

# Alzheimer's Disease, Caregiving, and Society

David A. Casey, M.D.

# An Epidemic of Alzheimer's Disease

- Approximately 80,000 Kentuckians suffer from Alzheimer's Disease (AD); more than 5 million nationally
- 12,000-15,000 in Louisville
- Numbers expected to double in 20-30 years
- 160,000 Kentucky families providing uncompensated caregiving for relatives
- If this care for purchased, cost would exceed \$1 billion annually

# Disproportionate Burden

- All sectors of society affected by AD
- Incidence greater for African-Americans
- Possible due to increased risk factors: such as diabetes, hypertension, obesity

# Caregiving

- Many AD patients require 24 hour care and supervision because of memory loss, activities of daily living, behavior problems
- Patients may live for years with disease

# Who Are the Carers?

- 80% of dementia care provided at home by family-uncompensated
- Majority of carers are women-wives or daughters-though men are increasingly involved
- Wives—elders themselves
- Daughters—sandwiched between parents, work, and children
- Informal networks-friends, neighbors

# Stress and Eldercare

- Depression, anxiety, physical illness
- Substance abuse
- Increased mortality; caregiver may predecease the “patient”

# Types of Caregiver Stress

- Disruption of household routine
- Restrictions on social life
- Sleep disturbance, exhaustion
- Time pressures—avg. 47 hours direct caring
- Marital strife
- Impact on work and family
- Problems with holidays

# Stresses of Caring

- Behavioral problems, agitation, psychosis
- Incontinence, sleep problems
- Anticipatory grief
- Guilt and self-criticism
- Criticism from family-denial, displacement
- Reemergence of old family conflicts, grievances

# Culture and Caregiving

- Increasing mobility, fragmentation, and distance in the family
- African-Americans: strong cultural value placed on family caregiving—more highly esteemed and supported

# Work and Caring

- AARP: 13% of workforce involved in caring for elder at any time; 25-35% in given year
- Number rapidly increasing
- Workforce issues: absenteeism, tardiness, lost productivity
- Challenges for employers in retaining valued employees who have eldercare responsibilities

# Carers Rights Movement

- Developing in the UK
- Support, education, respite, tax credits or stipends for family caregivers
- Not yet strong in US