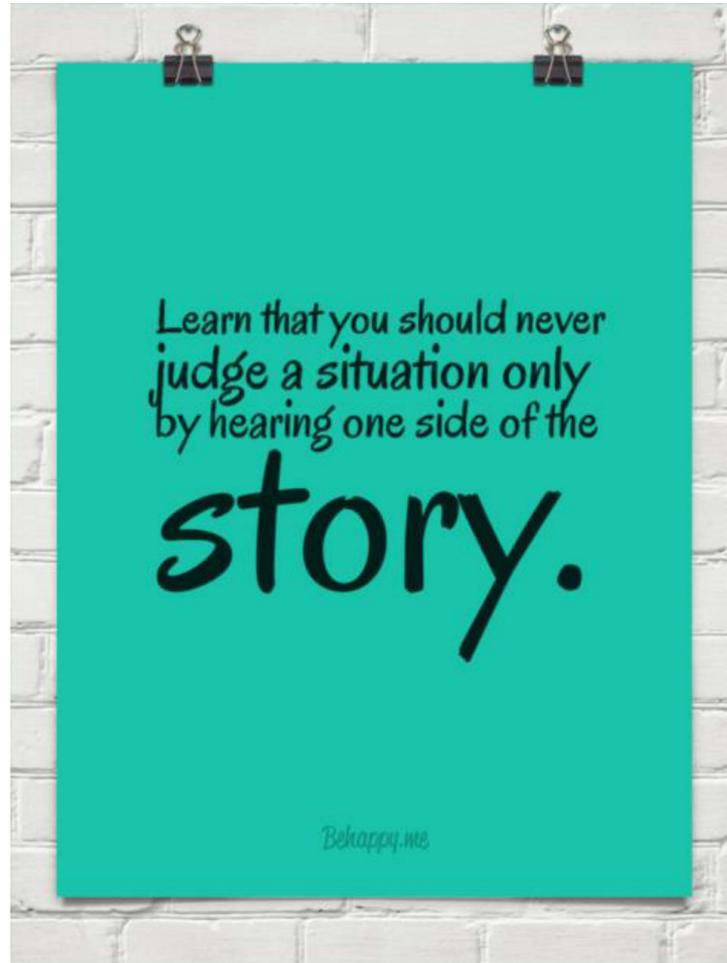
An individual can help to resolve grief by:

- Allowing time to experience thoughts and feelings openly to self
- Expressing feelings openly or writing journal entries
- Remembering that crying can provide a release
- Confiding in a trusted person about the loss
- Acknowledging and accepting both positive and negative feelings
- Finding bereavement groups in which there are other people who have had similar losses
- Seeking professional help if feelings become overwhelming

Grief: what hinders?

- Some factors may hinder grief and the healing process following a loss. These can include:
 - Overworking oneself on the job
 - Abusing drugs, alcohol, or other substances
 - Compulsive behavior
 - Avoiding emotions
 - Minimizing feelings

FAMILY CONFLICT



Learn that you should never
judge a situation only
by hearing one side of the
story.

Behappy.me

Minimizing family conflict

- **Teach family members to understand the wishes and needs of the person with dementia**
- **Be mindful that a dementia diagnosis affects everyone in the family**
 - Family members may have different life cycle considerations
 - There are many different coping styles and personalities in families
- **Sometimes family roles and responsibilities need to shift**
 - Facilitate conversations about how others may be able to help
 - Model how to identify and share feelings
 - Teach family members to ask for help
- **Recognize that everyone is usually motivated by love and concern**
- **Develop plans for care and support that are time-limited**

Sibling conflict

- Example: Siblings approach Mom's needs, care, and use of resources differently
- The value of assessment
 - What are the issues?
 - How do they feel about one another?
 - What is their relationship with the PWCI?

Need to shift roles

- Example: Daughter needs a break. Father is the patriarch.
- Value of assessment
 - Does the family member have “permission” to take on the new role?
 - Does the new role shift the family hierarchy?
 - Does “authority” come with the responsibility?

VALIDATE EMOTIONS

Validating Emotions

- Sometimes less is more!
 - Know when to be a “fixer” and when to “listen and validate”

QUESTIONS?

