THE LONGEST LOSS: ALZHEIMER’S DISEASE AND DEMENTIA

DESCRIPTION:
When the diagnosis is Alzheimer’s disease or another dementia, grief doesn’t wait for death. Grieving can begin before a formal diagnosis or in the doctor’s office when patients and families receive confirmation of illness. Over a span of what may be a decade or more, multiple losses associated with dementia become a pervasive part of everyday life for millions of patients, families and friends. After the death, survivors’ grief may be complicated by the nature of a lengthy disease process that has changed their relationship with the deceased. Through a combination of candid, compelling interviews and unscripted in-studio discussions, experts will identify how medical and social service professionals can best improve care for patients, families and themselves while coping with loss and grief associated with these progressive illnesses.

DATES/TIMES:
The Longest Loss: Alzheimer’s Disease and Dementia premiers April 22, 2015. The program is 2.5 hours, with an additional 30 minute local discussion, required for CE credits. The program is available for viewing and CE credits for 1-year; until April 21, 2016.

METHOD OF PRESENTATION:
The program will be available ONLINE* or on DVD**.
*Viewing instructions for the online webcast will be available to you in your download materials online.
**The DVD will be mailed to you a week or two before the premiere date.

TECHNICAL REQUIREMENTS

ONLINE FORMAT
To view this online program, you will need a computer and screen, reliable internet access, and speakers. If you are showing to a large group, you will need a way to project on a large screen and a sound amplification system. Please test your system ahead of time to ensure you have the capabilities to view and hear the program, as HFA does not provide refunds on registration. Please also be sure to test on the SAME equipment you will use on the day of the program viewing.

TEST LINK for Audio and Video:
http://media01.commpartners.com/CP/browser_test/iframe.html

Technical Questions? Please contact CommPartners at 1-800-274-9390 or via e-mail at: hospice@commpartners.com.

DVD FORMAT
This program has been authored to play in modern DVD players and display on any television. It also will play in computers with a DVD drive that have the software to play DVD movies.

Please test the DVD in the same player you will use to show the disc to your audience. Do not assume that if the DVD plays at home, it will play at work; or if it plays in your computer, it will play in a stand-alone DVD player or vice versa. Closed Captions must be activated on the television to be visible.
PROGRAM FEES/MATERIALS:
Early registration is available until October 31, 2014. Registration fees are as follows:

- DVD Registration $175 early / $225 regular
- Webcast Registration $110 early / $160 regular

Materials Include:
- Access to the ONLINE program or the DVD (view anytime you choose; from 4/22/15 until 4/21/16)
- One copy of HFA’s companion book, "The Longest Loss: Alzheimer's Disease and Dementia"
- Downloadable Materials:
  - Program Guide (pdf)
  - Tip Sheet (pdf)
  - Marketing Kit (editable flyers, brochures, and social media announcements)
  - Organizer’s Manual
  - Sample Discussion Questions
  - Additional helpful program information

HOW TO REGISTER:
Register directly online, on HFA’s registration site: https://register.hospicefoundation.org

DOWNLOAD AREA:
Once you are registered for the program, you will have immediate access to the "Download Area" online, where all of your downloadable materials, listed above, are located. Download materials are posted to this website only (register.hospicefoundation.org). To access your materials, simply log-in using the e-mail address that you registered with and click on "Downloads" on the left-hand menu.

TARGET AUDIENCE:
The program is primarily for professionals already working in the field, but is practical for all levels of education – entry level, intermediate or advanced. The information provided by the expert panel will be useful to clergy, counselors, nurses, nursing home administrators, social workers, case managers, psychologists, physicians, funeral directors, marriage and family therapists, caregivers, and those working with death, dying, grief or bereavement.

LEARNING OBJECTIVES:
At the conclusion of this webinar, participants will be able to:

1. Describe the characteristics of Alzheimer’s disease and other dementias, including unique challenges that these diseases present to patients and families;
2. Discuss the grief of persons with dementia, including nonfinite loss and anticipatory mourning, as it is experienced in early stages and during progression of disease;
3. Recognize changes in patient and family behaviors that may be indicative of grief, and describe therapeutic techniques that can be used effectively, including reminiscence and ritual;
4. Support families as they navigate and grieve changes in the relationship and transitions in care as the disease progresses, and understand the potential grief reactions brought about by these changes;
5. Identify the demands and challenges on professional caregivers when caring for individuals with Alzheimer’s disease and other dementias and list several strategies for employer support and self-care;
6. Describe innovative ways of supporting family caregivers exhibiting grief reactions throughout the illness as well as after the death of the individual with dementia, noting factors that compound grief, including guilt, ambivalence, fatigue and relief.
**PROGRAM OUTLINE:**

**Part I: Coping with Loss at the Onset of Disease**
- Although memory loss is part of the normal aging process, dementia is not. Dementia is the result of disease – most commonly Alzheimer’s disease – or circumstance, such as traumatic brain injury.
- Regardless of origin, the nature and progression of dementia can be dehumanizing for the patient and challenging for caregivers and clinicians. Professionals who care for the ill, dying, and bereaved generally possess the basic skillset to care for persons with dementia and can utilize that knowledge as a foundation to address the unique issues involved in caring for and supporting persons with dementia and their families.
- From the onset of symptoms, through diagnosis and progression of disease, grief is nearly constant as persons with dementia and their families deal with myriad losses including memory, abilities, and relationships. Professional caregivers should consider innovative approaches to assist persons with dementia and their families in coping with these losses.
- The ongoing provision of care can complicate and/or facilitate grief. Providers should recognize that as families attempt to navigate the progression of dementia, they may need additional support when encountering care transitions that have the potential to exacerbate grief.
- Families who believe they have prepared for the typical, long-term trajectory of dementia may need support if the person with dementia declines more rapidly than expected or dies suddenly from an acute event, such as a heart attack.

**Part II: Living with Grief and Dementia at Life’s End**
- There is scant research for guidance, but informed practice indicates that touch and other sensory therapies, including tone of voice used by caregivers, can help to calm or reassure distressed or agitated late stage dementia patients who may be suffering emotional or physical pain. Pharmacologic treatment of pain has been shown to be effective in very late stage dementia.
- The nature of dementia and the strain of isolation of caregiving can lead to ambiguous loss, disenfranchised grief, and complicated grief. Some individuals may need additional help and support adjusting to repeated losses.
- End-of-life decision making can be impacted by the nature of grief and dementia, especially if the person with dementia can no longer be a part of the process. Family members burdened with multiple loss experiences of the illness, as well as caregiving exhaustion, may disagree with each other, influencing end-of-life decisions and reactions. Health, social service and clergy professionals can offer critical support in guiding families through these challenging situations.
- Clinicians and other professional caregivers often form attachments to persons with dementia and may also grieve losses associated with their patients. Employers should develop a range of supports to offer staff, and professionals should be aware of and practice healthy self-care strategies.
- Because of their end-of-life care expertise, hospice and palliative care providers can provide services to community members coping with dementia prior to a death as well as afterward. Early provision of support services can serve as a bridge and provide a way to introduce hospice and palliative care to families. Online dementia specific support communities can also be a useful resource.

**CONTINUING EDUCATION (CE) CREDITS:**
CE credits (3 hours) are available by a number of professional boards after the program viewing. The cost is $15 per certificate. CE credits are available for one year; until April 21, 2016. A "Certificate of
Attendance" will be provided at no cost to attendees. Sites will be able to print this out ahead of time on the Download Area online. *Note: the Certificate of Attendance is not accepted by professional boards.

A complete list of professional board approvals for this program is posted to HFA’s website at www.hospicefoundation.org.

**CE credits are copyrighted by HFA.** Participants are attending an event of Hospice Foundation of America (HFA). All CE certificates must be obtained directly through HFA. Boards approve the content developed by HFA, not by the viewing organization. CE instructions will be provided to you on the download area online.

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**COURSE COMPLETION REQUIREMENTS:**
Participants must attend the entire 3-hour program (2.5 hour video presentation plus 30-minute local discussion). Partial credit is not awarded. Participants must also complete the entire CE process online, before the CE deadline of April 21, 2016. (In order to go online, attendees will need to enter in a Course Code, which is only provided at the end of the program). The online CE process includes a required evaluation form and exam. The exam must be completed at 80% or above (the exam may be re-taken, if necessary). Attendees will be able to choose the board they wish to receive credit from (from Hospice Foundation of America’s list of board approvals) and will then be able to print their CE certificate immediately after completing all CE requirements online (on HFA’s CE site at https://educate.hospicefoundation.org).

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**EXPERT PANELISTS:**

**Charles A. Corr, PhD,** is a volunteer member of the Board of Directors of the Suncoast Hospice Institute (an affiliate of Suncoast Hospice); Professor emeritus, Southern Illinois University Edwardsville; a long-time member and former Chairperson of the International Work Group on Death, Dying, and Bereavement; a long-time member of the Association for Death Education and Counseling; and Senior Editor of the ChiPPS (Children’s Project on Palliative/Hospice Services) quarterly E-Journal on pediatric palliative/hospice care. Dr. Corr's work as an educator and writer has been honored by numerous awards. His publications include well over 100 chapters and articles in professional journals, along with more than three dozen books and booklets, the most recent of which is the 7th edition of *Death & Dying, Life & Living* (Belmont, CA: Wadsworth, 2013).

**Kenneth J. Doka, PhD, MDiv,** is a professor of gerontology at the Graduate School of The College of New Rochelle and Senior Consultant to the Hospice Foundation of America. A prolific author and editor, Dr. Doka serves as editor of HFA’s *Living with Grief* book series, its *Journeys* newsletter, and numerous other books and publications. In addition, Dr. Doka has served as a panelist on HFA’s *Living with Grief* teleconference programs for 16 years. Dr. Doka was elected president of the Association for Death Education and Counseling in 1993. In 1995, he was elected to the board of directors of the International Work Group on Death, Dying and Bereavement and served as chairperson from 1997-1999. The Association for Death Education and Counseling presented him with an Award for Outstanding Contributions in the Field of Death Education in 1998. In 2006, Dr. Doka was grandfathered in as a Mental Health Counselor under New York’s first state licensure of counselors. He has been the keynote speaker at conferences throughout North America as well as Europe, Asia, Australia, and New Zealand, and is a frequent guest on television and radio news programs. Dr. Doka is an ordained Lutheran minister.

**Nancy Pearce, MSW, LISW-CP, MS,** is a licensed gerontological social worker with 30 years of experience in working in long-term healthcare and hospice settings. In her practice, she integrates her educational research foundations with understandings from both her work experience and studies in spiritual and religious wisdom traditions. Ms. Pearce specializes in working with persons who have dementia and
teaches families, friends and professionals, both nationally and internationally, how to communicate and connect effectively with persons with dementia, regardless of how advanced the dementia, and to co-create a more supportive community of care. She is the author of Inside Alzheimer’s (Forrason Press, 2011) and is a frequent contributor to Social Work Today and other publications.

Peter V. Rabins, MD, MPH, has been on the faculty of the John Hopkins School of Medicine since 1978. He is the emeritus Richman Family Professor and founding director of the Division of Geriatric Psychiatry and Neuropsychiatry in the Department of Psychiatry and Behavioral Sciences and a member of the Johns Hopkins Berman Bioethics Institute. Dr. Rabins has spent his career studying psychiatric disorders in the elderly. He was the first to demonstrate elevated mortality in persons with delirium and among the first to identify high rates of neuropsychiatric symptoms in persons with dementia. He is the author or editor of more than 280 peer-reviewed articles and 8 books, including The 36-Hour Day, a Family Guide for People who have Alzheimer Disease, Related Dementias and Memory Loss.

Kathie Supiano, PhD, LCSW, FT, F-GSA, is an Associate Professor in the College of Nursing, and the director of Caring Connections: A Hope and Comfort in Grief Program at the University of Utah College of Nursing. She teaches Interdisciplinary Approaches to Palliative Care for graduate students in Pharmacy, Social Work and Nursing, Geriatric Care Management and in the Interprofessional Education Program. Dr. Supiano’s research is in clinical interventions in complicated grief, suicide survivorship and prison hospice. She has been a practicing clinical social worker and psychotherapist for over 30 years. Her clinical practice has included care of older adults with depression and multiple chronic health concerns, family therapy, end-of life care, and bereavement care. Dr. Supiano is a Fellow in the Gerontological Society of America, a Fellow of Thanatology, and a founding member of the Social Work Hospice and Palliative Care Network. She received her PhD in Social Work at the University of Utah as a John A. Hartford Foundation Doctoral Fellow.

REVIEWERS:
Pamela Kushner, MA, MD, FAAFP, Clinical Professor Family Medicine, University of California Irvine
Lynda Shand, CHPN, CNE, Associate Professor, The College of New Rochelle

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This is based on individual site location(s). For program organizers, please post all ADA instructions when advertising the program.

CONFLICT OF INTEREST:
Planners (Panelists and Review Committee Members) disclose no conflict of interest relative to this educational activity.

FOR QUESTIONS, COMMENTS, OR ADDRESSING GRIEVANCES
Please contact Hospice Foundation of America (HFA)
1710 Rhode Island Ave. NW, Suite 400, Washington, DC 20036
educate@hospicefoundation.org / www.hospicefoundation.org
1-800-854-3402 toll-free / (202) 457-5811 phone / (202) 457-5815 fax