



North American Association of Christians in Social Work
A Vital Christian Presence in Social Work

PO Box 121
Botsford, CT 06404
www.nacsw.org
888.426.4712

SPRINKLING SPIRITUALITY
THROUGHOUT THE ALZHEIMER'S CAREGIVER'S JOURNEY

By: Sally Moore

Presented at:
NACSW Convention 2013
October, 2013
Atlanta, GA

Sprinkling Spirituality

Throughout The Alzheimer's Caregiver's Journey

Written By:

Sally Moore, Alzheimer's Caregiver, MSW, LCSW

Written: 5/07 Revised: 2/12

Learning Objectives

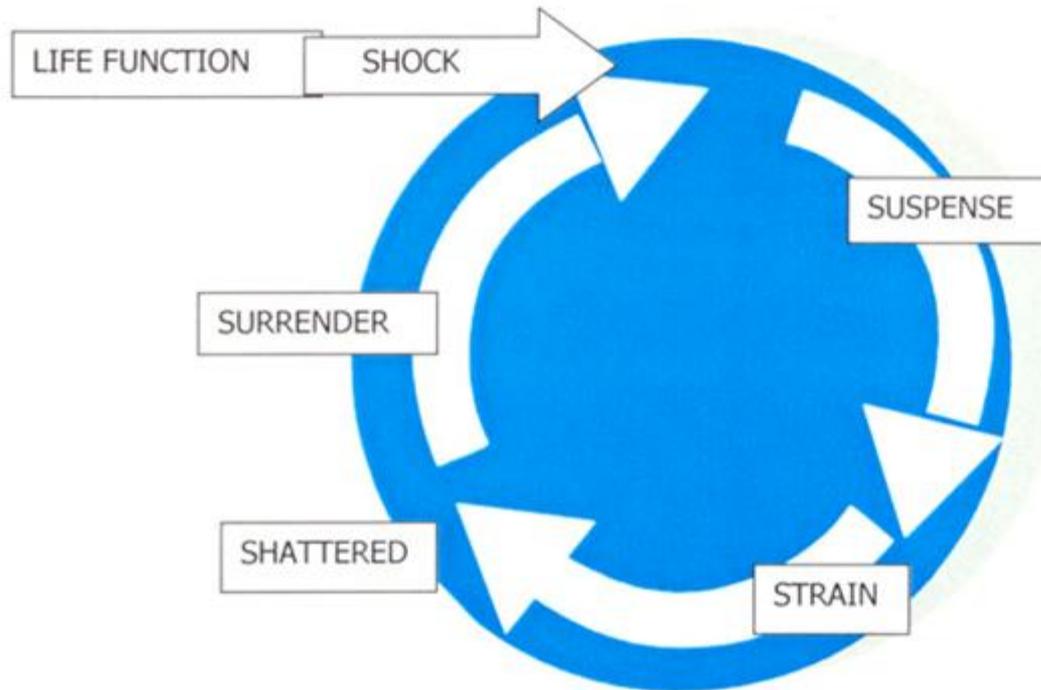
Participants will be able to:

- 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

Anticipatory Grief Wheel

“SURVIVING TODAY-AN ANCHOR FOR CAREGIVERS”

*ANTICIPATORY GRIEF WHEEL



*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”

(Barker, R.L. (1999) The social work dictionary (4th ed.)

Spirituality

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

Shewood, D.A., (1998). Spiritual assessment as a normal part of social work practice: Power to help and power to harm. Social Work & Christianity, 25 (2).

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."