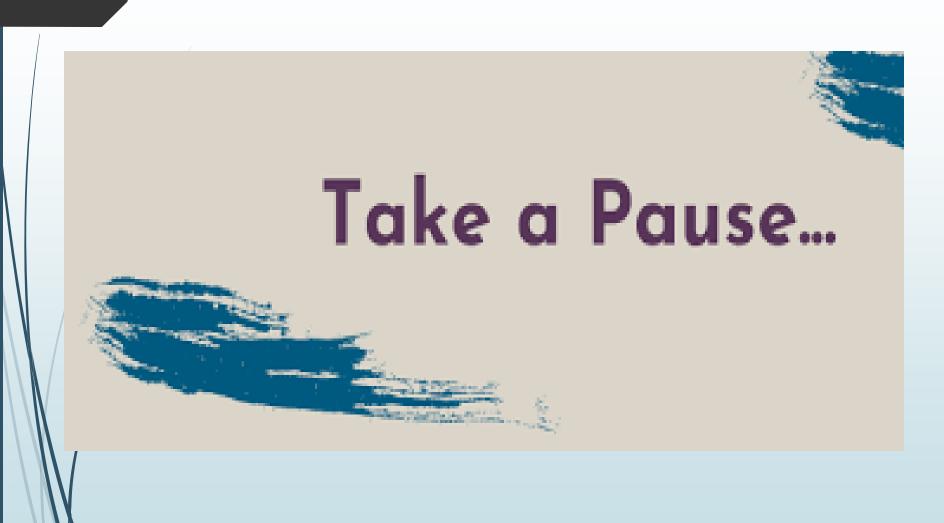
Twin Cities Je wish Community Mental Health Education Conference

Caregiving: Fostering A Circle of Caring

Ted Bowman – Grief Educator

tedbowman71@gmail.com

www.bowmanted.com





The Guest House

This being human is a guesthouse. Every morning is new arrival.

A joy, a depression, a meanness, some momentary awareness comes as an unexpected visitor.

Welcome and entertain them all!

Beginning lines of a poem by Rumi



Is A Time When Predictability Breaks Down

Our Predictable Ways
Of Thinking About And Doing Things
Are Interrupted By Change

Change Results

In Uncertainty

Five Principles

- If Something Is Unmentionable, It Is Also Unmanageable
- Not Everything That Is Faced Can Be Changed, But Nothing Can Be Changed Until It Is Faced
 - Understanding is more Important than Agreement
- The Direction in which you Look will Determine what you See
- HOW things are Handled is often as or more important than WHAT Happens

Losses and the Resulting Grief

LOSS refers to being deprived of or ceasing to have something that one formerly possessed or to which one was attached

LOSS can and does disrupt past, present and future stories

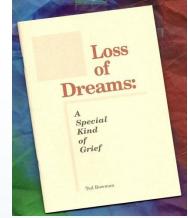
Grief is a whole body response to losses: emotional, cognitive, spiritual, and physical

Examples of Shattered Dreams and Elders

- the dream of aging, of retirement, of caring
- the dream about how or where a home
 "should be"
- the dream of time for self (autonomy/control)
- the dream of being or seen as competent
- the dream that the family relationship could withstand any stress or challenge
- the American dream of "social security"
- the dream that plans would be sufficient
- the dream of dying and death



Inquiries about Shattered Dreams



- When you pictured this time in your life, what did you picture?
- When you thought about being _____, what did you picture?
- If and when you thought of losses in your family, how did you think it would be, how would it happen?
- Tell me about the plans you and (the name of the person had?

Caregivers

There are only four kinds of people in the world:

Those who have been caregivers

Those who are currently caregivers

Those who will be caregivers and
those who need a caregiver

Rosalynn Carter

You ARE a caregiver...currently and in the future

You deserve and will continue to need a caregiver (s)

Ted Bowman



4 Phases and 4 Requirements

Caring About

Attentiveness

Taking Care Of

Responsibility

Care-giving

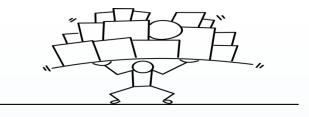
Competence

Receiving Care

Responsiveness

Joan Tronto – Who Cares?

Further Assertions



Caregiving is about skilled nursing, competent social work, rehabilitation efforts of physical and occupational therapists, and the hard physical work of home healthcare aides.

Yet, for all the efforts of the helping professions, caregiving is for the most part the preserve of families and intimate friends, and of the afflicted person herself or himself. They struggle to undertake the material acts that sustain the household, find practical assistance with activities of daily living, address financial aid, legal and religious tasks, emotional support, meaning making and remaking, and moral solidarity.

from Arthur Kleinman, adapted by Ted Bowman

Self Awareness - Families

The expectation that a family can live with a chronic condition and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.

The expectation that we can leave stresses in our personal, school and work lives and not bring them to other parts is also unrealistic.

The way we deal with distress and loss shapes our capacity to be present to life more than anything else.

The Almost Widow / The Gagging Daughter

I have read in a number of places that a woman married to a man with Alzheimer's is living a widow's life.

By the time I realized I had settled into the role of spousal caregiver, my role had changed to include the experience of mourning the relationship that, for better or worse, had been.

When I leave my home, grief is my escort.

EstherAltshul Helfgott

Handling Mother's body violated her and me. Carrying her bedside commode from her bedroom to the toilet...disgusted me. I would gag and that would never stop.

Lynne Tillman

Creative Care



Creative care is a reciprocal model. Each of the care partners is imagined to receive benefit; care is an exchange. Creative care is an agreement between people to imagine themselves, each other and their worlds a little differently.

A personal example, a threshold moment, while washing dishes together, her mother asked where a bowl went after drying ... a bowl whose place had been the same for years. Rather than respond with surprise or "don't you know!", even a scolding tone...a new choice can be something like "oh, let's look around and find it's home."

Basting suggests that too many exchanges with persons who live with dementia are factual, right or wrong, exasperation about memory loss, ... not choices using creativity with words and phrases that are respectful for all involved (2020).

Assumptive World

All of us from the moment of our birth, have been building inside ourselves a model of the world, a set of assumptions on the basis of which we recognize the world that we meet and plan our behaviour accordingly. Because this model is based on reality it is, most of the time, a valid and useful basis for thought and behaviour. We rely on the accuracy of these assumptions to maintain our orientation in the world and to control our lives.

Anything which challenges this model incapacitates us.



Ambiguous loss occurs when there are...

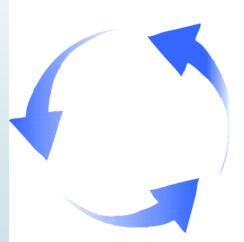
Unanswered questions, uncertainty and the disruption of family and work life due to Covid19 (and many other local, national, and world events)

"What is distressing us is not just the virus, but the ambiguity surrounding it, what it will do, and what we should do about it. Science provides some answers, but we are experiencing uncertainty, and that's very stressful for a society that is accustomed to solving problems and having definitive answers."

Therefore:

Families will routinely experience distress as they face caregiving matters. That can lead to:

ambivalence faith crises
ambiguity perspective
regret guilt
flashbacks/historycontext
second guessing conflicts
the need for an internal compass



Responses to Ambiguity

- Label what people are experiencing (responses will vary)
- Provide a structure and setting for contact
- Provide information
- Increase tolerance for ambiguity
- **▶** Be flexible, adapt routines, minimize helplessness, normalize situation
- Emphasize what can be changed or addressed and what can not...
- Move from "either/or" choices to "both/and choices"



SHRINKING GRIEF

GROWING YOUR WORLD



Storying And Re-storying
After Loss or Disruptive Change
Involves Grieving The Old Story

Before Creating The Next (Not Necessarily New) Story



Listen For

Major Components/Themes/Values
Of The Old Story

How Can They Be Reframed In The Next Story

Responses To Stresses/Losses

Name Losses

Address Stressors/Grieve Losses

Put The Loss In Perspective

Reinforce Or Build Support Connections (Support Groups, Teams, Informal Support)

Set Limits
(Saying No To Some Things So That You Can Yes To Others)

Develop A Healing Plan

Appreciative Inquiry

Examples of Resiliency

- Accepted What They Could Not Change, Changed What They Could
- Manageable Pieces/Steps
- Realized: Bad Things Happen To Good People
- Used Creativity
- Healed Themselves By Helping Others
- Did Not Allow Bitterness To Consume / Define Them
- Hopeful Visions Of Future
- Drew On Spiritual Resources

Assertion: It Takes a Team



Wisdom From Caregivers – March 2022 What do you know now, you wish you had known?

Get information about caregiving from various sources Few things will stay the same, be prepared for changes Support for caregivers is crucial

When attending a group or reading, make note of "take-aways"

Ask for help Accept help Know the difference Create a list of "help" you can pass on to friends, family, neighbors

Form a "team"

Don't be too hard on yourself

Group members often share what seems mundane, but which may be amazingly helpful to another caregiver

Hope



Definitions usually include: **EXPECTATION**

DESIRE

Which can involve GOALS, ATTRIBUTES, REDEFINITION, MEANING, PEACE, ENERGY

Reasonable Hope

Reasonable hope is relational

Reasonable hope is a practice

Reasonable hope maintains that the future is open, uncertain, and influenceable

Reasonable hope seeks goals and pathways to them

Reasonable hope accommodates doubt, contradictions, and despair Weingarten

GROUP DISCUSSION

