

Syllabus

Honors 3700: Think Tank on Alzheimer's Disease and Aging

Final Presentation to Community: <https://youtu.be/tdN1VmLZ1dU>

Faculty

Vicky Newman, Ph.D., Honors writing, literature, and ethnography
Phillip Bimstein, Composer, musician and elected community leader
Norman L. Foster, M.D., Geriatric neurologist and clinical research investigator
Professor, Department of Neurology; Director, Center for Alzheimer's Care, Imaging and

*Memory believes before knowing remembers. Believes longer than recollects,
longer than knowing even wonders.*

William Faulkner

Overview

This is a multi-disciplinary, team-taught, two-semester course that meets on Tuesday afternoons from 2-5 PM (3 hours), Location: MRSC 1205 (Seminar Room A, 1st Floor North Wing, Donna Garff Marriott Residential Scholars Community). Background knowledge on aging and Alzheimer's disease will be developed through faculty presentations, guest speakers, community engagement and assigned reading and multi-media sources. In the first semester groups will develop and identify action projects that address community gaps and priorities with the final product presented in the second semester. Grading will be based on the degree of active class participation, success in individual and group expression, summary and practical utilization of a substantial acquired knowledge base.

THIS CONTENT OF EACH CLASS IS SUBJECT TO CHANGE BASED UPON THE SCHEDULES OF GUEST SPEAKERS

Introduction

This Think Tank is designed to link our current scientific understanding of Alzheimer's disease with social and public policy issues facing patients, families, and society. In order to understand Alzheimer's disease we need to know what distinguishes it from normal aging. We also need to recognize its differences from other causes of cognitive changes that occur with aging.

Alzheimer's disease occurs in the context of our aging society and the expectations and cultural attitudes about aging. Alzheimer's disease and aging often have been conflated. The normal aging brain can be the repository of personal insight, knowledge and wisdom. It also has creative potential that too often is underestimated and underutilized. We will explore these potentials in this course. Thus this course is about Alzheimer's disease and about aging.

Recently, Alzheimer's disease has been an increasing focus of attention as the nation experiences the "gray tsunami" caused by the aging of the baby boom generation. Are we prepared to address the challenges Alzheimer's disease represents for society? Can we understand how individuals and family are affected? How can we provide supportive communities and spiritual support? The federal government recently issued a National Plan to Address Alzheimer's Disease and President Obama has proposed increased funding for Alzheimer's disease research and caregiving services. Despite having the youngest population of any state, over the next 10 years Utah will experience the greatest percent increase in the number of people with Alzheimer's disease. A State Plan for Alzheimer's Disease and Related Disorders was approved by the Utah Legislature, but few steps were taken to implement the plan and we are poorly prepared to meet the needs of patients and families seeking help. The Alzheimer's disease plans at both levels of government recognize the widespread need and urgency to address the disease and its complexities. There are reasons for hope. There have been significant breakthroughs in our understanding of Alzheimer's disease, its mimics, and management. Quality of life of those with dementing disease is improving. Among the recommendations of the Utah Plan is increasing awareness of Alzheimer's disease throughout the broader community through student education and engagement to achieve its outlined solutions. Honors students will gain the background and opportunity to lead the way to meet the many facets of Alzheimer's disease.

Involving faculty from the sciences, public policy, the humanities, and the arts will enable students to appreciate the linkages among intellectual fields, develop a basic scientific understanding of Alzheimer's disease, and explore the medical, ethical, philosophical, and public policy issues that accompany it. They will be able to apply their own interests and expertise to address this emerging problem. They will recognize how the medical and scientific approach to disease must draw upon the social sciences and public policy to be fully successful and must be informed by the humanities to best understand the ramifications of the disease. This kind of approach can reveal how society frames Alzheimer's and how that framework affects policy, knowledge and stigma.

The Alzheimer's Think Tank will concentrate on knowledge, communication, inclusion, and dignity by studying the intersections of science, narrative, the arts, humanities, philosophy, emotion, ethics, and public policy. It will ask students to consider these questions:

What does it mean to be old in America?

To be dependent on others when we become old?

What is it like to live with Alzheimer's disease?

What is it like to care for a loved one with Alzheimer's disease?

What does our community need to know about Alzheimer's disease?

How will you communicate what you have discovered?

Course Objectives

1. To provide to students through in-class presentations and community experiences a substantial knowledge base about aging and Alzheimer's disease.
2. To evoke in students an empathy for and deeper understanding of the emotional meaning and personal narratives of aging individuals in our society and those affected by Alzheimer's disease.
3. To provide an appreciation of the linkages between many intellectual fields, public attitudes and policies, and community services which affect the experience of aging and Alzheimer's disease.
4. To collaborate on a meaningful project through community engagement that enhances the quality of life for individuals with Alzheimer's disease and their families.

Required Texts and Films

Articles, reading assignments, and films will be available through E-reserve or otherwise provided.

Students will be responsible for additional independent research (based on bibliographies provided).

Americans with Disabilities Act: *The University of Utah seeks to provide equal access to its programs, services, and activities for students with physical, sensory, cognitive, systemic, learning, and psychiatric disabilities. Please let me know at the beginning of the semester if you will need accommodation. Reasonable prior notice must be given to the Center for Disabilities Services, 162 Union Building, 581-5020. You will need to contact the CDS and their office will notify your instructors.*

Course Requirements

Attendance and Participation

Students are expected to attend the entire 3- hour class. We expect that on average 2 hours of preparation will be needed for each hour of class time to fully benefit from the course and receive an outstanding grade. Students are expected to be attentive during in-class presentations (including multimedia presentations) and actively participate in class discussion. Some material presented in class will not be otherwise available. You also will be expected to participate in some field trips of 1-2 hours each during the course of the semester. These are considered essential, although options will be provided to allow you to attend and also accommodate your other commitments. Conflicts and absences must be identified to course directors before they occur. We will have outside speakers for a number of the class sessions. Some of these will be patients and their families. We expect timely arrival and appropriate dress demonstrating our respect for speakers and their willingness to participate. This is particularly important for patients and their families who may be discussing issues that are very emotional for them. Personal information patients and families provide should be considered confidential. Do not

identify to others (especially including the media) the names or private information about patients and family members without their permission. Remember you will be representing the University, our class, and yourselves in your interactions with the public.

Grading

Grades will be based on quality of effort and work, including clarity and coherence, originality, substance, proper understanding and integration of source material, good research, organization, and creativity. In addition, quality participation in assigned work and activities.

Curriculum

The instructors and guest speakers will guide students in their investigations of the different dimensions of aging and Alzheimer's using lectures, class discussion and through interviews of patients, caregivers, and families. In addition, they will guide students through the creative process of their documentary work or action piece, connecting it specifically to three strategies of the Utah State Plan for Alzheimer's awareness and education:

- Develop and disseminate culturally appropriate print, radio, and television information
- Promote realistic positive images of people with Alzheimer's disease and their caregivers to overcome existing stigmas and misconceptions
- Target Utah's unique challenges—rural areas and multicultural barriers

Topics

1. Aging in our society – the aging of society and its effect on the safety net and generational relationships
2. Meeting and Getting Acquainted with Alzheimer's disease: Students will meet with patients and their caregivers with discussion of the salient observations
 - a. Impact of early diagnosis and mild symptoms
 - b. How families are affected by Alzheimer's
 - c. Maintaining quality of life with disease progression
 - d. Behavioral complications of disease
 - e. Telling stories
 - f. Recognizing personal emotions
 - g. Positive images and stereotypes
3. Scientific understanding of Alzheimer's disease: Lectures will be presented discussing the causes, evaluation and treatment of Alzheimer's disease and promising new drug treatments and research
 - a. Basic biology of Alzheimer's disease
 - b. Normal and abnormal memory
 - c. Genetics and Alzheimer's disease
 - d. Brain imaging and Alzheimer's disease
 - e. Clinical drug trials in Alzheimer's disease and research ethics
 - f. What are the limits of science and medicine?
 - g. Framing disease

4. Family implications of Alzheimer's disease
 - a. Family responses to diagnosis
 - b. Identifying and preventing complications
 - c. Challenges of caregiving
 - d. Legal aspects of dementia
 - e. What personal barriers do families face?
 - f. What financial and insurance barriers do families face?
 - g. How can families express their fear, love, revulsion?

5. Society and Dementia
 - a. Long-term care and community services
 - b. Minority issues
 - c. The federal role and Medicare
 - d. The state role and Medicaid, the local role
 - e. What is the role of individuals vs. government?
 - f. How do we communicate effectively with the public?
 - g. How do we generate involvement of first responders?

6. Creativity and Aging
 - a. Impacts of professionally conducted cultural programs on the health and social functioning of older adults
 - b. Lastingness: How aging influences professional artists and writers
 - c. The portrayal of aging in the arts, literature and media and its influence on society
 - d. Personal storytelling and narrative as identity preservation and construction of meaning, and as a method of communication and expression
 - e. The creative age: Awakening human potential in the second half of life

7. Community Experiences
 - a. NIA Senior Friendly Writing
 - b. Visit to AD support group
 - c. Visit to Cognasium
 - d. Visit to Senior Center
 - e. Visit to Assisted Living Facility
 - f. Visit to Nursing Home

8. Developing a Meaningful Community Action Project; examples might include:
 - a. Assist the elderly, caregivers and patients with a dementing disease to artistically express their experiences
 - b. Designing and conducting age-appropriate, culturally sensitive public information programs about Alzheimer's disease
 - c. Develop a strategy and lobby to support a change in public policy related to Alzheimer's disease
 - d. Assess public, patient or caregiver attitudes as a mechanism for social change
 - e. Design and carry-out a community activity that increases public awareness and decreases social stigma of Alzheimer's disease
 - f. Assist in community and patient involvement in Alzheimer's disease research

Fall Semester 2012

Assignments

Review: During the second and third weeks of the course students will give 10-minute in-class oral reviews of an assigned text or film selected on the first day of class. (This will account for 10% of the final grade.)

Reading and research: Students will use the brief in-class reviews to select 4 texts and 2 films from an assigned list to review. These and 3 self-selected items to learn more about topics discussed in class will be used as the basis for written assignments.

Essays: Students will write 3 essays during the semester.

1. A 3-page written, hard-copy, single sided, Arial 11 font, 1 inch margin, double space, essay describing the reasons for taking this course and personal knowledge about aging and Alzheimer's disease will be due at the beginning of the second day of class August 28, 2012. An electronic copy will be sent to each instructor – Bimstein, Newman and Foster. These will be posted on Canvas for discussion. (This will account for 10% of the final grade.)
2. A 10-page written, hard-copy, single sided, Arial 11 font, 1 inch margin, double space, essay with proper citation describing the major knowledge gained in the course from class activities and outside readings will be due finals week Tuesday December 11. This must be submitted to the honors college office before noon. An electronic copy will be sent to each instructor – Bimstein, Newman and Foster. (This will account for 25% of the final grade.)
3. Students will identify a question they want to answer for the larger research project during spring semester and write a 3-page written hard-copy, single sided, Arial 11 font, 1 inch margin, double space, description including the motivation for this major project and the steps that the project would entail with a separate working bibliography on the relevant topic. This will be due at the beginning of the last day of class Tuesday December 4, 2012. An electronic copy will be sent to each instructor – Bimstein, Newman and Foster. (This will account for 20% of the final grade.)

Class participation: Attendance, quality of classroom contributions and off campus activities will account for 35% of the final grade. Instructors will provide an indication of perceived participation approximately half way through the semester.

Detailed Calendar – Fall Semester

August 21: Faculty - Newman and Bimstein

Introduction and Aging in Society

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| 2:00 - 2:20 | Introduction of faculty and students; review of objectives, methods, expectations, products, and grading – faculty |
| 2:20 - 2:40 | Aging: Perspectives of Philosophy and Literature - Newman |

- 2:40 - 3:00 Aging: A Medical Perspective – Rand Rupper, M.D., geriatrician, Director of Clinical Programs, Geriatric Research, Education and Clinical Center, VAMC, Center on Aging
- 3:00 - 3:20 Discussion
- 3:20 - 3:30 Break
- 3:30 - 4:00 Selecting initial assignments for in-class presentations and first essay
- 4:00 - 4:20 Aging: Demographics and a Social Perspective – Ken R. Smith, Ph.D., M.S., Professor, Human Development and Family Studies, Department of Family and Consumer Studies; Adjunct Professor, Department of Biomedical Informatics, School of Medicine; Director, Pedigree and Population Resource, Huntsman Cancer Institute; Investigator, Institute for Public and International Affairs; Member, Center on Aging
- 4:20 - 4:40 Discussion
- 4:40 - 5:00 What have we learned?

August 28: Faculty - Newman and Bimstein

Aging: Personal Experience

- 2:00 First Essay Submissions
- 2:00 – 2:20 The Portrayal of Aging in the Arts-and Media and Its Influence on Society - Bimstein
- 2:20 - 2:40 Discussion
- 2:40 - 3:20 Mobility Changes and the Importance of Exercise in Aging – Paul LaStayo, P.T., Ph.D., C.H.T., Professor, Division of Physical Therapy, College of Health, Center on Aging
- 3:20 - 3:40 Discussion
- 3:40 - 3:50 Break
- 3:50 - 4:00 What have we learned?
- 4:00 - 4:10 Student #1 assignment review
- 4:10 - 4:20 Student #2 assignment review
- 4:20 - 4:30 Student #3 assignment review
- 4:30 - 4:40 Student #4 assignment review
- 4:40 - 4:50 Student #5 assignment review
- 4:50 - 5:00 Student #6 assignment review

September 4: Faculty - Newman and Bimstein

Aging and Cognition

- 2:00 - 2:20 Aging and Cognition – Kevin Duff, Ph.D., ABPP (Cognitive Neuropsychology), Associate Professor, Division of Cognitive Neurology, Department of Neurology
- 2:20 - 2:40 Discussion
- 2:40 - 3:00 Definitions of Cognitive Impairment – Kevin Duff
- 3:00 - 3:20 Research in Aging and Cognition – Kevin Duff
- 3:20 - 3:40 Discussion
- 3:40 - 3:50 Break
- 3:50 - 4:00 What have we learned?
- 4:00 - 4:10 Student #7 assignment review
- 4:10 - 4:20 Student #8 assignment review
- 4:20 - 4:30 Student #9 assignment review
- 4:30 - 4:40 Student #10 assignment review
- 4:40 - 4:50 Student #11 assignment review
- 4:50 - 5:00 Student #12 assignment review

Selecting additional assignments: 4 text, 2 film (on-line)

September 11: Faculty – Newman, Bimstein and Foster

Alzheimer's Disease – Medical Perspective

- 2:00 - 2:20 Discussion of First Essay and Posted Comments
- 2:20 - 2:40 Cognitive Evaluations - Foster
- 2:40 - 3:00 The Biology of Alzheimer's Disease and Related Disorders - Foster
- 3:00 - 3:20 Discussion
- 3:20 - 3:30 Break
- 3:30 - 3:50 Clinical Trials – Tammy Floore, RN, BSN, Lead Clinical Research Coordinator, Center for Alzheimer's Care, Imaging and Research
- 3:50 - 4:10 Discussion

- 4:10 - 4:30 Imaging Research in Dementing Diseases - Foster
- 4:30 - 4:50 Discussion
- 4:50 - 5:00 What have we learned?

September 18: Faculty – Newman, Bimstein and Foster

The Experience of Young-onset Alzheimer’s Disease

- 2:00 - 2:30 Living with Alzheimer’s disease – a family experience – Emily Wallis
- 2:30 - 3:00 Questions for Emily
- 3:00 - 3:30 Commentary and discussion - faculty
- 3:30 - 3:40 Break
- 3:40 - 4:00 Proactive dementia care – Troy Andersen, MSW, MS, LCSW, Medical Social Worker, Center for Alzheimer’s Care, Imaging and Research
- 4:00 - 4:20 Discussion
- 4:20 - 5:00 Action plan discussion – faculty

September 25: Faculty – Newman, Bimstein and Foster

The Experience of Alzheimer’s Disease and Society’s Role

- 2:00 - 2:30 Living with Alzheimer’s disease – quality of life – the Romneys
- 2:30 - 3:00 Questions for the Romneys
- 3:00 - 3:30 Commentary and discussion - faculty
- 3:30 - 3:40 Break
- 3:40 - 4:00 The Role of the Alzheimer’s Association – Nick Zullo, MPA, MC, CPC, Director of Programs and Advocacy, Alzheimer’s Association Utah Chapter
- 4:00 - 4:20 Utah State Dementia Plan – Nick Zullo
- 4:20 - 4:40 Discussion
- 4:40 - 5:00 Possible ways to translate and express what you are learning into a Think Tank project – Bimstein and faculty

October 2: Faculty – Newman, Bimstein and Foster

Emotional and Artistic Expression in Aging

- 2:00 – 3:00 Aging in Literature Over the Centuries - Newman
- 3:00 - 3:30 Discussion
- 3:30 - 3:40 Break
- 3:40 - 4:40 Lastingness: How Aging Influences Artists and Writers - Bimstein
- 4:40 - 5:00 Discussion

October 9: Fall Break

October 16: Faculty – Newman and Foster

Legal and Financial Issues that Arise with Aging and Alzheimer’s Disease

- 2:00 - 3:15 Senior Law, Guardianship, Conservatorship, POLST, Advanced Directives – Mary Jane Ciccarello
- 3:15 - 3:30 Questions and discussion
- 3:30 - 3:40 Break
- 3:40 - 4:20 What kinds of care are available and who pays? – Sylvia Brunisholz, LCSW, CMC, Family Services Counselor, Alzheimer’s Association Utah Chapter
- 4:20 - 4:40 Discussion
- 4:40 - 5:00 Reporting 4 reading and 2 film selections

Event - October 18: Hinckley Institute of Politics – Arrive by 12:15pm, Ends by 1:30

Panel discussion and media event for the Utah State Plan for Alzheimer's Disease and Related Dementia. The panel includes: Matthew Baumgart of the Alzheimer's Association, Washington DC, Dr. Norman Foster of the Center for Alzheimer's Care, Imaging and Research, Senator Karen Morgan, and Nick Zullo, Alzheimer's Association Utah Chapter

October 23: Faculty – Newman, Bimstein and Foster

Frontotemporal degeneration

- 2:00 - 2:20 Discussion of the Hinckley Institute – Faculty, Students and Bonnie Shepherd
- 2:20 – 3:00 Family experience of frontotemporal degeneration – Bonnie Shepherd
- 3:00 - 3:20 Questions for Ms. Shepherd
- 3:20 - 3:30 Break

- 3:30 – 4:00 Kid Logic – This American Life - Foster
- 4:00 - 4:10 Questions
- 4:10 - 4:30 Extraordinary artistic expression in frontotemporal dementia - Bimstein
- 4:30 - 5:00 Steps for Final Essays - Newman

October 30: Faculty – Newman, Bimstein and Foster

- 2:00 - 4:00 Midterm Review – Faculty and Students
- 3:40 - 4:15 On Golden Pond, Henry and Jane Fonda – Foster
- 4:30 - 5:00 How to conduct research and find additional resources for the final essay; utilizing librarians; selecting 3 personal resources – Foster and faculty

November 6 Faculty - Newman and Bimstein

Creative Response to Aging and Alzheimer’s Disease

- 2:00 - 2:15 Progress and trouble shooting in identifying personal resources for final essay
- 2:15 – 3:00 The Mature Mind: The Positive Power of the Aging Brain and The Creative Age: Awakening Human Potential in the Second Half of Life – Bimstein
- 3:00 – 3:30 Discussion
- 3:30 – 3:40 Break
- 4:15 - 4:30 Old Men Dancing - Newman
- 4:30 - 5:00 Ways to translate and express what you are learning into one or several Think Tank projects – Faculty

November 13 Faculty - Newman and Bimstein

Art and Alzheimer’s Disease

- 2:00 - 3:30 Personal storytelling and narrative as identity preservation and construction of meaning, and as a method of communication and expression, including Utermohlen Self Portraits and Eric Stern Demolition Derby – Bimstein and Newman
- 3:30 - 3:40 Break
- 3:40 - 4:20 P.O.V. and Discussion - Newman
- 4:20 - 5:00 Action plan discussion – faculty

November 20: Faculty – Newman, Bimstein and Foster

Genetics and Ethics in Alzheimer's Disease

- 2:00 - 2:30 Genetic causes of Alzheimer's disease and frontotemporal dementia – Renee Rider, MS, LGC, Genetic Counselor, Salt Lake City Veterans Administration Medical Center, University of Utah Center for Alzheimer's Care, Imaging and Research
- 2:30 – 2:45 Questions
- 2:45 - 3:30 Exploring family disease with genetic counseling, biobanking, autopsy
- 3:30 - 3:40 Break
- 3:40 - 4:00 Ethics of dementia care - Foster
- 4:00 - 4:20 Discussion
- 4:20 - 5:00 Composing a community friendly to Alzheimer's care - Bimstein

November 27 Faculty - Newman

Art and Caregiving

- 2:00 - 3:30 Viewing of "The Dutiful Daughter", evolution of a caregiver – Newman
- 3:30 - 3:40 Break
- 3:40 - 4:40 Caregiving and Loss in Literature - Newman
- 4:40 - 5:00 Discussion

December 4: Faculty – Newman, Bimstein and Foster

Summary Session with video recording
Proposal organization

December 11: Final assignment due

Spring Semester 2013

Assignments

Presentation of Proposals from 1st Semester: Revise 3-pagers from 1st semester based upon grading comments and discussion of overview; post to Canvas by 5PM Friday January 11 BEFORE class. Each student should read everyone else's proposal. Each student over the following 2 weeks will have 15-minutes to advocate for their proposal (Why is this address and contribute to overall project goals and how does it relate to the other proposals.) (This will not be graded separately in this semester's grade.)

Progress Reports: During the semester each individual student will prepare 5 incremental 3-5 page progress reports due before the class sent to each faculty member by email attachment. Each report should focus on progress and modifications made since the previous report. These progress reports will consist of 1) a restatement of project purpose and goals, 2) methods and results so far, 3) next steps and goals for the next reporting period, 4) a statement of the student's individual contributions to the project, 5) candid assessment of group progress and obstacles.

The progress reports will be used in part to assess:

1. Individual project contributions, which will account for 50% of the final grade, and
2. Ability to work with others, which will account for 25% of the final grade.

Final Project: The faculty will judge the value to the community of the results of the final project and quality of the presentation. (The final success of the project will account for 25% of the final grade.)

Detailed Schedule

January 8: Faculty – Newman, Bimstein and Foster

2-2:45 PM Discussion of Class Expectations and 1st Semester Essays

2:45-3:00 PM Break

3:00-5:00 PM Final Project: Nominate two Group Leaders and Scribes, Timeline, Goals, Methods, Results

January 15: Faculty - Newman and Bimstein

2-2:30 PM Elise Maxwell

2:30-3:00 PM Adam Jones
3:00-3:30 PM Alex Butler
3:30-4:00 PM Anna Adams
4:00-4:30 PM David Skidmore
4:30-5:00 PM Nicholas Shifrar

January 22: Faculty – Newman, Bimstein and Foster

2-2:30 PM Steven Clark
2:30-3:00 PM Rowan Arave
3:00-3:30 PM Amanda Miller
3:30-4:00 PM Kelsey Strong
4:00-4:30 PM Lindsay Tarbet
4:30-5:00 PM Discussion of overall project

January 29: Faculty – Newman, Bimstein and Foster

2:00-5:00 PM Final Project: Timeline, Goals, Methods, Results

February 5: Faculty – Newman, Bimstein and Foster – Progress Report #1 Due

February 12: Faculty – Newman, Bimstein and Foster

February 19: Faculty – Newman, Bimstein and Foster – Progress Report #2 Due

February 26: Faculty – Newman, Bimstein and Foster

March 5: Faculty – Newman, Bimstein and Foster – Progress Report #3 Due

Outside speaker

March 12 – Spring Break

March 19: Faculty - Newman and Bimstein

March 26: Faculty – Newman, Bimstein and Foster – Progress Report #4

April 2: Faculty – Newman, Bimstein and Foster

April 9: Faculty – Newman, Bimstein and Foster – Progress Report #5

April 12: National AFTD meeting

April 16: Faculty – Newman, Bimstein and Foster

April 23: Faculty – Newman, Bimstein and Foster

Final assignment due: April 30

Essential Download for Reference

1. *2010 Alzheimer's Disease Progress Report: A Deeper Understanding (NIA)* A layman's overview about the cause and biological basis of Alzheimer's disease. It also discusses latest research effort (For a copy go to <http://www.nia.nih.gov/alzheimers/publication/2010-alzheimers-disease-progress-report-deeper-understanding>)
2. *Utah's State Plan for Alzheimer's disease and Related Dementias* A blueprint for public policy in Utah for addressing the challenges of dementing diseases (For a copy go to http://act.alz.org/site/PageNavigator/state_plans.html and choose Utah. This page also has copies of the 23 published state Alzheimer's plans and a comparison of the elements of each of the plans both as a single comprehensive document and broken down into 16 different categories.)
3. *National Plan to Address Alzheimer Disease* A national agenda for Alzheimer's disease (For a copy go to <http://napa.alz.org/napa-released>. The last sentence of the text on this page allows you to retrieve the Plan in either pdf format or html format.)
4. *2012 Alzheimer's Disease Facts and Figures* Basic data on the costs, demographics and management of Alzheimer's disease (For a copy go to <http://napa.alz.org/additional-resources>).

Selections for assignments – books

1. *Tangles: A story about Alzheimer's, My Mother and Me* – graphic novel of the personal experience with Alzheimer's disease (complete)
2. *Hannah's Heirs: The Quest for the Genetic Origins of Alzheimer's Disease* by Daniel Pollen – genetics and history of familial Alzheimer's disease (Part I and the Descendants section Part II)
3. *King Lear* by Shakespeare (Acts I and II) – Making adjustments with aging and power
4. *When Words Have Lost Their Meaning: Alzheimer's Patients Communicate through Art* by Ruth Abraham (Introduction, Chapters 1 and 7) – Art therapy and Alzheimer's disease and how Alzheimer patients can express themselves and communicate through art
5. *Musicophilia* (Chapters 27 and 29) and *The Man Who Mistook his Wife for a Hat* (Chapter 1) by Oliver Sacks – stories about medical science and philosophy perspective on living with illness
6. *Self, Senility and Alzheimer's Disease in Modern America: A History* by J.F. Ballenger (Introduction and Chapters 1 and 6) – historical and cultural perspective on dementing diseases
7. *The Mature Mind: The Positive Power of the Aging Brain* by Gene Cohen (Chapters 6 and 8) – Advice for how to age successfully and awakening the potential of age
8. *One Nation, Uninsured: Why the U.S. Has No National Health Insurance* by Jill S. Quadagno (Introduction and Chapters 7 and 8) – Medicare and the public policy history of our health system.

Selections for assignments – film

1. *Away from Her* (2006): A man coping with the institutionalization of his wife
2. *Young@Heart* (2007): A documentary on a chorus of senior citizens singing rock and punk
3. *The Savages* (2007) – film about a brother and sister deal with the realities of caring for their father with dementing disease
4. *The Alzheimer's Project – The Memory Loss Tapes*; one of 4 one-hour films and supplemental materials (<http://www.hbo.com/alzheimers/>)

Annotated Bibliography and Resources

(Referred to in class and for individual study in addition to those listed above)

Artistic Expression

Aging

1. Visions of Aging: Images of the Elderly in Film
2. The Art of Growing Older: Writers on Living and Aging, by Wayne C. Booth
Anthology by some of our greatest writers focuses on the physical and emotional aspects of aging.
3. The Art of Aging: A Celebration of Old Age in Western Art, by Patrick McKee and Heta Hauppinen, Human Sciences Press, 1987
4. Wild Strawberries (1957): A Ingmar Bergman film on an aging professor forced to reflect on his life and integrates his experiences
5. Chivers, Sally. *The Silvering Screen: Old Age and Disability in Cinema*. University of Toronto Press, 2011.
Uses theories from disability studies, critical gerontology, and cultural studies to examine how the film industry has linked old age with physical and mental disability and at the same time has promoted youth culture.

Alzheimer's Disease and Frontotemporal Dementia

1. An Art Exhibition: The Later Works of William Utermohlen 1995-2000; A Lecture Event Portraits & Promises in Alzheimer's Disease (DVD) – An artist who records through self-portrait his decline caused by Alzheimer's disease
2. Demolition Derby: When A Mind Loses its License to Drive created by Erik Stern and Sternworks (DVD) – A dance performance reflecting the personal experience of the choreographer in caring for both parents who had dementing diseases
3. Music Therapy in Dementia Care, edited by David Aldridge, especially Chapters 1 and 8 – The role of music in Alzheimer's care
4. The Dutiful Daughter (1995) (DVD) - Inspiring commentary about how a daughter learns to adjust to her mother's progressive dementia and how both learn to make the most out of life. Originally on the PBS series POV in 1995
5. Espinel CH. de Kooning's late colours and forms: dementia, creativity, and the healing power of art. *Lancet* 1996;347:1096-1098.
6. Miller BL, Hou CE. Portraits of artists: emergence of visual creativity in dementia. *Arch Neurol* 2004;61:842-844.
7. Rockwood K. Lending a helping eye: artists in residence at a memory clinic. *Lancet Neurol* 2004;3:119-123.
8. A disease that allows torrents of creativity by Sandra Blakesly, *New York Times*, an article about a remarkable patient with frontotemporal dementia. Available at: <http://www.nytimes.com/2008/04/08/health/08brai.html?ex=1208318400&en=dcc9b07bc23aeeb2&ei=5070&emc=eta>
9. "Unraveling Bolero" Radiolab podcast. A story about obsession, creativity, a biologist and a composer with frontotemporal dementia. Available at: <http://www.radiolab.org/blogs/radiolab-blog/2012/jun/18/unraveling-bolero/>

Literature and Culture

Aging

1. Composing a Further Life: The Age of Active Wisdom (2010) Mary Catherine Bateson
2. I Remember Nothing and Other Reflections by Nora Ephron (160 pages, pages 1-16) – a comic view about how getting old isn't so good as advertised
3. On Golden Pond, a movie starring Henry Fonda, Jane Fonda and Katherine Hepburn
4. The Creative Age: Awakening Human Potential in the Second Half of Life by Gene D. Cohen
5. Lastingness: The Art of Old Age by Nicholas Delbanco
6. Cole, Thomas, Ray, Ruth, and Kastenbaum, Robert. *A Guide to Humanistic Studies in Aging: What Does It Mean to Grow Old?* The Johns Hopkins University Press, 2010
Explores the moral, spiritual, and cultural aspects of aging through interdisciplinary scholarship and clinically based research. The second section is devoted to applying interdisciplinary humanities to questions about aging and the third section to using theoretical frames to identify social issues related to aging.
7. Cole, Thomas. *The Journey of Life: A Cultural History of Aging in America*. Cambridge University Press, 1992.
Examines the political, philosophical, and religious influences on societal attitudes about aging as well as gender and familial ideals.
8. Cruikshank, Margaret. *Learning to Be Old: Gender, Culture, and Aging*. Rowan and Littlefield, 2009.
Compares the aged to colonized people and looks at how the onus of aging, especially for women, is growing, not diminishing. The volume also pays attention to multicultural traditions and the medicalization of natural processes. A dense and complex look at aging issues.
9. Franzen, Jonathan. *The Corrections*. Farrar, Straus and Giroux, 2001.
A novel about a family with a dominating father who slips into dementia.
10. Gullette, Margaret. *Aged by Culture*. University of Chicago Press, 2004.
Scholarly work that looks at the "pernicious" nature of what our culture does to aging and the problems that follow when Americans internalize it. Uses sociology and critical theory to examine the relationship between physical and conceptual age.
11. Kohn, Martin, Donley, Carol, and Wear, Denise. *Literature and Aging: An Anthology*. Kent State University Press, 1992.
Collection of over 60 short stories, plays, and poems that addresses the joys and sorrows of growing older. Selections represent the experiences of aging from the perspectives of persons of diverse color, ethnicity, and background.
12. Leibing, Annette and Cohen, Lawrence (eds). *Thinking About Dementia: Culture, Loss and the Anthropology of Senility*. Rutgers University Press, 2006.
Volume of essays by nineteen respected scholars that approaches dementia from different angles and examines the historical, psychological, and philosophical implications. It explores questions of age, mind, voice, self, loss, temporality, meaning, and affect from a cross-cultural and medical anthropological perspective.
13. Nelson, Todd. *Ageism: Stereotyping and Prejudice Against Older Persons*. MIT Press, 2002.
Looks at how although age discrimination is found around the world it is especially prevalent in the United States. Presents theoretical and empirical findings on the origins and effects of ageism.
14. Tan, Amy. *The Bonesetter's Daughter: A Novel*. Ballantine, 2003.

- Revolves around memories set down by the protagonist's mother who has been diagnosed with Alzheimer's disease. It interrogates the meanings of memories and investigates the dilemmas of children who must become their parents' caretakers
15. Woodward, Kathleen. *Aging and Its Discontents*. Indiana University Press, 1991.
Analyzes modern Western culture's "anxiety, fear, denial, repression" of aging in works by writers such as Proust, Woolf, Mann, Beckett, and others. Based on psychoanalysis, argues that ageist ideology privileges youth over age and has become part of a structural social hierarchy.

Alzheimer's Disease and Frontotemporal Dementia

1. *Scar Tissue* by Michael Ignatiff – a novel about Alzheimer's disease in a Midwestern family, torn by the stress of disease, yet still connected
2. *The Banana Lady* by Andrew Kertesz – a behavioral neurologist describes frontotemporal dementia for the lay public
3. *Elegy for Iris* by John Bayley – an author describes his wife's journey with Alzheimer's disease
4. *Life in the Balance* by Thomas Graboys – a physician learns to live with having dementia with Lewy bodies
5. *Still Alice* (2007) by Lisa Genova. A very readable and realistic description of the things that someone afflicted with AD often goes through. It's written by a neuroscientist and has good reviews from several AD organizations and authorities.
6. *Ten Thousand Joys & Ten Thousand Sorrows* by Olivia Ames Hoblitzelle, Endorsed by the Dalai Lama and many top Buddhist authors as well as Alzheimer's associations, valuable insights about the spirituality and psychology (the author has training and practice in both) of Alzheimer's care.

Public Policy

Aging

1. *Social Security: The Inside Story*, 2012 edition by Amy Landis - an advice book about what social security offers and doesn't offer
2. *The Battle for Social Security: From FDR's Vision to Bush's Gamble* by Nancy J. Altman – the history and ingenious structure of social security and commentary on recent reform efforts.
3. *Social Security: History and Politics from the New Deal to the Privatization Debate (Studies in Government & Public Policy)* by Daniel Beland – comparison with programs in other countries and how controversy has evolved
4. *Retooling for an Aging America: Building the Health Care Workforce: Committee on the Future Health Care Workforce for Older Americans*, Institute of Medicine available at <http://www.nap.edu/catalog/12089.html>
5. *Growing Older in America: The Health and Retirement Study*, the National Institute on Aging; available at <http://www.nia.nih.gov/health/publication/growing-older-america-health-and-retirement-study/> - review of the results of a longitudinal study of aging and economics
6. Stoller, Eleanor Palo and Gibson, Rose Campbell. *Worlds of Difference: Inequality in the Aging Experience*. Sage, 1999.
Useful book for undergraduates that addresses the diversity of aging experiences in society by race, gender, and social class.

Alzheimer's Disease

1. Alzheimer's Association Policy and Advocacy – a review of current key legislation available at http://www.alz.org/research/funding/alzheimers_policy_and_advocacy.asp
2. Open Wound: The Tragic Obsession of Dr. William Beaumont by Jason Karlawish – a historic episode that raises questions ethical questions about medical research
3. Jones JH. Bad Blood: the Tuskegee Syphilis Experiment. New York: Free Press, 1993. – clinical trials and ethics
4. Post, Stephen. *The Moral Challenge to Alzheimer's Disease*. The Johns Hopkins University Press, 2000.
Covers ethical issues of interest to health care professionals, families, and affected individuals including things such as autonomy through advance directives, behavior control, quality of life in relation to treatment limitations, hospice care, and euthanasia. Argues for the dignity of patients as central to their emotional and relational well-being.
5. Joe & Flo: A Senior Couple's Struggle to Stay United by Michael Chandler, NPR's Morning Edition January 7, 2006 A story from Salt Lake City's Silverado Senior living about family decisions, marriage, behavior changes, dementia and aging. Available at: <http://www.npr.org/templates/story/story.php?storyId=5133103>

Science and Medicine

Aging

1. Damasio H, Grabowski T, Frank R, Galaburda AM, Damasio AR. The return of Phineas Gage: clues about the brain from the skull of a famous patient [published erratum appears in Science 1994 Aug 26;265(5176):1159]. Science 1994;264:1102-1105. Also "The Face of a Famous Skull Found on Flickr" available at <http://www.npr.org/templates/story/story.php?storyId=122810679>
2. Hunter EJ, Kapsner-Smith M, Peard P, Engar MZ, Brown WR. Age and speech production: a 50-year longitudinal study. J Am Geriatr Soc 2012;60:1175-1177.

Alzheimer's Disease and Frontotemporal Dementia

1. Charlie Rose: The Brain Series on Alzheimer's disease available at <http://www.charlierose.com/view/interview/12171>. – Alzheimer disease experts discuss current understanding and scientific challenges
2. Charlie Rose: Recent developments in Alzheimer's disease with Scott Small M.D., available at <http://www.charlierose.com/view/interview/12134>. - A recent breakthrough in how abnormal tau protein spreads throughout the brain
3. Hodges JR. Alzheimer's centennial legacy: origins, landmarks and the current status of knowledge concerning cognitive aspects. Brain 2006;129:2811-2822. A historical perspective on scientific approaches to Alzheimer's disease
4. One Brain Shrinks, Another Brain Grows, Act Four, Kid Logic, This American Life available at: <http://www.thisamericanlife.org/radio-archives/episode/188/kid-logic>
5. The 36-hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias and Memory Loss (5th edition) by Nancy Mace and Peter V. Rabins – the original and now classic book with information for caregivers
6. Valenstein ES. Great and Desperate Cures: The Rise and Decline of Psychosurgery and Other Radical Treatments for Mental Illness. New York: Basic Books, Inc., 1986. A cautionary tale about when we are desperate to cure or at least control serious and scary diseases.

7. My Lobotomy by Howard Dully; November 16, 2005; National Public Radio, All Things Considered. The results of a medical therapy that alters frontal lobe function. Available at: <http://www.npr.org/2005/11/16/5014080/my-lobotomy-howard-dullys-journey>