THE ROMAN CATHOLIC ARCHDIOCESE OF ATLANTA



"We Are Because God Sustains Us in God's Memory": A Pastoral Response to Dementia

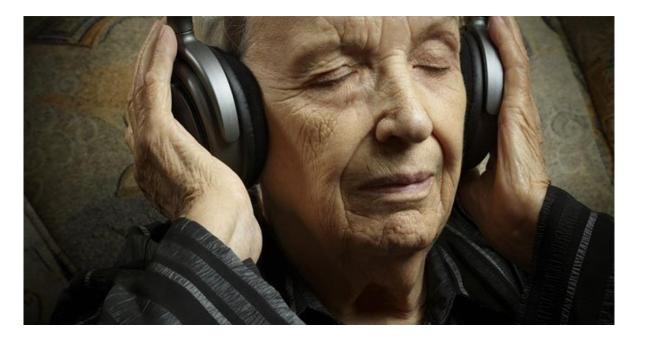
Co-Presented by: Maggie Rousseau, M.Ed. - Director of Disabilities Ministry Mary Cohen, MPH - Associate Director of Senior Adult Ministry

Thursday, January 21, 2021 @10am

FOR MORE INFO AND ZOOM LINK VISIT: TINY.CC/CATHOLICSENIOR

Opening Thoughts

- Who we are
- Objectives
 - Raise awareness & understanding
 - Consider a theological and ethical response to dementia
 - Ideas and resources
 - Open up the conversation





What is dementia?

"The loss of cognitive functioning -thinking, remembering, and reasoning -- and behavior abilities to such an extent that it interferes with a person's daily life and activities." – National Institutes of Health



What is dementia?

- Progressive and irreversible loss of neurons and brain functioning, including loss of
 - memory
 - language skills
 - visual & hearing perception
 - problem-solving ability
 - emotion control
 - self-management ability
 - focus and attention.
- Stages-early, middle, late.
 - In severe stages, person depends completely on others for even the most basic activities of daily living.





What is dementia?

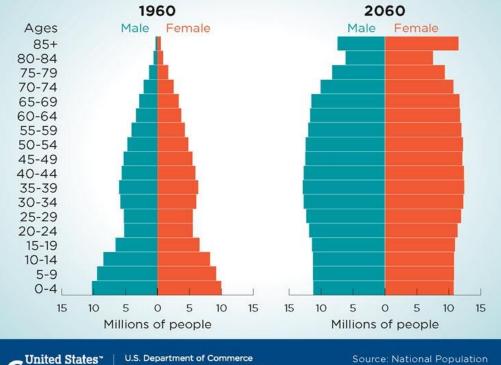
- "Umbrella" term
 - Alzheimer's Disease, Lewy-Body, vascular, frontotemporal disorders, Parkinson's-related, etc.
 - Also referred to as "progressive cognitive impairments"
- Diagnosis affects a community of people





From Pyramid to Pillar: A Century of Change

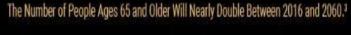
Population of the United States



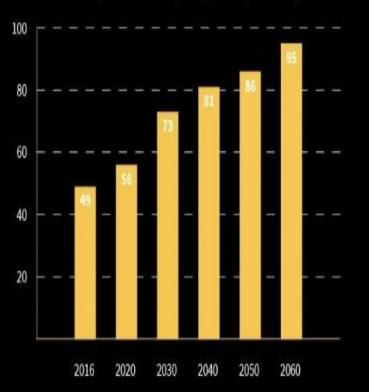
Census Bureau U.S. Department of Commerce Economics and Statistics Administration U.S. CENSUS BUREAU *census.gov* Source: National Population Projections, 2017 www.census.gov/programs-surveys /popproj.html The proportion of older people with dementia is declining 1-2.5% per year.¹



However, as Americans live longer and the baby boomers age, the **number** of people with dementia is increasing.²



Projected Older People Population (in Millions)



Source: Population Reference Bureau



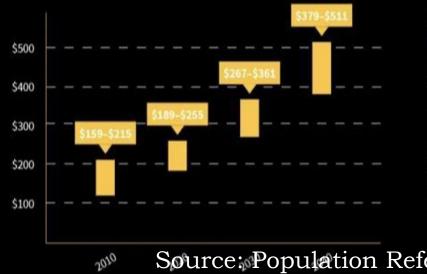
Key Statistics

- Alzheimer's 6th leading cause of ٠ death in US (2019)
- Approximately 1 in 3 older people ٠ die with some form of cognitive impairment present
- Around 16 million people -- mostly ٠ women -- currently offer unpaid care to persons with progressive cognitive impairments.

Cost

Dementia is one of the most expensive U.S. health conditions.



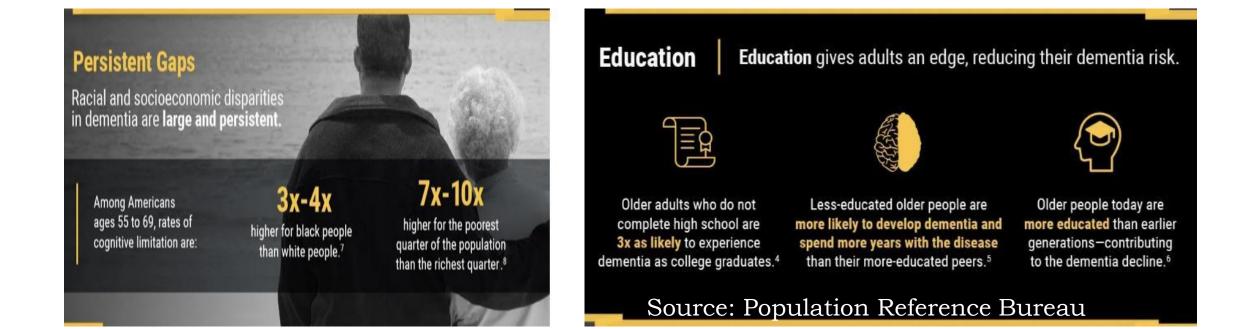


Estimated yearly costs reach \$215 billion and could more than double by 2040 as the large baby boom generation ages.*

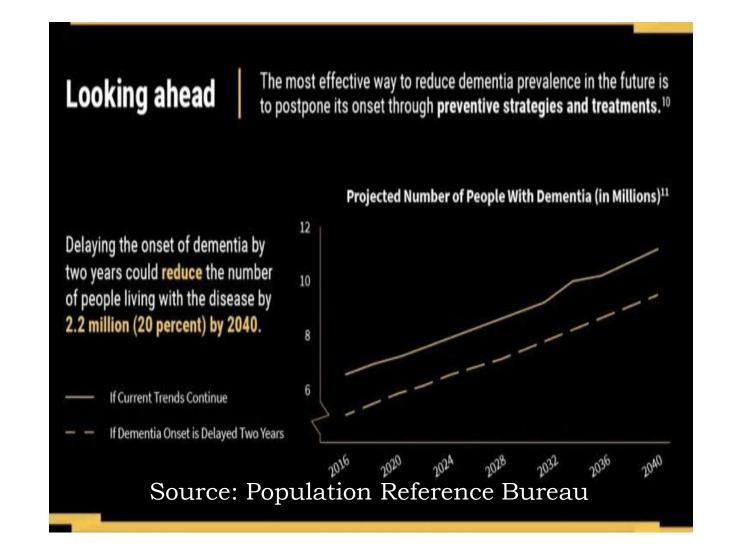
*The estimated total U.S. dementia costs for 2010 range from \$159 billion to \$215 billion, depending on how unpaid caregivers' time and lost wages are valued. For 2040, the range is \$379 billion to \$511 billion in 2010 dollars. Families tend to provide nearly all unpaid care

Source: Population Reference Bureau

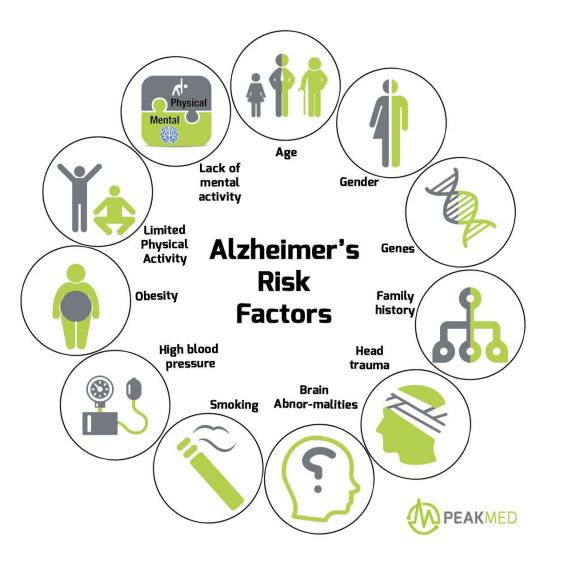














A Moral Challenge

"[T]he care of people with dementia...will severely test the moral fabric of the family and society. The moral basis of our commitment to those with significant progressive and irreversible loss of cognitive function must be reaffirmed and rearticulated. [There is] a new urgency of the ethics of dementia."

• Stephen Post, bioethicist and theologian -- The Moral Challenge of Alzheimer Disease



Being Remembered by God

"Our hope lies in the fact that we are living in the memories of God. As long as God remembers us, who we are will remain: 'I will not forget you. See, I have engraved you on the palm of my hands (*Is. 49:15-16*).'"

John Swinton, Dementia: Living in the Memories of God





Foundational Principles

- Intrinsic dignity and worth of human beings
- Unity of the being
- Identity of the human being
- Human relationships
- Stewardship of human life
- Human limitations
- Solidarity, Social Justice, and Self-Giving Love (Caritas)



- International Association of Catholic Bioethicists, *Caring for and Giving Hope to Persons with Progressive Cognitive Impairments*



Ethical Principles

- Respect intrinsic dignity
- Encourage participation
- Ensure that care is holistic and person-centered
- Human relationships
- Support families and other caregivers
- Judge appropriate limits of treatment
- Allocate according to demands of social justice



International Association of Catholic Bioethicists, *Caring for and Giving Hope to Persons with Progressive Cognitive Impairments*



Recommendations to Cultivate Respect

- Avoid language, attitudes and behaviors that depersonalize
 - Fear, "taking over", ignoring
- Encourage interaction and befriending
 - Especially intergenerational
- Protect against neglect or abuse
- Challenge cultures and ways of thinking that hold that aging, disability, dependency on others, suffering and death lack meaning.
 - Never a burden!
- Support a different response to human limitation and suffering than assisted suicide and euthanasia



International Association of Catholic Bioethicists, *Caring for and Giving Hope to Persons with Progressive Cognitive Impairments*





A Pastoral Response

"Catholic parishes are encouraged to develop structures to provide pastoral care for persons living with progressive cognitive impairments and their caregivers that address their material, psychological, social, spiritual needs."

> - International Association of Catholic Bioethicists, *Caring for and Giving Hope to Persons with Progressive Cognitive Impairments*



Promote Holistic, Person- and Family Centered

- Involve persons living with dementia in decisions regarding their care to the extent they are capable
 - May require supports because of specific vulnerabilities
- Pay attention to person's expressed wishes, affective and behavioral cues, and involvement of those who know the person well





Safety

- If the safety of a person living with dementia is of concern
 - Least intrusive and restrictive options appropriate for the person's needs should always be tried before more intrusive & restrictive
 - MedicAlert
- Safe Environment policies apply

archatl.com/ministriesservices/safe-environment/safeenvironment-compliance/





Praying for Needs

- Prayers of the Faithful
- Masses
 - Considering plans for AoA Mass on September 21, 2021 – World Alzheimer's Day or another patron saint day
- Rosaries, Divine Mercy Chaplets
- Adoration
- Novenas
- Include family members, caregivers, and others





Facilitating Reception of the Sacraments

- Eucharist to the homebound
 - Recruitment and training in encountering people living with dementia
 - www.usccb.org/committees/divineworship/policies/guidelinessacraments-persons-withdisabilities
- Transportation
- Accommodations for reconciliation
- Anointing of the Sick
 - Serious illness
 - Suggest to person and make arrangements
 - Healing service





Encourage Advance Healthcare and End-Of-Life Planning

- Ideally addressed while the person is still capable
 - Surrogate decision makers, advanced directives, etc
 - Trusts, Wills, Estate
 - Preferences
 - General organization of personal & business affairs
 - Funeral planning
- Do in consultation with spouse, family, other caregivers, etc.
- Resources at

archatl.com/ministries-services/respectlife-ministry/end-of-life-issues/Assistance in facilitating conversations

- Legal and Financial Professionals
- Counselors





Counseling, Support Groups, and Education

- Caregivers support groups
- Stephen's Ministry
- Talks Senior groups, Knights of Columbus, Children, Teen & Young Adults, too!
- Provide mental health resources & info
- Georgia Memory Net gamemorynet.org





Assistance With Activities of Living

- Meals, household repair, yard work, shopping, etc
- Where to turn for help in finding/selecting
 - Home care assistance
 - Long-term care options
 - State of Georgia, Department of Human Services, Division of Aging Services

aging.georgia.gov/locations



Social Events & Respite

- Regular gatherings for those living with dementia and their caregivers
- Art classes, dances, concerts, pet therapy
- Involve younger generations!
 - Polka party
 - Fish fry table dates
 - Adopt a retired priest
- Consider a launching a day program
 - Or knowing ones in your area





Support Healthy Behaviors

- Physical activity!
 - Walking group
 - Exercise classes
- Nutrition classes/dinner club
- Reduce isolation and loneliness





Let's Talk!

- Questions?
- Comments?
- Stories?
- Challenges?
- What do you want to know more about?

