SPRINKLING SPIRITUALITY

THROUGHOUT THE ALZHEIMER’S CAREGIVER’S JOURNEY

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Sprinkling Spirituality

Throughout The Alzheimer’s Caregiver’s Journey

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Learning Objectives

Participants will be able to:

• Identify three dynamics of the anticipatory grief process as it relates to the caregiver role

• Explore & identify with an Alzheimer’s caregiver’s journey & understand the many challenges & burdens of this disease

• Discuss the importance of providing a venue for caregivers to share their spiritual experiences
“SURVIVING TODAY—AN ANCHOR FOR CAREGIVERS”

*ANTICIPATORY GRIEF WHEEL

LIFE FUNCTION  →  SHOCK  →  SUSPENSE  →  SURRENDER  →  SHATTERED  →  STRAIN

*Adapted from Donna O’Toole’s “Grief Wheel” (1982) by Sally Moore, MSW
Isomorphic Model

Social Worker & Caregiver

Caregiver & Loved One
Step into their Shoes

• Caregiver had to change because the disease process makes it impossible for loved one to change

• Social Worker has to change because the caregiver’s burden makes it impossible for caregiver to change
Professional Relationship
Meet the caregiver where he is
See her as she sees herself
Stay with the caregiver
Encourage him to tell his story
Validate her feelings
Respect his viewpoint
Silence is golden
Be empathic
Don’t be shocked by what he says about his loved one’s “shameful” behavior
Be flexible
Admit that you don’t know all the answers
Empower the caregiver
SMILE

SMILE

SMILE
Selections from “One Word, An Alzheimer’s Caregiver’s Journal” by sally moore
How often can my heart break in the course of a day?

So many bittersweet moments tearing me apart.

Why try to keep the tears from falling. He doesn't even see them.
Since it has to be one of us, I wish it could be me.

I don't want to see his torment, I wish it would be me.

I'm no good in a crisis, it should have been me.
I've dreamt of growing old, of sharing the twilight years with him.

Oh, the places we'd go, the friends we'd visit NO MORE.

Oh, the things we'd do, the fun we'd share NO MORE.
Today he took me in his arms, he held me tight.

He told me that he loved me; he kissed me.

I won’t think about tomorrow, will he remember who I am?
Have you seen him? Did he come this way?
Did he stop and chat, or wave as he walked on?
I wish he hadn’t gone alone, if only he would take me too.
He just doesn’t seem to understand, it’s lonely here without him.
Spirituality

“is the devotion to the immaterial part of humanity and nature rather than worldly things such as possessions”

Spirituality

“the human sense of and search for transcendence, meaning, and connectedness beyond the self”

Grief and Spirituality

“The worry and sadness that death was closer was always before me. Because I lived with death every day, I was no longer fearful of it. Death is a part of living. I realized that one moment could last a lifetime.”
Grief and Spirituality

“My faith never waned; it gave me the courage to accept the impending death of first my mother and then my husband.”
Spiritual Beliefs

Important in meeting daily challenges by:
– Nurturing
– Assisting
– Strengthening

Relied on to get them through the day
– Guidance
– Support
– Comfort
Transcendent Properties

Live in the moment
Face death on a daily basis
Personal relationship with God
Limitless compassion
Abiding gratitude
When all else failed, faith remained
Anticipatory Grief

Complex & multidimensional experience:

“phenomenon encompassing the process of:
mourning,
coping,
interaction,
planning, &
psychosocial reorganization”
“that are stimulated & begun in part in response to

the awareness of the impending death of a loved one

& the recognition of associated losses in the past, present, & future.”

“Loss & Anticipatory Grief” Rando, 1986
Caregivers to Professionals

• Need to hear the voice of the caregiver

• Listen with ears, eyes & heart

• Respect the caregiver’s expertise – she lives with the disease

• Include in the decision-making process
• Flexible & open to unpredictable situation & behaviors

• Meet caregiver where she is NOW

• Validate caregiver's role as part of the process
• Devise creative, concrete & flexible interventions

• Adjust to dynamic nature of caregiving role & stages

• Don’t ignore/overlook caregiver’s pain
• Talk to caregiver about her fears & feelings

• No platitudes (don’t sweat the small stuff)

• Comfortable with talking about spirituality

• Initiate the conversation about faith, etc.
• Caregivers don’t willingly adopt advice & instructions from SW with 2nd-hand acquaintance with AD, its progress & loved one’s behavior patterns

• Partner with caregiver to better meet her needs & those of the loved one
Format for Support Group

• Our group – Our time

• We want to talk

• Want to listen to other caregivers & their daily struggles

• We’re here to support one another
• Don’t want to listen to latest medical & research findings about AD

• Hand us the information & we’ll read it at home

• Listen to what we’re SAYING, not what you think we NEED
Caregivers

Thankful for opportunity to openly discuss spiritual beliefs & practices

Welcomed sharing inmost thoughts about God

Experienced catharsis after telling story

Gained perspective on past & future
Approaching Spirituality

Initiate conversation – Just ASK
Be open to her personal spiritual beliefs
Encourage professed religious beliefs of caregiver
Be non-intrusive
Let the caregiver pray, if wishes
Explore past solutions to the problem
Validate feelings
Stay in the “NOW”
Use concrete words
Avoid platitudes: “Don’t sweat the small stuff”
Empower
Selections from
“One Word, An Alzheimer’s Caregiver’s Journal”
by sally moore
I have no regrets, Well, maybe just one.

That I can’t tell him of...

The happiness he brings to me.

The joy of being with him.

The love we still share.
Will you stay a little longer? Must you go away?

We've hardly been together. Why must we be apart?

Can't you stay the night? Will you come again tomorrow?
There's so much yet to say - we've haven't shared enough.

Why must you slip away? Why must I stay behind?

I want him to know that I still love him.

I want him to know that I'll always care.
He's still my love, my knight in shining armor.

He's still my companion, we share each day and night.

He's still my life, I couldn't live without him.
Slowly the mists began to clear and sunshine pierced my heart.

I fell in love with him all over again.

Although his mind will fade and sink into darkness,

my love for him will light his way.
The days are filled with wonder. The nights are wrapped in love.

Each memory he loses is captured in my heart.

“I had to start living my life as a Catholic and trust God. It was a leap of faith; I put my trust in God regarding Alzheimer's. I had to give the outcome to God. I had to let it go. I no longer worried. I started to enjoy every single moment with my mother and my husband. I had a blast.”