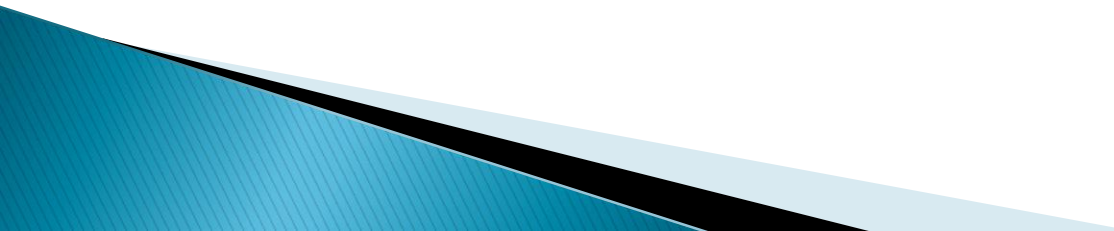


Caring for the Spirit of Persons Living with Dementia and their Care Partners

Rev. Candace McKibben,
Director of Faith Outreach, Big Bend Hospice
Care Partner for Mother

Objectives

- ▶ Define spirituality and explore the implications of memory loss to who we are as persons
 - ▶ Consider ways our understanding of dementia impacts our own spirit and that of those living with dementia
 - ▶ Hear and watch ways we can nurture the spirit of those living with middle stage dementia
 - ▶ Develop a care plan for the spirit of the person living with dementia and the care partner
- 

George Clooney John Turturro Tim Blake Nelson with John Goodman

O Brother, Where Art Thou?

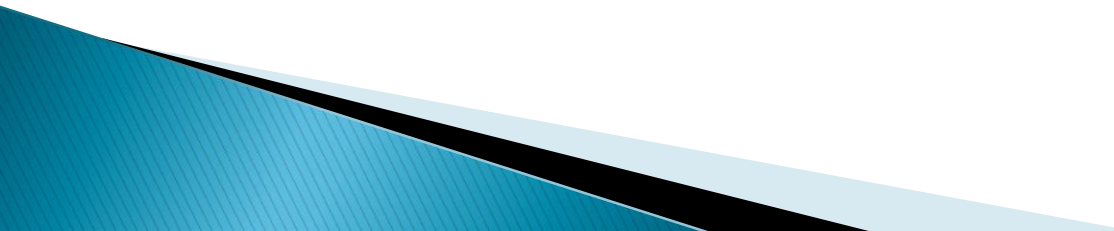
From the makers of
'The Big Lebowski' & 'Fargo'

They have a plan...
but not a clue



*“What we’ve got here is a spiritual gamut.
My friends Pete and Delmar just gave their
souls to the Lord Jesus Christ and
you’ve sold your soul to the devil.
I reckon I’m the only one
not yet affiliated.”*

We want to respect wherever someone is on
their spiritual journey.



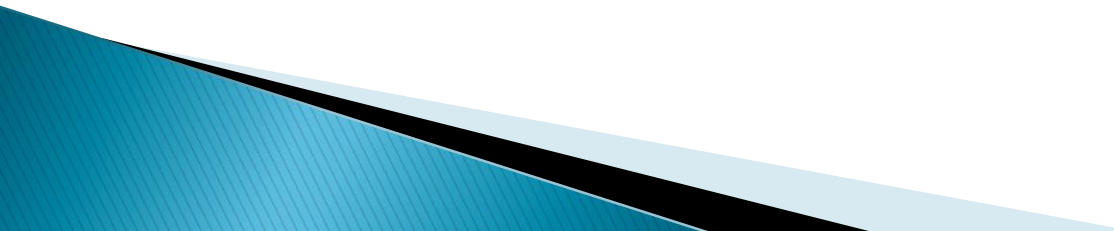
How do you define religion?



Defining Religion

Religion involves belief systems and worship practices. ~David Aldridge

A religion is a unified system of beliefs and practices relative to sacred things, that is to say, things set apart and forbidden—beliefs and practices which unite into one single moral community, all those who adhere to them.” ~Emile Durkheim



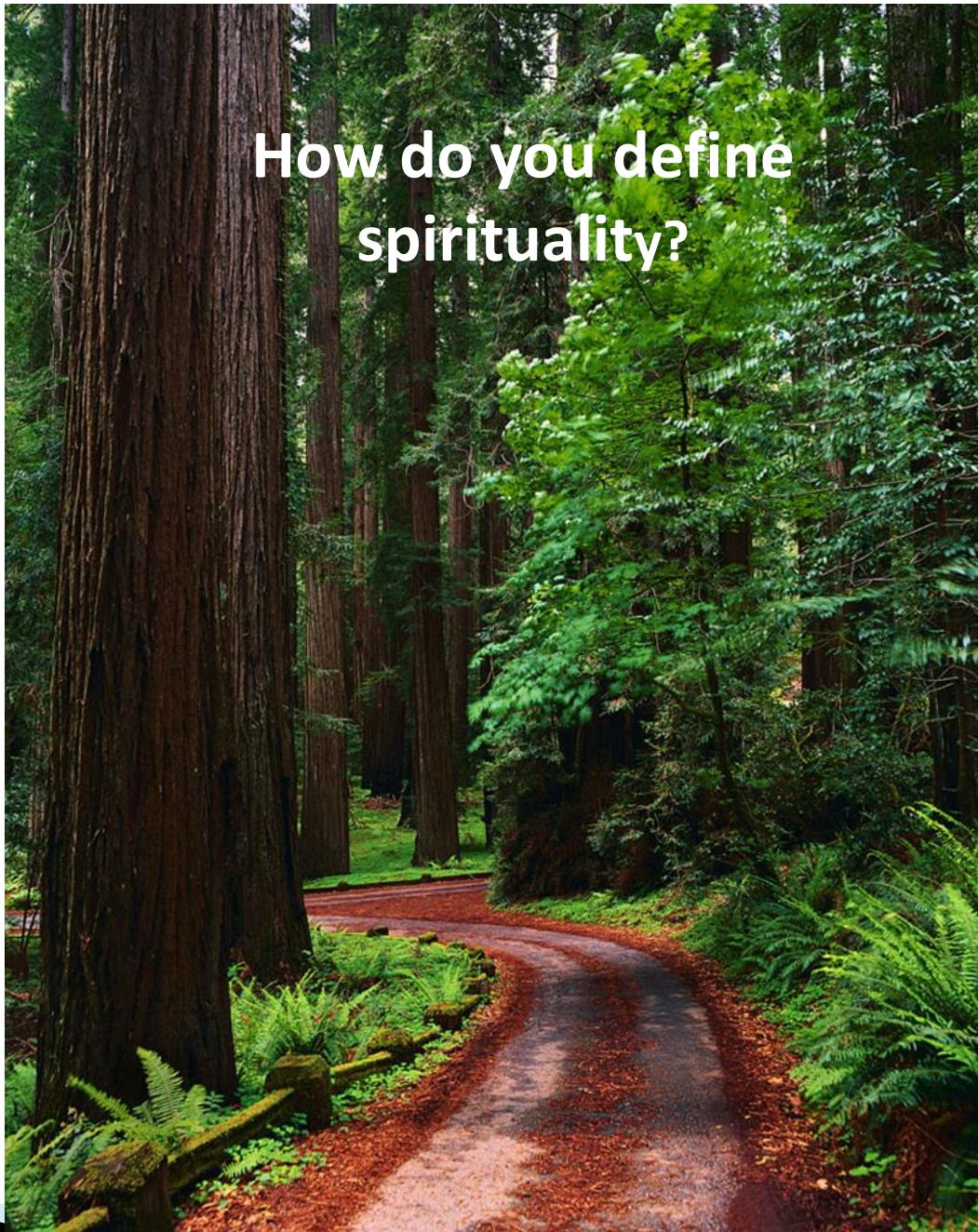
Defining Religion

“Religion’s task has always been and should continue to be “to help us live creatively, peacefully, and even joyously with realities for which there [are] no easy explanations and problems that we could not solve: morality, pain, grief, despair, and outrage at the injustice and cruelty of life.”

~Karen Armstrong



How do you define
spirituality?



Defining Spirituality

The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts.

~Association of American Medical Colleges



Defining Spirituality

Spirituality may be the name for a longing — for more meaning, more feeling, more connection, more life. It is the More to life than meets the eye that is found in nature, in love, in art and in grief. It is a deeper reality. It is experienced when we engage the most ordinary physical activities with the most exquisite attention we can give them.

~Barbara Brown Taylor

Defining Spirituality

The Latin word “spiritus” originally meant breath and breath is what you have when you are alive and don’t have when you’re dead. Thus spirit = breath = life, the aliveness and power of your life, and to speak of your spirit is to speak of the power of life that is in you. To speak of spirituality is to speak of the power of life that is in the world.

~ Frederick Buechner



Defining Spirituality

Spirituality is that which connects us to something beyond ourselves and to that which is truest about ourselves.

~Candace McKibben




Comparing Religion and Spirituality

Religion codifies, brings structure to spirituality.

Religion is a specific system for dealing with ultimate reality and for deciding what matters most.

Spirituality is a burning, a longing, that moves us beyond ourselves to experience transcendent meaning in life. That movement may be God, but it may be art or music or nature or family or community....whatever gives a person a sense of meaning or value.



Can you be religious and not be spiritual?



Can you be spiritual and not religious?



Is everyone spiritual?



Spirituality and Dementia

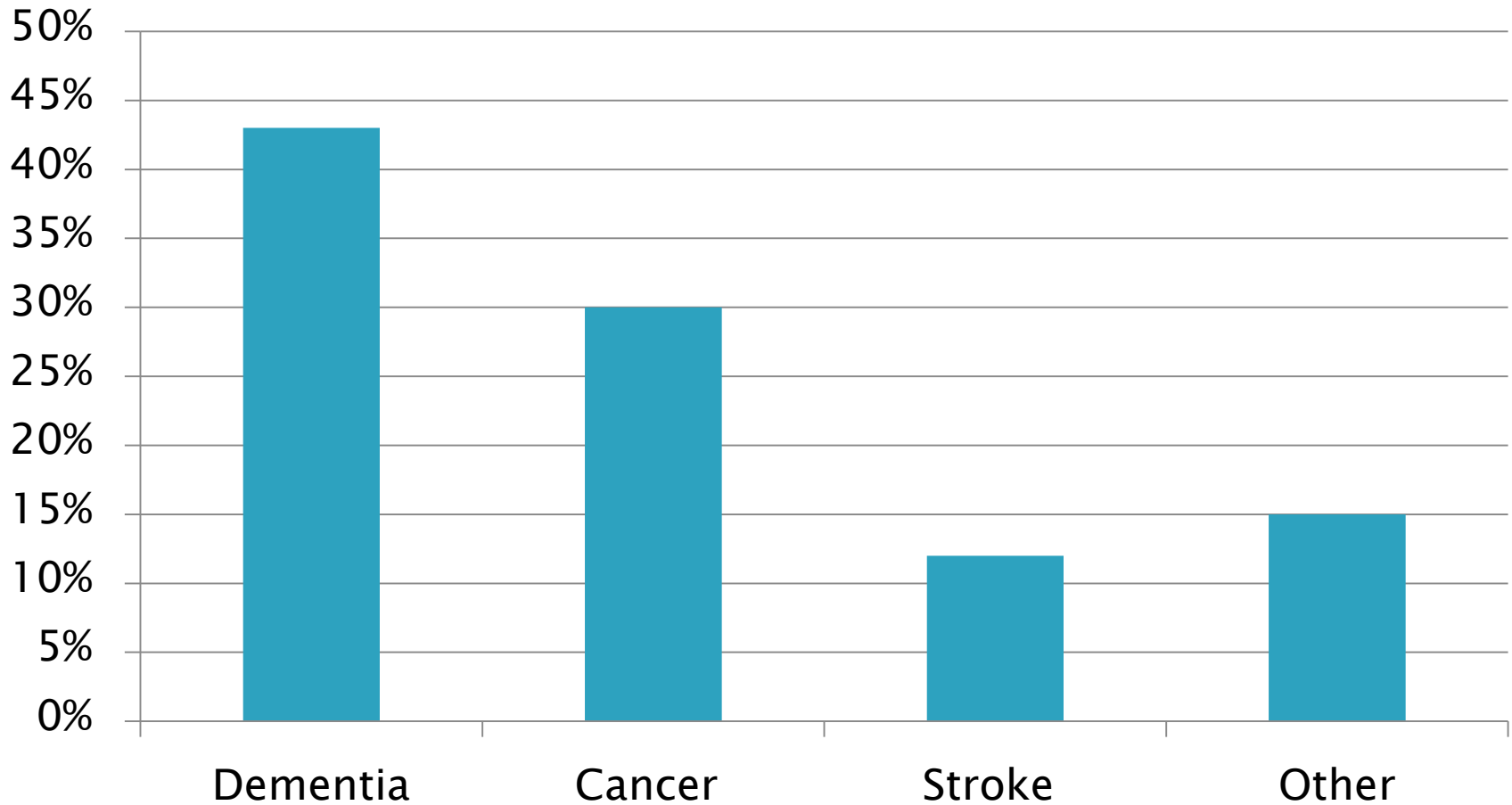
While cognitive functioning steadily declines during the disease trajectory of Alzheimer's and other related dementias, emotionally sensitivity remains functional and perhaps even enhanced.

“The ability to experience and maintain emotions, as well as to accurately perceive others' emotions, remains intact right up until nearly the end.”

Rev. Dr. Jade Angelica,

Where Two Worlds Touch

People over 50 fear dementia more than cancer




Hypercognitive Culture

The Moral Challenge of Alzheimer Disease by
Stephen Post, 1995

We live in a society that prizes intellect and reason above other values. The essence of who you are is what you think of who you are. If we are unable to reconstruct answers to those existential questions of:

Who am I? Where do I come from? Where am I going? **then the question becomes** are we lost to ourselves and lost to others?



What makes you a self?

Dr. Steven R. Sabat – Three-fold self
Rethinking dementia – don't lose self

Self is constructed by society

Experiencing self – you know you
are in the world

Social context – eye color, height,
where you were raised, social roles

Identity given by community – most
fragile dimension of who we are



How we frame dementia matters

- ▶ I think therefore I am – Western culture
- ▶ *Ubuntu* – I am because **we** are – South African culture

Not so much that persons with dementia **have** forgotten but they **are** forgotten.

Body memory still operative; music can be a bridge to memories that cannot connect otherwise; also to emotions that are still felt keenly in persons living with dementia.

John Swinton



Shift Cultural Thinking

Persons living with dementia belong to us.

People with dementia are rarely missed – or if missed, they are missed for who they used to be. How can we engage the person before us in new and fresh ways?

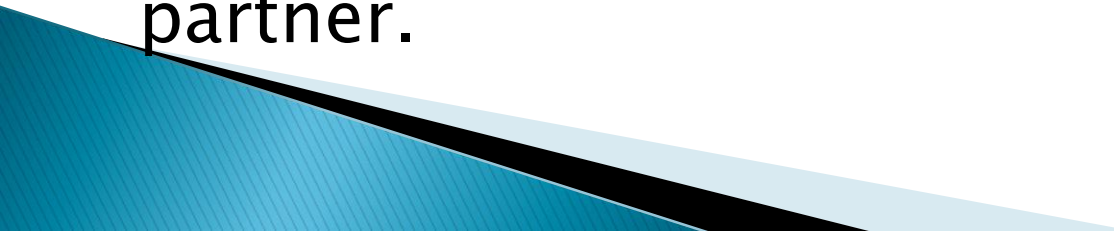
These people are people – new possibilities are before us.



Universal Spiritual Needs

- ▶ Purpose and meaning in life
- ▶ Connection to others – to belong – have respect and appreciation
- ▶ To love and to be loved
- ▶ Hopefulness, comfort, peace of mind
- ▶ Ability to contribute, to give back, to be useful and grateful
- ▶ Forgiveness and reconciliation

Dementia does not erase spiritual need – for the person living with dementia or their care partner.

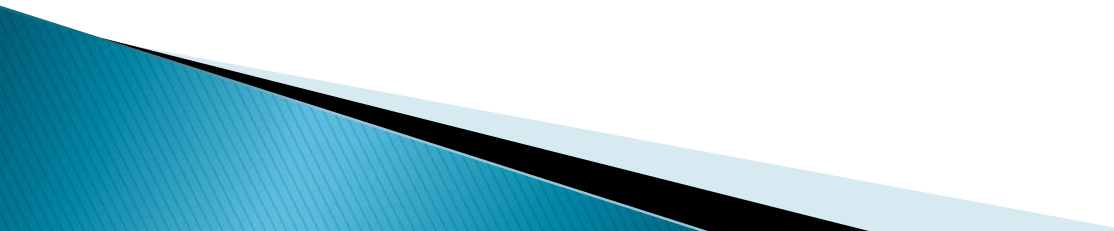


Connection Matters

“We need four hugs a day for survival. We need eight hugs a day for maintenance. We need twelve hugs a day for growth.”

Virginia Satir, Peoplemaking

In a Carnegie Mellon University Study in 2015 involving 404 adults, hugs were found to be important for stress reduction, illness prevention, and mental wellbeing. Persons living with dementia often receive no human touch at all except for hygiene or correction.



Spiritual Assessment

- ▶ What gives the person strength?
- ▶ What meaning did or does suffering have?
- ▶ What is the person's philosophy of life?
- ▶ Does faith help the person cope with illness, pain, change, loss?
- ▶ Are there any signs of spiritual distress – fear or sadness or concern?
- ▶ How are they coping with grief?

What reinforces spiritual wellbeing?

Religious icons

Holy books

Stained glass

Candles

Paraments

Beauty of nature or art

Drumming

Music

Singing

Reading familiar
passages

Spoken Prayer

Singing Bowl

Sights

Sounds

What reinforces spiritual wellbeing?

Common phrases

Peace be with you

Thanks be to God

Shalom

Namaste

I love you

God loves you

Familiar prayers

Familiar scripture

Family sayings

Prayer Shawl

Rosary

Hand held cross

Yarmulke

Turning pages in

hymnal, scripture,

devotional literature

Feeling grass on feet,

feather on cheek

Hugs, holding hands

Words

Touch

What reinforces spiritual wellbeing?

Bread

Wine

Passover meal elements

Dumplings

Comfort foods

Incense

Flowers

Rosemary

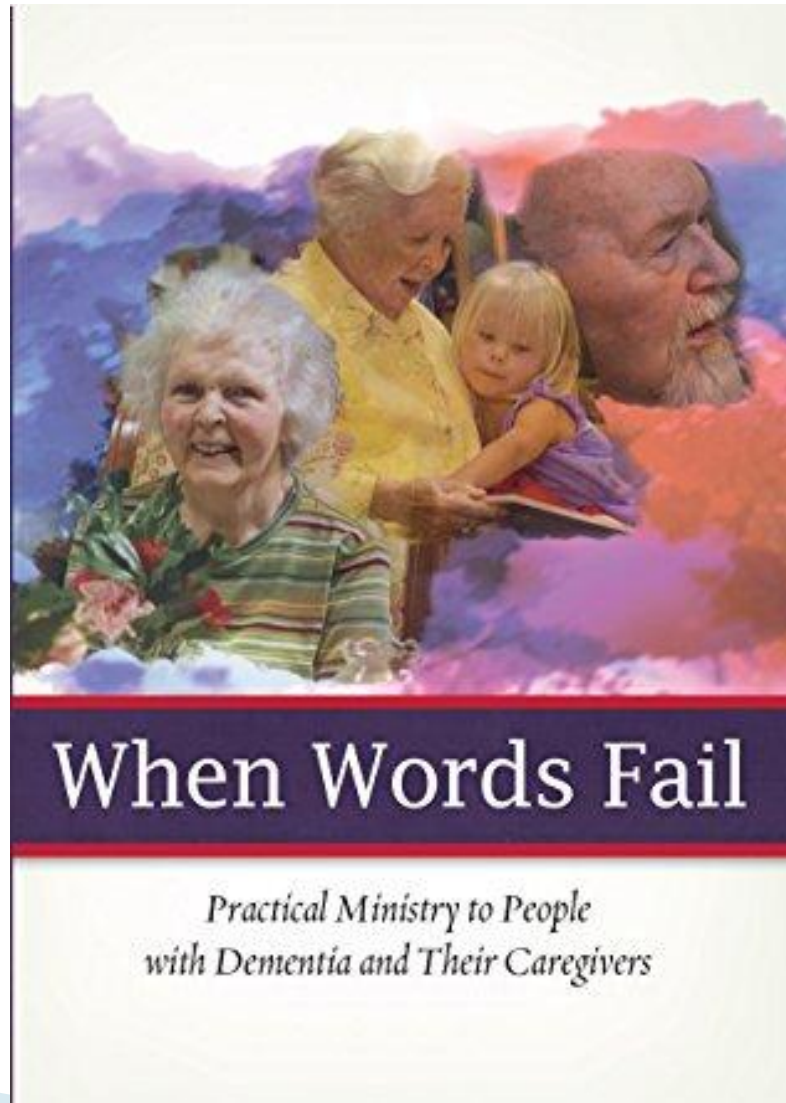
Sandalwood

Favorite food aromas

Tastes

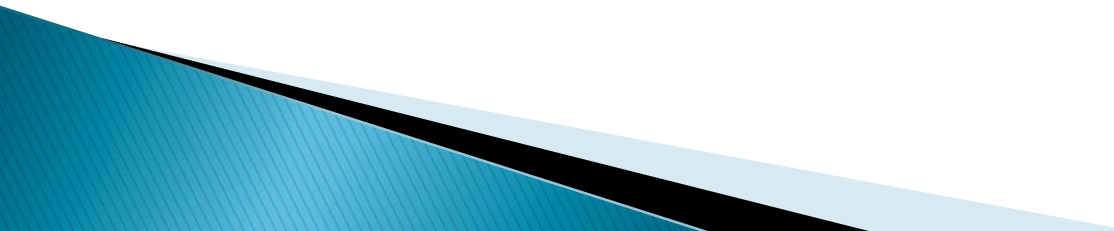
Smells

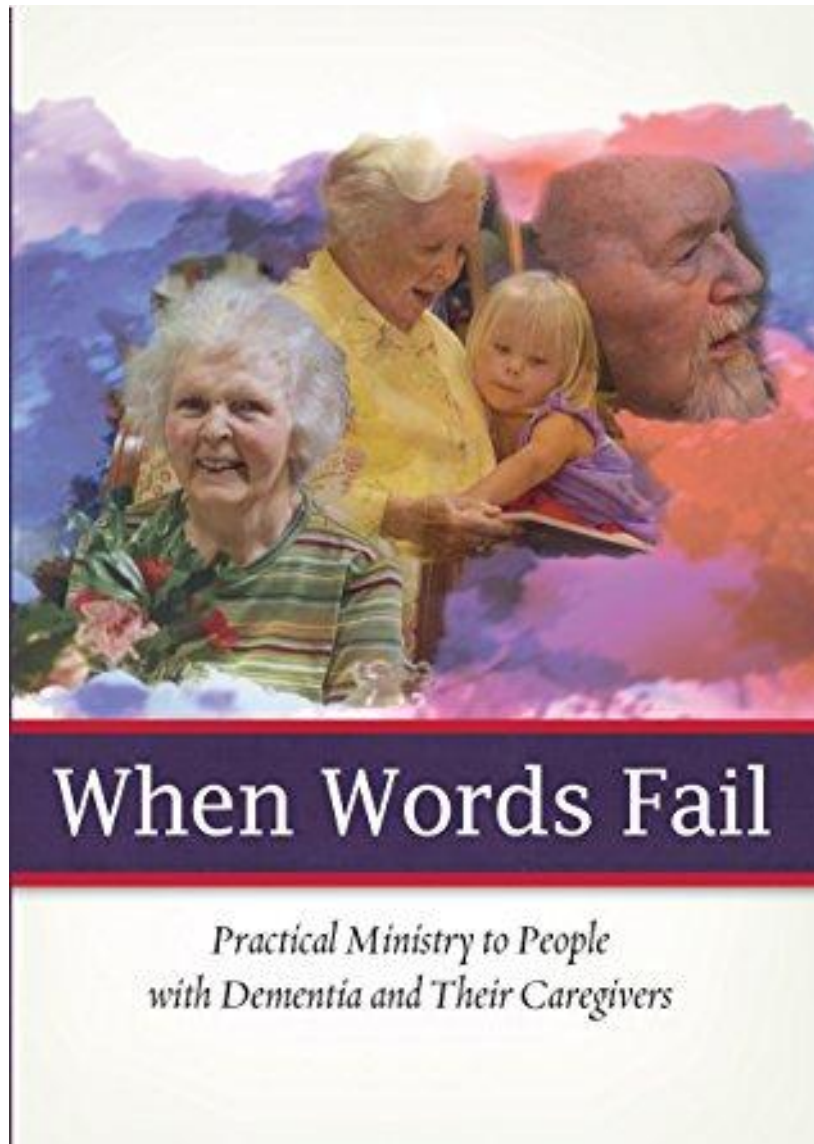
When Words Fail



When Words Fail

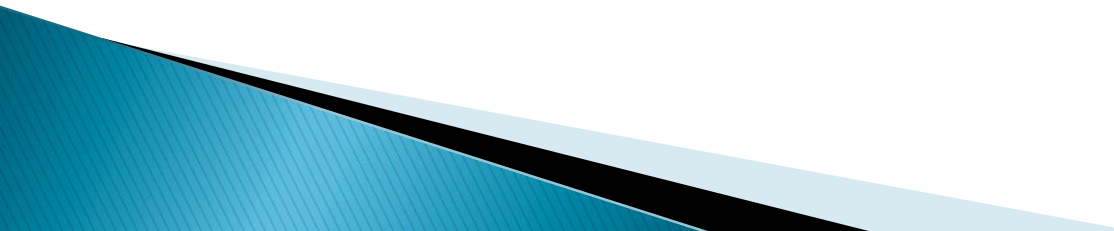
Summary of the Book

- ▶ Encouragement to connect
 - ▶ Overview of brain function and types of dementia
 - ▶ Early, middle and late stages characteristics and needs
 - ▶ Reminders of what to do and not do
 - ▶ Encouragement to connect
- 




► Middle Stage Visits

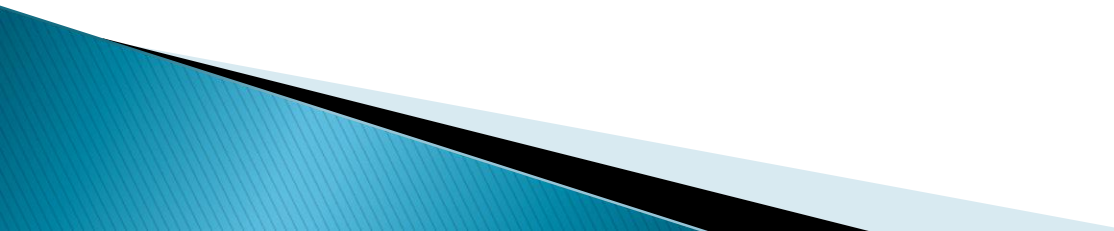
Inspired Caregiving

- ▶ Acceptance
 - ▶ Entering your loved one's reality
 - ▶ Validating his or her experience
 - ▶ Improvisational Techniques –
Make your partner look good
 - ▶ Accepting worth and dignity
- 

Inspired Caregiving

- Self-care– resting, eating well, exercising, sleeping
 - Enjoying nature, music, activities that are meaningful alone – and with your loved one
 - Keeping a journal or writing a blog
 - Letting others help
 - Letting go of guilt
- 

Inspired Caregiving

- ▶ Humor
 - ▶ Reframing the situation
 - ▶ Living in the moment
 - ▶ Doing something personal for your loved one
 - ▶ Keeping a grateful spirit
 - ▶ Celebrating strengths
- 

Care of your own spirit

Handouts:

Inspired Caregiving

Take a Daily Walk

Communicating with Persons with Limited
Capacity to Communicate Verbally

Psalm 139 for Caregivers

Support:

Care Team – We cannot/should not do this alone

Create your “to do” list and allow others to help

Read/attend Training – This conference; Dealing
with Dementia (RCI); Powerful Tools for Caregiving;
Online Support Groups; Alz. Project Support

Remembered Well

Assurance and love is what we offer as we create a community that embraces those living with dementia. We remind them they are not forgotten.

Spirituality is experienced when we engage the most ordinary physical activities with the most exquisite attention we can give them.

~Barbara Brown Taylor




Dementia and Caregiving

The elements of pain, tragedy, and affliction cannot be avoided or written out of the story of dementia and caregiving for those living with it. Healing begins with an honest acknowledgement of this truth. But the sadness of dementia must not be allowed to have the final word. As we create a sense of belonging to each other and to God, love continues in ever-evolving forms.

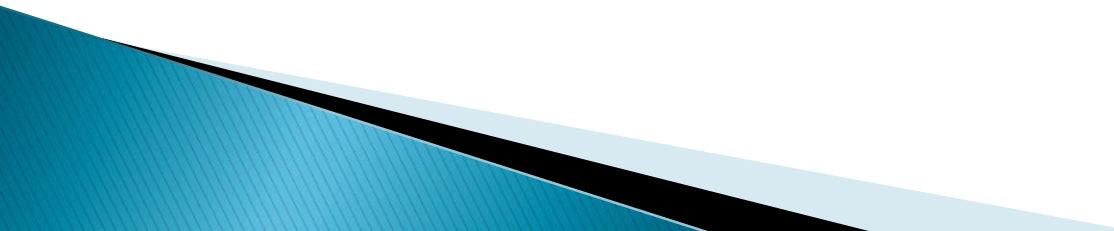
Adapted from John Swinton,

Dementia, Living in the Memories of God

Resources

- ▶ Stephen Post, The Moral Challenge of Alzheimer's Disease, 1995.
 - ▶ Rev. Dr. Jade Angelica, Where Two Worlds Touch, A Spiritual Journey through Alzheimer's Disease, 2014.
 - ▶ Steven R. Sabat, Alzheimer's Disease and Dementia: What Everyone Needs to Know, 2018.
 - ▶ John Swinton, Dementia: Living in the Memories of God, 2012.
 - ▶ Kathy Berry, When Words Fail: Practical Ministry to People Living with Dementia and Their Caregivers, 2016.
- 

Thank you

- ▶ For caring for your loved one
 - ▶ For caring for yourself
 - ▶ For caring about the wellbeing of those who are living with dementia
 - ▶ For being here today
- 

Rev. Candace McKibben, MDiv.
Director of Faith Outreach
Big Bend Hospice
candace@bigbendhospice.org
850-671-6029

