Dementia Care for Churches
How the Church Can Better Respond to Alzheimer’s and Other Dementias
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Dementia Care for Churches

Objectives & Overview of Webinar

1. Why The Church Should Re-invent it’s Response to those who have Alzheimer’s and other Dementias.

2. Foundational Knowledge of Cognitive Impairments for Church Leaders and Volunteers.

3. Opportunities for Ministering with Dementia Members of the Community and their Supporters.

4. Don’t Go it Alone...It Takes a Community.. Available Partnerships.

5. Conclusion, Proposals, Resources
Why The Church Should Re-invent its Response to those who have Alzheimer’s and other Dementias.
1. Expanding Prevalence of Alzheimer's

- An estimated 5.3 million Americans of all ages have Alzheimer's in 2015.
  - est. 5.1 people age 65 + & approx. 200,000 individuals are under age 65 (younger-onset).

- Two-thirds of Americans with Alzheimer's are women.
  - 3.2 million to 1.9 million. Women on average live longer than men.

- More non-Hispanic whites with Alzheimer's.
  - However African-Americans and Hispanics are more likely than whites to have Alzheimer's disease and other dementias.
Alzheimer's will continue to expand

• Alzheimer's will grow as size/proportion of population age 65+older increases.
  – 10 years from now 65+ with Alzheimer's is estimated to grow by 40% to 7.1 million
  – 25 years from now 65+ with Alzheimer's will triple, from 5.1 million to a projected 13.8 million

What’s the impact to your church?
• **Caregiver Impact:** friends and family provided an estimated 17.9 billion hours of unpaid care for those with dementia

  – Approximately two-thirds of caregivers are women and 34 percent are age 65 or older.
  – Over half of primary caregivers of people with dementia take care of parents.
  – Alzheimer's takes toll on caregivers. 60% of dementia caregivers report high stress, fatigue, 40% depression, and caregivers had $9.7 billion in additional health care costs of their own in 2014.
3. Prepare to respond to Alzheimer’s

✓ Clergy see increase in requests for support and visits.
✓ Church giving and attendance decrease as those with Dementia and their caregivers are unable to participate or be active in life of church.
✓ Both clergy and lay volunteers become more involved in support and care for caregivers
✓ Clergy are called upon for funeral or remembrance services, plus increased follow-up grief care and support.
✓ Increased risk in Loss of relationships and good leaders in service of the church
4. Training or Knowledge of Dementia Care

1. Knowledge of the common forms of dementia, symptoms, progression of illnesses.

2. Training in communication with Dementia patients, and how to proceed with their spiritual care.

3. Understanding of how to offer support to those who are Caregivers.

4. Look for opportunities for advocacy or research on behalf of those you serve.

5. Look for opportunities to experience with common pastoral issues in this area. Local partnerships.
5. Alzheimer’s is a topic of discussion and fear

1. After the *Glen Campbell Movie* and *Still Alice* which both drew attention to the illness, it is in the consciousness of many.

2. According to several surveys, Cognitive Impairment is the #1 fear among Baby Boomers.

3. Many adults are sandwiched between care of Older Adult Parents, some of which have dementias and children and are challenged on all sides to be able to remain a part of their support networks and communities like church.

How does your church respond to this?
It's the only cause of death in the top 10 in America that CANNOT BE PREVENTED, CURED OR SLOWED.

ALMOST TWO THIRDS of Americans with Alzheimer's disease are women.

1 IN 3 SENIORS dies with Alzheimer's or another dementia.

6 Alzheimer’s disease is the 6TH LEADING CAUSE OF DEATH IN THE UNITED STATES.

Only 45% of people with ALZHEIMER’S disease or their caregivers report BEING TOLD OF THEIR DIAGNOSIS.

More than 90% of people with the four most common types of CANCER have been TOLD OF THEIR DIAGNOSIS.

By 2050, these costs could rise as high as $1.1 TRILLION.

In 2015, Alzheimer’s and other dementias will cost the nation $226 BILLION.
Alzheimer's Disease Facts in Each State

The 2015 Alzheimer's Disease Facts and Figures report contains data on the impact of this disease in every state across the nation as well as other reports by state. You can locate this map at [http://www.alz.org/facts/](http://www.alz.org/facts/) at the Alzheimer’s Association Website. Just click on your state.
Audience Poll

Use the polling panel
Foundational Knowledge of Cognitive Impairments for Church Leaders and Volunteers.
Ten Most Common Dementia’s Besides Alzheimer’s

1. Vascular Dementia - Second most common form of dementia, vascular dementia is caused by poor blood flow to the brain, can result from any number of conditions which narrow the blood vessels, including stroke, diabetes and hypertension.

2. Mixed Dementia - Sometimes dementia is caused by more than one medical condition. The most common form is caused by both Alzheimer's and vascular disease.

3. Dementia with Lewy Bodies - Sometimes referred to as Lewy Body Syndrome is characterized by abnormal protein deposits called Lewy bodies on nerve cells in the brain stem which impaired cognition and behavior and can cause tremors.

4. Parkinson's Disease Dementia - Parkinson's disease is a chronic, progressive neurological condition, which in its advanced stages can affect cognitive functioning. Symptoms include tremors, muscle stiffness and speech problems. Reasoning, memory, speech, and judgment maybe affected.
Ten Most Common Dementia’s 
Besides Alzheimer’s

5. Frontotemporal Dementia Pick's disease is the most common form is a rare disorder which causes damage to brain cells in the frontal and temporal lobes. Pick's disease affects the individual's personality significantly, usually resulting in a decline in social skills, coupled with emotional apathy. Unlike other types of dementia results in behavior and personality changes manifesting before memory loss and speech problems.

6. Creutzfeldt-Jacob Dementia is a degenerative neurological disorder is very rare with no cure. Caused by viruses dementia due to CJD progresses rapidly, usually over a period of several months. Symptoms include memory loss, speech impairment, confusion, muscle stiffness and twitching, and general lack of coordination, making the individual susceptible to falls. Occasionally, blurred vision and hallucinations are also associated with the condition.

7. Normal Pressure Hydrocephalus (NPH) involves an accumulation of cerebrospinal fluid in the brain's cavities caused by impaired drainage resulting in pressure on brain, interfering with the brain function and develop problems with ambulation, balance and bladder.
Ten Most Common Dementia’s Besides Alzheimer's

8. Huntington's Disease - inherited progressive dementia affecting cognition, behavior and movement. With memory problems, impaired judgment, mood swings, depression and speech problems (especially slurred speech). Delusions and hallucinations may also occur.

9. Wernicke-Korsakoff Syndrome is caused by a deficiency in thiamine (Vitamin B1) and occurs in alcoholics, those with malnutrition, or spreading cancer, and long-term dialysis and diuretic therapy. The symptoms caused by it include confusion, permanent gaps in memory, and impaired short-term memory. Hallucinations may also occur.

10. Mild Cognitive Impairment (MCI) Dementia can be due to medical illness, medications and a host of other treatable causes. With mild cognitive impairment, an individual will experience memory loss, and sometimes impaired judgment and speech, but is usually aware of the decline. These problems usually don't interfere with the normal activities of daily living. Individuals with mild cognitive impairment may also experience behavioral changes that involve depression, anxiety, aggression and emotional apathy.
Common Alzheimer’s Progression

Alzheimer's disease progresses in three general stages.

Rate of progression varies:

- Brain changes begin years before any exhibition of symptoms. This period is referred to as preclinical Alzheimer's disease.
- May be difficult to place a person with Alzheimer's in a specific stage as stages may overlap.
- On average a person with Alzheimer's lives 4-8 years after diagnosis but can live as long as 20 years.

Mild
(early stage)

Moderate
(middle stage)

Severe
(late stage)
Early Stages of Alzheimer’s

1. A person still functions independently. They may still drive, work and be part of social activities. Despite this, the person may experience an awareness of memory lapses, such as forgetting familiar words or the location of everyday objects.

2. Friends, family or neighbors also notice difficulties.

3. Doctors may be able to detect problems in memory or concentration.

4. Common difficulties include:
   - Problems coming up with the right word or name
   - Trouble remembering names when introduced to new people
   - Having greater difficulty performing tasks in social or work settings
   - Forgetting material that one has just read
   - Losing or misplacing a valuable object
   - Increasing trouble with planning or organizing
Middle Stages of Alzheimer’s

1. Moderate Alzheimer's is longest stage and lasts for many years requiring more and more care.

2. Noticeable a person confuses words & then get frustrated or angry; they may act out in unexpected ways (e.g. refusing to bathe).

3. Damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks.

4. Common symptoms may include:
   - Forgetfulness of events or about one's own personal history
   - Feeling moody or withdrawn, especially in challenging situations
   - Confusion about where they are or what day it is
   - The need for help choosing proper clothing for the season or the occasion
   - Trouble controlling bladder and bowels in some individuals
   - Changes in sleep patterns, e.g. sleeping during the day and becoming restless at night
Late Stages of Alzheimer’s

1. Individuals lose the ability to respond to their environment, to carry on a conversation and control movement. They may still say words or phrases, but communicating pain becomes difficult.

2. As memory and cognitive skills continue to worsen, personality changes may take place and individuals need extensive help with daily activities.

Common Characteristics:

- Require full-time, around-the-clock assistance with daily personal care
- Lost awareness of recent experiences as well as of their surroundings
- Require high levels of assistance with daily activities and personal care
- Experience changes in abilities, including the ability to walk, sit and, swallow
- Become vulnerable to infections, especially pneumonia
Stages

- Early Stage
- Mid Stage
- Late Stage

Reaction

- Denial
- Confusion
- Illusionary

- Frustration,
  Helplessness,
  Escapist
  Response,
  False
  Acceptance

- Embarrassment
  Guilt,
  Fear

- Stress,
  Depression

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### Common Family Reactions - Early Stage

1. **Denial** - Refusal to accept diagnosis or notice warning signs.
2. **Confliction/Confusion** - Not sure how to respond so is uneven in their response feeling confused and conflicted.
3. **Callused Response** - Put a wall up against feeling a lot. May excise the loved one from their lives as a result and be unsympathetic.
4. **Hostile Response/Jealousy** - When focus is upon the person with Alzheimer’s other family members may feel ignored which can lead to jealousy and even hostility.
5. **Illusionary Response** - Looking for signs of disease reversal or believing the latest treatment protocol will result in a cure.
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<thead>
<tr>
<th>Common Family Reactions-Middle Stages</th>
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<tr>
<td>1. <strong>Embarrassment</strong> - Feelings of being ashamed; not wanting to be seen with person who has Alzheimer’s.</td>
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<td>2. <strong>Grief Response</strong> – Profound Sadness over the changes and typical grief patterns.</td>
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<td>3. <strong>Guilt Response</strong> -Feelings of unworthiness as caregiver, relative, or friend.</td>
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<td>4. <strong>Fear/Anxiety/Stressed</strong> including being easily irritated and annoyed, fearing they may have the illness as well.</td>
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<td>5. <strong>Depression</strong> - which is more profound than sadness and longer lasting.</td>
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### Common Family Reactions-Late Stages

1. **Frustration**-acted out not only with their loved one but toward everything being irritated. Expressed through hypercriticism.

2. **False Acceptance/Martyrdom**- Owning suffering and seeing this as a defining badge or identity.

3. **Helplessness** Wishing they could change things or regain power over the situation. Severe Regret is a part of this.

4. **Escapist Response**- Particularly through chemical assistance or any means possible. Wishing their loved was already gone is common.
Opportunities for Ministering with Dementia Members of the Community and their Supporters.
Reminder - Those who have Dementia are still have active Spirits and have spiritual needs like anyone else. Spiritual Care with those with Alzheimer’s is different because of communication limitations imposed by the illness but it can be vibrant and vital through worship, the arts and self expression, through pastoral conversations and visits.
Spiritual Care Opportunities

1. Worship-Special Worship Services for Families
2. Support Groups for Caregivers & Group Activities
3. Respite Care as an opportunity for Community
4. Spirituality Boxes, Ritual Celebrations-Holidays
5. Godly Play-Play is about Joy which is spiritual
6. Memory Cafes- With objects like photographs and other items design to evoke memory
7. Arts - Art and Music Therapy
Suggestions for Worship

1. People with dementia lose ability to follow text-based presentations including sermons.
   - Instead try short proclamations done by visual images (art), short stories, etc.

2. Abstract and complicated thought processes can break down with people with dementia.
   - Focus upon 1 repeated theme like grace, hope, gratitude, faithfulness of God, love, heaven, joy etc.

3. Often what people with dementia miss most about their own church worship is ritual.
   - Employed familiar ritual like Apostle’s Creed, Communion, Advent Lighting, Lord’s Prayer or create new ritual done consistently like always beginning with a handshake with each person or singing the same song in closing like Jesus Loves Me.

4. Music is single most crucial element of worship for it bypasses cognition & reach spiritual selves. Music connects us with community and family conveying comfort.
   - The music and hymns chosen for the service should be those that would have been sung and heard by participants when they were children or young adults so as to tap into implicit memory.

5. Often people with progressive dementia will become restless, anxious, or agitated.
   - Worship Services should be kept short to a limit of 30 minutes.
Suggestions for Worship

6. People with dementia as they lose their concept of time and space can not read or remember new details.
   • Use the familiar - Read scripture from King James or Old Revised Standard Version selection should focus on commonly loved scriptures.

7. Worship with people with dementia actually requires more planning, coordination, set-up, and follow-through so should never be attempted without assistance in all phases.
   • Try involving loved ones and caregivers in worship services

8. Sensory cues provided by religious objects and symbols are important, like candles, Communion sets, vestments, cross, banners, musical accompanists.
   • This cues participants to know where they are and stimulate retained behavioral abilities.

9. There may be a variety of functionality together so Interruptions and mistakes are common
   • Allow for these mistakes and interruptions and levels of functionality (e.g. discuss with relatives or caregivers swallowing abilities particularly in serving communion).

10. Communication with God doesn’t stop just because of inability to vocalize words.
    • The liberal use of prayer is a good way to focus worship.
Don’t Go it Alone... It Takes a Community. Available Partnerships:
Partnership with Others

Training & Support
- Alzheimer’s Association
- Alzheimer’s Society
- Caring.com
- National Council on Aging

Advocacy
- US Against Alzheimer’s
- Clergy Against Alzheimer’s
- DASN-
- Alzheimer Information Center
Conclusion, Proposals, Resources
**Video & Movies About Alzheimer’s**

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<th>Movies</th>
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<td>• Still Alice</td>
<td>• MESSAGE Communication in Dementia</td>
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<td>• The Notebook</td>
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<td>• Lovely Still</td>
<td>• Experience 12 Minutes In Dementia</td>
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<td>• Aurora Borealis</td>
<td>• TEDtalk What is Alzheimer's with Ivan Seah Yu Jun</td>
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<td>• Iris: A Memoir of Iris Murdock</td>
<td>• When love becomes an instinct</td>
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<tr>
<td>• A Song for Martin</td>
<td>• Meet Bob</td>
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<td>• Still Mine</td>
<td>• Do You Know Me Now</td>
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<tr>
<td>• Robot &amp; Frank</td>
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<tr>
<td>• I’ll Be Me</td>
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Book Resources

**Seasons of Caring**, The book is organized around themes and metaphors of seasonal transition, with each of the four seasons paralleling the various stages of life. The 141 entries open with quotes from scripture, sacred text or other inspirational text. The original writings by seventy-two authors representing a great diversity of spiritual traditions range from thoughtful meditations to poignant personal stories, moving poems and meaningful songs.

**Treasure for Alzheimer’s** – Reflecting on experiences with the art of Lester E. Potts, Jr., by Richard L. Morgan, PhD & Daniel C. Potts, MD, FAAN. The book contains a series of reflections on Dr. Morgan’s experiences using the artwork of Lester E. Potts, Jr. to connect with people who have Alzheimer’s disease or Dementias of other causes.
Book Resources

**No Act of Love is Ever Wasted**, Relying on their many years of experience in this area, Jane Thibault and Richard Morgan offer this book to provide a fresh, hopeful model of dealing with life and death in the realm of Alzheimer's and other forms of dementia. Caregivers have two basic needs: affirmation that caregiving is not in vain and reassurance that the lives of those for whom they care are not being lived in vain. Care receivers need more than medical attention; they need tender care, involvement in the community, and a sense of connection with a loving God.

**Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease**, Jade C. Angelica shares the wisdom and hope she gleaned from caring for her mother and from many years working closely with Alzheimer's patients and caregivers. Challenging the predominant belief that people with Alzheimer's no longer have purpose, potential, or the capacity for meaningful relationship, Where Two Worlds Touch is both a spiritual memoir and a pastoral guide for those who love someone with Alzheimer's.
Walking With Grace: Tools For Implementing And Launching A Congregational Respite Program, Robin Dill’s Walking with Grace is a manual that will aid churches and faith based communities in the process of starting a Congregational Respite Program. It is filled with time proven details, ideas and activities to ensure the success of their program. From the very beginning idea to the actual day to day running of a program, this manual will equip and inspire all who read it!

Sanctuary in the Midst of Alzheimer’s: A Ministry for Spousal Caregivers and Their Churches, Dr. Elizabeth Young’s manual shows that most churches are not that well-equipped to minister to those caring for a spouse with Alzheimer’s. Sanctuary in the Midst of Alzheimer’s is a resource for both spouses and their churches, encouraging congregations to walk in the shoes of a spousal caregiver while providing the opportunity for spouses to find meaning and a sense of peace in their role as a caregiver.
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Thank You