

## 2019 FORUM ON AGING IN RURAL OREGON -- "THE EXPERIENCE OF GRIEF AND LONELINESS"

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## Friendship Line – 800.971.0016



24-Hour Accredited Crisis Intervention Telephone Hotline/Warm-line – Founded in 1973:

- Call-In Service Confidential telephone discussions for people 60+ (their caregivers or younger disabled) who may be lonely, isolated, bereaved, depressed, anxious and/or thinking about death or suicide
- A caller does not need to be in a suicidal crisis to use the call-in service
- Mia Grigg, Friendship Line Director, <u>mgrigg@ioaging.org</u>
- Patrick Arbore, parbore@ioaging.org or 415.750.4133



## FRIENDSHIP LINE



 Call-Out Service – Friendship Line Staff or Trained Volunteers will make phone calls to older adults for emotional support – Referrals can be arranged by going to the website: https://www.ioaging.org/services/allinclusive-health-care/friendship-line or contact Mia Grigg Mgrigg@ioaging.org 415.750.4138 for assistance

## According to the CDC

- According to the Centers for Disease Control and Prevention report, <u>The State of</u> <u>Aging and Health in America 2013</u>, the population 65 years and older is expected to double over the next 25 years, due to longer life spans and the large number of baby boomers reaching retirement age.
- On average, rural populations are older than populations in other parts of the country.

## **Older Adults Living in Rural Areas**

- Older adults living in rural communities are at a disadvantage in terms of available services, resources, and activities and the social "glue" these provide.
- Although it may come as a surprise to many people living in the country's more populous areas, approximately 25% of Americans older than age 65 live in a small town or other rural area.

#### Population Research Center at Portland State University

- Between 2010 and 2015, Crook County's senior population increased by about 26 percent, while Jefferson County's rose by about 22 percent.
- The Census Bureau estimates there were 33,117 residents in Deschutes County in 2015 who were 65 or older, which is nearly 19 percent of 175,268, the total county population at the time
- Central Oregon is a desirable place for retirees because of relatively affordable housing compared with other states and the many available outdoor activities.

#### **US Population Living Alone**

According to the American Psychological Association (2016):

- 12 million Americans 65+ live alone
- 69% of those 12 million are older women
- Some researchers found that elderly individuals who live alone are lonelier than age-matched individuals living with others despite comparable social interaction frequency and personal network adequacy

### Loneliness

- Loneliness has many faces, many causes
- It is a convoluted mental condition that hides itself in bereavement, divorce, geographical isolation, shyness, the lack of opportunity or the inability to establish relationships or simple friendships.
- It has no regard for position or age -- it affects countless thousands of people most of whom suffer in silence year after year
- Some we would never suspect of being victims

### Loneliness

- Older adults are at increased risk of being socially isolated or lonely
- By the time people reach their 80s, the majority live on their own, mostly because of widowhood
- This is particularly the case for older women who are more likely to be widowed than older men
- Older people's social networks often get smaller for other reasons as well – children may have moved away, along with grandchildren, and aging siblings and friends may have died

### Loneliness and Social Isolation

- Social isolation arises in situations where a person does not have enough people to interact with, an objective state
- Loneliness is the subjective experience of distress over not having enough social relationships or not enough contact with people
- A person can be socially isolated but not feel lonely, whereas an individual with a seemingly large social network can still experience loneliness.

#### Loss and Loneliness

 Living alone, health problems and disability, sensory impairments such as hearing and vision loss, and major life events such as loss of a spouse have all been identified as risk factors for social isolation and loneliness

### Mortality and Loneliness

- A number of researchers have concluded that lack of social relationships is as strong a risk factor for mortality as are smoking, obesity or lack of physical activity
- Older adults who are lonely have an increased risk of dying sooner and are more likely to experience a decline in their mobility, compared to those who are not lonely

### Loneliness and Grief

- People who are grieving are at a disadvantage when it comes to loneliness because the person they long for is forever gone
- I have learned that grief is the ache of having loved someone so much that pieces of you became them and pieces of them became you
- When they were taken from this Earth a piece of you, your heart, and your history went with them and you were left behind to live a life that feels forever incomplete

### **Normal Grief**

- "Normal" grief is intensely emotional the expectation is that the bereaved individual should return to normal functioning as quickly as possible
- If the bereaved cannot detach in an acceptable period of time, then pathological systems emerge
- Mourning is a private affair; death is final

## **Anticipatory Loss**

- Knowing that there is no cure for Stage IV Cancer, Dementia, or other terminal diseases family, friends grieve as they observe the mental and physical decline of their loved one – often hoping for a miracle
- Family members may be reluctant to talk about their sadness and grief for fear of distressing their loved one

#### Ambiguous Loss

There are two types of ambiguous loss (Boss, 1999):

1.People are perceived by family members as physically absent but psychologically present – it's unclear whether they are dead or alive

2.People are perceived as physically present but psychologically absent – this condition is illustrated by people with Alzheimer's disease

In each situation those who suffer have to deal with something very different from ordinary, clear-cut loss

### Ambiguous Loss & Grief in Dementia

- Ambiguous loss complicates grief
- Family & friends may not recognize your need to grieve the many losses you experience at different stages of the disease
- Grief can be frozen and life put on hold
- Ambiguous loss is often not recognized nor well understood by family caregivers

## According to Robert Butler

"After one has lived a life of meaning, death may lose much of its terror. For what we fear most is not really death but a meaningless and absurd life. I believe most human beings can accept the basic fairness of each generation's taking its turn on the face of the planet if they are not cheated out of the full measure of their turn."

## Grieving

- Although grief myths suggest the grieving process lasts a year, there is no "normal and expected" period of time for grieving.
  - Some people adjust to a new life within several weeks or months.
  - Others take a year or more, particularly when their daily life has been radically changed or their loss was traumatic and unexpected.

## **GRIEF AND SORROW**

There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than 10,000 tongues. They are the messengers of overwhelming grief, of deep contrition, and of unspeakable love. ~ Washington Irving

 Feelings of hopelessness, anguish and despair are normal following any major loss -- the intensity and duration of these feelings will vary from one person to the next, as the reality of the loss becomes more apparent in daily life

## **Grief and Sorrow**

- The sorrow of grief saps energy, making even simple tasks like getting out of bed in the morning, tending to personal grooming, fixing a meal or going somewhere with friends seem overwhelming and exhausting
- The person may feel negative and critical toward everything and everyone, including themselves
- Even in the company of others the person may still feel lonely, and may prefer to avoid gatherings of any size.

#### **Depression and Grief** -- Differences

- Depression inhibits the capacity to experience positive emotions – Grief does not
- Depression interferes with the capacity to care about other people and to understand their good intentions – Grief turns a person inward but the desire to be with others and appreciation of others is preserved
- Both depression and grief take one out of ongoing life – the reasons for withdrawal are very different

## Symptoms of Grief and Loss

- While feeling shock, numbress, sadness, anger, guilt, anxiety, or fear, people may also find moments of relief, peace, or happiness
  - (This is one characteristic that distinguishes grief from depression)
- Grieving is not simply sadness, "the blues," or depression, but individuals may become depressed or overly anxious during the grieving process

### Symptoms of Grief and Loss

- Grief can cause prolonged and serious symptoms, including depression, anxiety, suicidal thoughts and actions, physical illness, posttraumatic stress disorder, and traumatic grief
  - After a death, individuals may have vivid dreams about their loved one, develop his or her behaviors or mannerisms, or see or hear the loved one.
  - If an individual feels fearful or stressed by any of these experiences, talking to a professional experienced in grief counseling is warranted.

#### **Families and Grief**

- Research studies have suggested that grief is most intense for people bereaved due to the death of a child or a life partner; these are people most likely to experience complicated grief
- Bereaved family members are at elevated risk for depression and anxiety for close to a decade or longer after the loss

### Families and Grief Continued

- Vary in their ability to express and to tolerate feelings
- If expressed feelings are not tolerated, various types of acting out can occur
- Healthy coping families are open to discussions about the deceased; they can admit and accept feelings of vulnerability
- Closed families not only lack this freedom but provide excuses for people to stay quiet

#### Families and Grief Continued

- Worden (2002) discussed three main areas of family grief:
- 1. Role the deceased played in the family
- 2.The emotional integration of the family3.How families facilitate or hinder emotional expression

#### **Families and Grief Continued**

Three essential tasks for grieving families:

1.Must be recognition of the loss and acknowledgment of the unique grief experiences of each family member

2.Family must reorganize with roles reassigned to other family members or abandoned

3.Reinvestment of family members in this "new" family while staying connected with the deceased

## **Emergence of Trauma**

"One day we are absorbed by dressing well, following the news, keeping up, coping, what we might call staying alive; the next day we are not." --- Joan Didion



### Complicated Grief (CG)

According to Shear, MD, (2012):

- CG occurs in about 7% of bereaved people
- People ruminate about the circumstances of the death
- People use excessive avoidance in order to steer clear of reminders
- People experience intense emotions
- Prolonged (complicated Grief Disorder) has been added to the DSM-V

## Integration of Losses

- To feel "whole" a person must be integrated into the here and now
- Losses over the life span rupture selfcoherence and self-continuity
- There is an inability to comfort the self
- Losses that accompany aging and the confrontation with one's death threaten selfesteem



## **Trauma Recovery Process**

- Mourning for Losses
- Giving meaning to trauma
- Accepting trauma
- Establishing self-coherence and selfcontinuity
- Achieving (ego) integration



## **Trauma Distress**

- Associated with repetitive, intrusive, and enervating thoughts, images and stories about the trauma event and its impact on self
- Dysfunctional images of the event that contain terror and helplessness;
- Pain associated with feelings of helplessness as the event unfolds;
- Dysfunctional images of the self associated with the loss of control over the traumatic event



## PTSD & Trauma

- Traumatized individuals may develop posttraumatic stress disorder
- The memory of the traumatic event dominates their consciousness, depleting their lives of meaning and pleasure

# **Denial & Numbing**

- Found in virtually all forms of complicated mourning
- Initially numbing helps the individual avoid painful memories, thoughts and feelings about the trauma
- Numbing contributes to disturbance in the normal integration of thoughts and feelings into consciousness



## **Intensification of Denial**

 Can lead to maladaptive avoidance – withdrawal, drug and alcohol abuse, feelings of frenzy and other non-helpful behaviors



# **Implications for Treatment**

- Many groups and individuals are or will be traumatized in our present society
- The symptoms associated with the trauma may not surface until a person's later years
- Professional helpers may misconstrue trauma symptoms as part of a degenerative process of aging
- May deny this person compassion and empathic understanding
- Invite the person instead to share their "story"



## Ethnic/Cultural Experiences and Trauma

 How trauma is experienced by ethnic/racial groups has not been adequately studied; more research needs to be initiated regarding trauma, age, and ethnicity (Thompson and Kyle, 2000)



#### Shaping Our Stories – Atul Gawande

 Our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives p. 243

## Death in the ICU



Based upon research from the Dana Farber Cancer Institute:

- Was associated with 11 times higher rates of post-traumatic stress disorder and 9 times higher rate of generalized anxiety disorder among bereaved caregivers
- Hospital deaths were associated with 10 times higher rates of prolonged grief disorder in bereaved caregivers

# Stories about Illness, Suffering, Grief and Coping

- People use stories to tell about their experience with the grief associated with losses of all kinds including death
- Stories convey their attitudes and feelings/emotions about their loss
- Stories help people cope with suffering

# How Helpers Support the Storytelling

- Help the person tell their story as clearly as possible
- The story needs to be told whether it comes out at once or in pieces over time
- Must have effective connections with the person who grieves
- Help the bereaved person identify and work on problems related to the trauma



#### **Unfinished Business**

 Dr. Elisabeth Kubler-Ross defined unfinished business as "something that is incomplete in our lives that deprives us of a sense of peace." It is almost always about relationships and includes things said or unsaid, done or not done. It is often reflected in statements preceded by the words "if only" or "what if."

# Techniques to Experience Emotional Expression

- Creation of bereavement rituals
- Writing
- Art
- Movement
- Music
- Construction
- Guided imagery
- Story-telling

# Helpers Can

- Listen
- Be Empathic
- Normalize
- Acknowledge



# **Resolving Traumatic Grief**

- Support the use of cultural customs and rituals that help individuals control their emotions
- Customs and rituals help grievers order their behavior, link the griever to social groups and serve as symbols of continuity
- If a culture loses important aspects of its ability to function and cannot guide grief reactions, individuals are left unprotected and on their own

#### Interventions for Social Isolation and Loneliness

- Research suggests that creating opportunities for social interaction, such as attending social programs, telephone interventions, may help to reduce social isolation
- For loneliness, interventions that focused on changing people's maladaptive perceptions were more effective than all other types of interventions

# Summary

- Survivors can benefit from personal storytelling
- Storytelling invests our lives with more meaning
- It connects us more vitally with others
- It develops our creativity
- It strengthens our humor
- It increases our courage and confidence
- It renders our lives more manageable

#### Grief According to Anne Lamott

• "But what if the great secret insider-trading truth is that you don't ever get over the biggest losses in your life? Is that good news, bad news or both? The good news is that if you don't seal up your heart with caulking compound, and instead stay permeable, people stay alive inside you, and maybe outside you, too, forever. This is also the bad news, not because your heart will continue to hurt forever, but because grief is so frowned upon, so hard for even intimate bystanders to witness, that you will think you must be crazy for not getting over it."

Arbore, P., Katz, R., & Johnson, T.A. (2016). Suffering and the caring professional. In Katz & Johnson (ed) <u>When</u> professionals weep, 2<sup>nd</sup> ed.

Bruce, M.L. (2002). Psychosocial risk factors for depressive disorders in late life. <u>Society of biological psychiatry</u> 52, 175-184.

Conwell, Y, Duberstein, P.R. & Caine, E.D. (2002). Risk factors for suicide in later life. <u>Society of biological</u> <u>psychiatry</u> 52, 193-204.

Dalenberg, C.J. (2000). <u>Countertransference and the</u> <u>treatment of trauma.</u>

Drapkin, M.L., Yusko, D., Yasinski, C, Oslin, D, Hembree, E.A., & Foa, E.B. (2011), Baseline functioning among individuals with posttraumatic stress disorder and alcohol dependence. Journal of substance abuse treatment, 41, 186-192.

Kauffman, J. (2010). On the primacy of shame. In Kauffman (ed) <u>The shame of death, grief, and trauma,</u> 3-24.

Roy, A. (2010). Combination of family history of suicidal behavior and childhood trauma may represent correlate of increased suicide risk. Journal of affective disorders, 130, 205-208.

Thompson, S.C., & Kyle, D.J. (2000). The role of perceived control in coping with the losses associated with chronic illness. In Harvey and Miller Loss and trauma: General and close relationship perspectives, 131-145.

Real, T. (1997). I don't want to talk about it: Overcoming the secret legacy of male depression.

Gawande, A. (2014). Being Mortal.

Didion, J. (2005). <u>The year of magical thinking</u>. Didion, J. (2011). Blue nights.

Van der Kolk, B.A., McFarlane, A.C. & Weisaeth, L. (eds) <u>Traumatic stress: The effects of</u> <u>overwhelming experience on mind, body, and</u> <u>spirit.</u>

Yalom, I. (2008). <u>Staring at the sun: Overcoming</u> the terror of death.