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Dementia
and Dignity

INDEPENDENT
Presbyterian Church

MEMPHIS, TENNESSEE

DEMENTIA AND DIGNITY

FOUNDATIONAL AFFIRMATIONS

1. God is loving
2. God is powerful
3. God is in control

WHAT DO WE NEED TO KNOW?

1. de- “lack of” + ment “mental capacity”

2. How common is it?

- a) In US ~ 6 Million
- b) At 65 ~ 5% and double every 7 years
- c) Age 90 ~ 50% some degree
- d) 1/3 of us will die with some degree of dementia

3. Healthy brains

- a) Healthy brain will begin to forget occasionally
 - i) Lapses (senior moments=old timer’s disease)
 - ii) Names and nouns.
 - iii) Still high level of function
- b) Areas of healthy brain function
 - i) Memory and learning
 - (1) Immediate, remembering next word in sentence, that we are eating and next thing to do
 - (2) Episodic certain things or episodes, like where we put our keys
 - (3) Short term—weeks—hard disk is full
 - (4) Long term—years
 - ii) Speech and language
 - iii) Intellect—including problem solving, judgment
 - (1) Insight into our inabilities
 - (2) Restraining bad behavior
 - iv) Muscle strength and coordination
 - v) Emotions and Personality
 - (1) Not only displaying emotions but remembering how we felt
 - (2) Emotional memories last longer

- (3) Feelings remain though facts are forgotten
 - (a) When I see someone with dementia well aware they won't remember anything I say
 - (b) They will remember the hug and that we laughed
- vi) Procedural—also longer lasting
 - (1) Playing piano
 - (2) Bridge—two patients
- vii) Visual/spatial—being able to picture objects and work with them in your mind; Rubic's cube
- viii) Executive function—the ability to plan and complete an activity

“I praise you, for I am fearfully and wonderfully made. Wonderful are your works; my soul knows it very well.” Psalm 139:14
- c) Minimal cognitive impairment (MCI)
 - i) Impairment in two areas of brain function
 - (1) Typically short-term memory and one other area, but still functional
 - ii) 12% per year progress to dementia
 - iii) Some will improve
- d) Dementia—progression of memory loss and problems in more areas of brain function
 - i) 3 stages
 - (1) Stage 1—impaired but living independently in community, 2-4 years from onset
 - (2) Stage 2—Increasingly dependent, 2-4 years
 - (3) Stage 3—totally dependent 1-2 years
 - ii) Function is slowly but progressively compromised

4. Kinds of dementia

- a) First, what it is not
 - i) It is not normal aging, it is a disease
 - ii) It is certainly not the individual trying to be difficult—it's the disease.
 - iii) Delirium (may be an early sign of dementia)
 - iv) Depression (though often coexistent)
- b) Alzheimer's ~70%
 - i) Specific disease pathology in the brain Amyloid plaques and tau tangles
 - ii) Damage starts years before any evidence
 - iii) Slowly causes nerve cell death
 - iv) Progressively unable to make the chemicals that carry signals from one nerve to the next
 - v) Typically starts with short-term memory and then slowly follows a very predictable pattern through the brain like a smoldering fire.
 - vi) Average life from diagnosis is about 7 years, range up to 20
 - vii) Life span getting longer but likely represent earlier diagnosis

- c) Early onset—different causes but same microscopic appearance and pattern of spread
 - i) Genetic autosomal dominant, 50% of victim's children will have it, but to variable degrees
 - ii) Typically starts < 50 years
 - iii) Shorter life expectancy
- d) Frontotemporal degeneration 10% incidence may be underestimated
 - i) Typically starts with one of two variants speech or judgment and personality, not memory loss
 - ii) Often lack of insight which in whatever form of dementia it is seen makes care much more challenging
- e) Lewy body—three characteristics 20%
 - i) Seen early in Parkinson's or even before symptoms of Parkinson's
 - ii) Hallucinations
 - iii) Lucent intervals
- f) Dementia of Parkinson's often late in the disease
- g) Vascular associated with many small strokes-commonly A Fib ~20%
 - i) More step wise progression
 - ii) Less predictable course.
- h) Normal pressure hydrocephalus
 - i) Dementia
 - ii) Ataxia (gait disturbance)
 - iii) Urinary incontinence
- i) Mixed types about 40% Alzheimer's, Lewy body, and Vascular

5. Diagnosis

- a) How to diagnose—often not very difficult once it comes to attention—often blurred by denial
 - i) Careful history and physical
 - ii) Often some “mini IQ” test
 - iii) Rule out correctable causes that can mimic, blood work including thyroid and Vitamin B12, electrocardiogram, and frequently an MRI or CT
- b) When to diagnosis
 - i) As a general rule, the earlier the better
 - (1) When it is clear that both patients and family are concerned, patient knows there is a problem and wants an answer
 - (2) Though our meds are not great, they seem to help the most if started early
 - ii) Challenge when family is frustrated and needs to know, but diagnosis can be destructive for the patient, destroying all will to keep on going
 - (1) Here it is best to know the patient well
 - (2) Typically, will discuss their memory problem or even dementia often, avoid Alzheimer's

6. Things to be done soon after the diagnosis

- a) Learn as much as possible as soon as possible
 - i) Alzheimer's association office or internet, for any dementia
 - ii) Read, references in the back of my book
 - iii) Meet with doctor to discuss specific diagnosis, prognosis, and treatment
- b) Family meeting to talk about who will do what.
 - i) Best to have one primary caregiver with back up
 - ii) Divide up the work when possible
 - (1) Researching visiting nurses, day care or residential facilities
 - (2) Dealing with insurance and paying bills need not be local
 - iii) At some point the victim is best not to be moved to unfamiliar places
 - iv) Set up regular meetings in person or electronically
- c) Contact church, solicit prayer and support
 - i) Find out whom you need to contact for help
 - ii) Possibly have a deacon or pastor designated
- d) Advance directives online
 - i) Honoring Choices Tennessee
 - ii) Power of attorney designating your health care agent
 - iii) Living Will
 - iv) DNR or POLST
- e) See lawyer for Power of Attorney for finances

7. Treatment

- a) Nothing known to reverse the underlying problem of Alzheimer's.
- b) Vascular, anything to reduce strokes
- c) Prayer-for the patient, for the caregiver, for healing, strength and that God will be honored.
- d) Things to slow it down
 - i) Hearing aids—more than simply we don't remember what we cannot hear
 - ii) Exercise
 - iii) Heart healthy diet
 - iv) Social involvement, including church attendance
 - v) Using the brain, reading and talking, playing games—may not help the damaged parts, but may help the healthy parts
 - vi) Maintaining a regular, not too hectic, schedule
 - vii) Treating depression—so prevalent in dementia
 - viii) Supplements—of many studied, only Vitamin E shows any promise, and there studies are not clear

- ix) Avoiding drugs that make things worse
 - (1) Alcohol sedatives, sleeping pills (may be indicated for quality of life)
 - (2) Most bladder incontinence drugs
 - (3) Sedating antihistamines—benadryl
- x) Cholinesterase inhibitors (Aricept, Razadyne, Exelon) stage 1 and 2 or Namenda stage 2 and 3, not enthusiastic but often worth a try.
- e) Convinced that the most effective thing to improve the quality of life of those with dementia is showing respect for their dignity.

EXPERIENCE OF DEMENTIA

1. Compassion=need to feel with

2. In early to mid-stages

- a) Paranoia
- b) Confusion
- c) Boredom
- d) Dominated
- e) Embarrassed
- f) Irritable
- g) Lack of inhibition

3. In stage 3, when you are totally dependent, we don't know how it feels.

- a) They cannot reflect what is going on in their minds
- b) Some seem to have a great feeling of peace
- c) Others more agitated; Helen
- d) They may sit there without showing any sign of thinking at all and that may well be true

4. Important to recognize that the world of the demented is always getting smaller

- a) No longer concerned about world or national events, less interest in family
- b) No concern about the past or the future.
- c) Eventually it boils down to me in the here and now

THE ROLE OF THE CHURCH

1. Proactively the Church (plural) needs to prepare believers to face the challenges of life with confidence and trust in the Lord.

- a) We need a theology of suffering—a theodicy
 - i) Proactive
 - ii) Allowing our difficulties to push us to God not away from him.
- b) We need to be molded into a caring community
 - i) Not saying if you need any help let me know
 - ii) Taking the initiative to help in specific ways.
- c) We need an eschatological perspective—our joy will not be found strictly in this life

2. Reactively the church (singular) needs to organize specific help.

STRESS OF CAREGIVING

1. The overlooked victims

2. Challenges for caregivers

- a) Challenges from the patient
 - i) Repetition, especially early in the course
 - ii) Anger out of frustration
 - (1) Frustrated by their inability to be in control
 - (2) Tired of being dominated and role reversal
 - (3) Often most directed against the one they are most dependent on
 - iii) Vacillation in abilities
 - (1) Did it yesterday why not today?
 - (2) Inability to push themselves
 - iv) Unappreciative
 - v) Apathy—may be harder on caregiver than patient
 - vi) Loss of inhibition
 - (1) Embarrassment
 - (2) Socially awkward
 - vii) Slowness
 - (1) Takes so much time to do anything
 - (2) Helping patient takes a lot longer than doing it yourself

- viii) Shadowing
 - (1) Constantly being followed
 - (2) Never time to yourself
- ix) Meltdowns—temper tantrums when situations cause them to be overstressed
- x) Sleep disturbance—day night reversal, patient and then caregiver
- b) Challenges from family and friends
 - i) Unappreciative
 - ii) Do not take time or interest to know what is happening
 - iii) Lack of help
 - iv) Criticism
- c) Challenges from the system
 - i) Making appointments, perhaps arranging transportation
 - ii) Even things that are intended to spare you time and energy, visiting nurses, home health aides, day care, etc., all take time on the phone, filling out forms, managing insurance
- d) Challenges from yourself
 - i) Older
 - ii) Weaker
 - iii) May be sick or dealing with some dementia yourself

3. Tolls on caregiver

- a) Physical
 - i) Stress, blood pressure, GI problems, headaches
 - ii) Sleep deprivation and poor diet may compromise immunity and lead to more infections.
 - iii) 30% of caregivers die before patient—adding additional burden of contingency planning.
- b) Mental
 - i) Constant demands, no rest, many decisions
 - ii) Mental decline themselves
- c) Social
 - i) Hard to get out
 - ii) Lonely and isolated
 - iii) Friends may feel uncomfortable visiting
- d) Financial
 - i) Many unexpected expenses even with insurance and public support, e.g. nursing help, modifying house
 - ii) Often going without salary of patient or caregiver

- e) Emotional
 - i) Grieving relationship they had earlier with the patient
 - ii) Fear of what will happen down the line
 - iii) Easy to respond with anger at the patient, family, medical system, even at God
- f) Spiritual
 - i) Limited time for church or daily time with God
 - ii) Feeling disappointment with God

— BREAK —

HELP FOR CAREGIVERS

1. **Critical to understand the value of the victim—who it is you are caring for**

- a) Made in the image of God; loved by him; and for believers, redeemed by Christ
- b) Full person who is sick
 - i) Not half person
 - ii) Not a body without a soul
 - iii) Still the same person they always were in God's eyes
 - iv) It is not easy, but just as we value the body of one who is sick, so with the mind
- c) Value what God values
 - i) We value intellect and productivity
 - ii) God values us not because of who we are, but because of who he is. He is gracious.
 - iii) He values relationships and loving service

2. **Knowing you are doing what God wants you to do and that this is his plan**

- a) Loving and serving unselfishly
- b) Sacrificing your own comfort for others.
 - i) “And the King will answer them, ‘Truly, I say to you, as you did it to one of the least of these my brothers, you did it to me.’” Matthew 25:40
 - ii) “But love your enemies, do good to them, and lend to them without expecting to get anything back. Then your reward will be great, and you will be sons of the Most High, because he is kind to the ungrateful and wicked.” Luke 6:35
 - iii) This is your calling

3. Caregiving will allow you to grow in your walk with the Lord. Look for that growth.

- a) Prayer—we were told years ago that having children would teach you to pray—same as caring for one with dementia
 - i) Lament—cry out to the Lord
 - ii) Bring your requests
- b) Trust
- c) Love—learn what truly unselfish love looks like
- d) Hope
- e) Fruit of the spirit—particularly gentleness, patience, faithfulness, and self-control
- f) Perseverance

4. Recognize the importance of having your own needs met right from the outset.

- a) Otherwise, you will fail in the task you have taken on.
- b) Do not be too independent yourself. Get help early before exhaustion and bitterness set in.

5. Places to get help—wise to investigate long before needed-may need to delegate

- a) Government supported help—Alzheimer’s society
- b) Day care
- c) Visiting nurses
- d) Home health aides
- e) Assisted living, including dementia facilities
- f) Nursing homes
- g) Hospice

THEOLOGICAL FOUNDATIONS

1. God is in control. He is sovereign over all things.

“Our God is in the heavens; he does all that he pleases.” Psalm 115:3

2. He is loving and kind.

“Once God has spoken; twice have I heard this: that power belongs to God and that to you, O Lord belongs steadfast love.” Psalm 62:11-12a

3. God has purpose in all things.

“I cry out to God Most High, to God who fulfills his purpose for me.” Psalm 57:2

4. He never makes mistakes.

“This God—his way is perfect;” 2 Samuel 22:31a

5. Life is not about us, but about God and his glory.

“For from him and through him and to him are all things. To him be glory forever. Amen.”

Romans 11:36

6. Dementia was not part of God’s good creation.

Genesis 1: “It was good” appears 7 times

7. All humans are made in God’s image and are his by right of creation.

“Then God said, “Let us make man in our image, after our likeness.” Genesis 1:26

“Then the LORD God formed the man of dust from the ground and breathed into his nostrils the breath of life, and the man became a living creature.” Genesis 2:7

“The earth is the LORD’s and the fullness thereof, the world and those who dwell therein,”

Psalm 24:1

i) Image of God is a fact, not a description, of our attributes or abilities. It is true of all persons.

ii) Provides a foundation for human dignity shared by all people

iii) MLK: There are no gradations of the image of God

8. Sin led to dementia, but did not diminish God’s image.

“Whoever sheds the blood of man, by man shall his blood be shed, for God made man in his own image.” Genesis 9:6

“With it we bless our Lord and Father, and with it we curse people who are made in the likeness of God.” James 3:9

9. God uses bad to accomplish good.

10. God will eventually destroy all disease and transform us to fully reflect his image

“And we all, with unveiled face, beholding the glory of the Lord, are being transformed into the same image from one degree of glory to another. For this comes from the Lord who is the Spirit.”

2 Corinthians 3:18

11. As we reflect on dementia, we lament the tragedy, but we can confidently affirm that

God is in control. He is accomplishing his purpose, even though we may not see it in this life.

RESPECTING DIGNITY IN DEMENTIA

1. **Said earlier that I feel the best way to improve quality of life of those with dementia is to respect their dignity. Now, how?**
2. **Respect their autonomy and their current ability to direct their own lives**
 - a) When you go for ice cream, do not give choice of 31 flavors. Choose their two favorites.
 - b) Do not ask them to decide about heart surgery.
3. **Protect their reputation where autonomy could endanger others.**
 - a) Work
 - b) Driving
4. **Needs of demented people**
 - a) One of the greatest challenges of the disease is to figure out what they need. And yet, showing you care is an opportunity to show respect for their dignity.
 - b) “I feel lousy” challenge is the same as a screaming six-month-old old baby: hungry, need to be changed, position change, just to be picked up and loved, or ill.
 - i) Physical—needs often communicated not by words but by behavior
 - (1) Hot—may be expressed by undressing in public
 - (2) They have definite diet preferences.
 - (a) Spitting out food may simply be saying “I don’t like this—could you feed me something else.”
 - (b) Okay to give them the same thing all the time. And once you get to stage 2 and 3, their arthritis hurts just as much as any other.
 - (c) Do not insist on healthy diet.
 - (3) Physical activity feels good—loosens them up, helps them sleep.
 - (4) They care about how they are dressed and that their hair looks good.
 - ii) Emotional
 - (1) They need complements
 - (2) Told they are loved
 - (3) Hugs and kisses where appropriate
 - (4) They need some degree of self-respect
 - (5) They do not appreciate being embarrassed
 - (a) Do not correct in public
 - (b) Do not ask questions they cannot answer
 - (i) Not “What did you do today?”
 - (ii) “Did you enjoy what you did today?”

- (6) Reality orientation
 - (a) Mom thinking I was Dad—initially could orient her
 - (b) “No, I am your son, John.”
 - (c) When upset
- (7) Validation
 - (a) “Lois, I love you.”
 - (b) Remember the trip we took together.
 - (c) Jamie, the frog
- c) Meaning
 - i) They want to feel they are making a meaningful contribution
 - ii) Grandma folding napkins.
 - iii) Dad, you make me feel so good when I am with you
- d) Social
 - i) Sometimes the best present is presence.
 - ii) The three-month-old cannot say, “Mommy, I love you, thank you for being here,” but is very conscious of mom’s presence.
 - iii) Do better with other people around but they may not want to be with just anyone—some people will in their confusion elicit inappropriate bad memories thinking they are someone else.
 - iv) Large groups can be confusing.
- e) Spiritual
 - i) Repeatedly talking about Jesus, his love, and Heaven
 - ii) God can still work in their spirits
 - (1) I do not believe scripture makes a distinction between soul and spirit
 - (2) It does seem that the Spirit may work in specific parts of our minds
 - (3) What am I to do? “I will pray with my spirit, but I will pray with my mind also; I will sing praise with my spirit, but I will sing with my mind also.” 1 Corinthians 14:15
 - iii) Opportunities to practice their faith at a level consistent with their abilities
 - (1) Praying may be a part of procedural memory and they can continue to pray aloud.
 - (2) Dad reciting Scripture
 - (3) Mom singing
 - iv) Offering communion
 - v) Be ready to listen if they share feelings
- f) Help them enjoy their memories of the past
 - i) Dorothy reading *The God I Love*
 - ii) Pictures, movies, gardens, music help them to relate to their past pleasures
- g) Help them find meaning and service
- h) Enter their worlds—incarnational

MANAGING SPECIFIC SITUATIONS

1. Visits

- a) Approach from front so as not to startle
- b) Introduce yourself and usually give a connection
- c) Talk about familiar things that they remember from the past—Drew with Clinton
- d) Maintain eye contact with the patient, talk to them even if the content of what you are saying is directed to others.

2. Deciding on residential care

- a) One of the most difficult decisions—feels like abandonment
- b) When caregiving becomes a burden
- c) This will be delayed if you have taken small steps earlier
 - i) Adult day care
 - ii) In home help
- d) When the sacrifices are no longer appreciated by the patient
- e) May be forced by sudden change, fall, stroke, hospitalization, etc.
- f) Still requires a major commitment to be present
- g) Previous promises

3. Meltdowns

- a) Loss of control similar to a two-year-old's tantrum
- b) Triggers
 - i) Unfamiliar Surroundings
 - ii) A task that is too complicated
 - iii) Difficulty in Communicating
 - iv) Travel
 - v) Large Gatherings
 - vi) Guests
 - vii) Illness
 - viii) Noise
 - ix) Drug side effects
 - x) Pain
 - xi) Hunger/thirst
- c) Response
 - i) Avoid triggers
 - ii) Use few words
 - iii) Touch if accepted

- iv) Get to a quiet place not too bright
- v) Engage in a familiar activity-walk, ride, etc.
- vi) Music
- vii) Comfort food

4. Hallucinations

- a) Similar to dreams
- b) Unable to distinguish if real or not
- c) If agitating, will require medications; if not, okay to ignore

5. Driving

- a) Often problem is getting lost, not the mechanics of driving.
- b) Family may be overly cautious, not sensitive to the huge blow that not being able to drive is
- c) So often is link to independence
- d) May lead to isolation and loneliness
- e) Often best if family not make decision, especially for men
 - i) Driving schools
 - ii) OT departments

END OF LIFE CARE BIG PART OF RECOGNIZING DIGNITY

1. Recognize it is a terminal disease that will progress

- a) Do not put them through suffering
- b) Hospitalize only when absolutely necessary; they will be more confused

2. No aggressive interventions

- a) Comfort care
- b) Hospice
- c) My advance directive
 - i) I want everything done to prolong my life if it is likely that I will be able to serve others. But if for physical, mental, emotional, or spiritual reasons, I am not expected to return to serve others, I do not want my life prolonged (based on Philippians 1).
- d) Heaven's not so bad we need to fight too hard to keep out.

FINDING GOD'S PURPOSE

1. For patient

a) Pride

“On behalf of this man I will boast, but on my own behalf I will not boast, except of my weaknesses— though if I should wish to boast, I would not be a fool, for I would be speaking the truth; but I refrain from it, so that no one may think more of me than he sees in me or hears from me. So to keep me from becoming conceited because of the surpassing greatness of the revelations, a thorn was given me in the flesh, a messenger of Satan to harass me, to keep me from becoming conceited.” 2 Corinthians 12:5-7

b) Independence

2. For caregiver

a) Unselfish love

b) Dependence on God

3. For church

a) Learning to value what God values

b) Becoming a serving community

c) Accepting those who are different or disabled

d) Working together

4. For community

a) Demonstrating what Christian love looks like

“God Moves in a Mysterious Way”

God moves in a mysterious way
His wonders to perform;
He plants his footsteps in the sea,
And rides upon the storm.

Deep in unfathomable mines
Of never-failing skill
He treasures up his bright designs,
And works his sovereign will.

Ye fearful saints, fresh courage take;
The clouds ye so much dread
Are big with mercy, and shall break
In blessings on your head.

Judge not the Lord by feeble sense,
But trust him for his grace;
Behind a frowning providence
He hides a smiling face.

His purposes will ripen fast,
Unfolding every hour;
The bud may have a bitter taste,
But sweet will be the flower.

Blind unbelief is sure to err,
And scan his work in vain.
God is his own interpreter,
And he will make it plain.

