

## Hospice Foundation of America's Program

# INTIMACY AND SEXUALITY DURING ILLNESS AND LOSS

## Self-Study ONLINE Course

### DESCRIPTION

Holistic treatment of individuals who are terminally ill or bereaved should include the needs of the whole person. Yet the most basic of human desires, those that include intimate and sexual relationships, are frequently avoided, dismissed, or unaddressed by healthcare, social service, clergy and bereavement professionals. Patients, family caregivers, and clients can be inhibited by the deeply personal nature of intimacy and sexuality and often do not raise concerns with professionals.

In this program, Hospice Foundation of America identifies barriers to intimacy and sexuality for terminally ill persons and the bereaved. The program emphasizes the knowledge and skills that professionals must have to sensitively address intimacy and sexuality and suggest interventions that can help dying and bereaved persons address these elemental human needs.

### PROGRAM DETAILS

Hospice Foundation of America has taken this popular *Living with Grief*<sup>®</sup> program and created a self-study course for professionals. This educational program combines a moderated discussion, informative interviews, and additional complimentary learning materials.

<b>RELEASE DATE:</b>	Program originally premiered September 24, 2020
<b>ON DEMAND:</b>	to registered individuals for 1 year after purchase
<b>LENGTH:</b>	120 minutes + selected book reading (two PDF chapters)
<b>CE HOURS:</b>	2.5 hours for a wide variety of professional boards
<b>CE FEE:</b>	One CE certificate is included in the cost of registration. Additional certificates (if selecting more than one board) are \$10 each.
<b>CONTENT LEVEL:</b>	The program is mainly for professionals already working in the field but is practical for all levels of education – entry level, intermediate or advanced.
<b>TARGET AUDIENCE:</b>	The course is useful to Health professionals, psychologists, counselors, clergy, social workers, nurses, and other health care workers, educators, and community members who support older adults.

### HOW THE ONLINE SELF-STUDY PROGRAM WORKS

**Step 1** - Register/purchase the course

**Step 2** - View the course online through the link in your confirmation email or in your account.

**Step 3** - Read the pdf chapters provided

**Step 4** - Follow the instructions provided to receive your CE certificate\*.

\*An evaluation and a short exam are a part of this process.

### TECHNICAL REQUIREMENTS

To view this online program, you will need a computer and screen, reliable internet access, and speakers. Please test your system ahead of time to ensure you have the capabilities to view and hear the program. Mobile service provider charges may apply.

TEST LINK for Audio and Video:

<http://hospicefoundation.org/Professionals/All-Programs/All-Self-Studies/Video-Test-Page>

## REGISTRATION INFORMATION/FEEES

Register directly online, on HFA's website: [www.hospicefoundation.org](http://www.hospicefoundation.org). To have a registration form mailed to you, contact HFA at 800-854-3402 or by email at [educate@hospicefoundation.org](mailto:educate@hospicefoundation.org).

For current prices, please refer to HFA's website at <https://hospicefoundation.org/Education/HFA-CE-Programs>.

**There are no refunds on registration.** \*Few exceptions may occur depending on the circumstance. To request a refund, a written request must be received (and granted) by HFA.

## REGISTRATION POLICY

### INDIVIDUAL REGISTRATION

Provides one person, the registrant, access to the self-study course for personal viewing.

### MULTIPLE VIEWER REGISTRATION

Provides one person, the registrant, access to the webcast for streaming from one computer to a group of people. Program access fees remain the same; CEs are included in course fees for the registered user and are \$12 per additional participant per course. **Please note that self-study courses accommodate individual learners only unless prior arrangements are made through HFA for additional certificates.** Contact HFA at 202-457-5811 or email us at [educate@hospicefoundation.org](mailto:educate@hospicefoundation.org) to register the additional participants.

## MATERIALS AREA

Course materials are accessible to all registered individuals immediately after registering. Program materials are available on HFA's website at <https://hospicefoundation.org/Shop-HFA/My-Account>. From here, click on "Orders/Courses." Materials contain the full-length video, CE instructions, the program's slides, and additional program material. Information will be posted to your account as they become available.

## LEARNING OBJECTIVES

AT THE CONCLUSION OF THIS PROGRAM, PARTICIPANTS WILL BE ABLE TO:

1. Define and contrast intimacy and sexuality and describe how these needs may affect the care and well-being of dying and bereaved individuals.
2. Describe barriers to meeting the needs of intimacy and the sexual desires of individuals who are coping with life-threatening illness.
3. Discuss sensitivities, skills and knowledge that end-of-life professionals should possess to use appropriate interventions that address the intimacy and sexual needs of dying persons.
4. Describe the intimacy and sexual needs of individuals who are bereaved and identify barriers that inhibit opportunities to address such needs.
5. Discuss sensitivities, skills, and knowledge that end-of-life professionals should employ when addressing issues of intimacy and sexuality with bereaved individuals.
6. Identify the ethical issues, including boundaries, that healthcare professionals should be aware of when helping clients and patients meet intimate and sexual needs.
7. Discuss how barriers to intimacy can be overcome in the midst of a public health crisis that restricts visits and contact with family and friends at end of life.
8. Identify three ways that grief is impacted by when intimate contact near death or during the dying process is prohibited and when death rituals such as memorials and funerals are delayed; Discuss counseling interventions to support these grievers.
9. Discuss how barriers to intimacy can be overcome in the midst of a public health crisis that restricts visits and contact with family and friends at end of life; and
10. Identify three ways that grief is impacted by when intimate contact near death or during the dying process is prohibited and when death rituals such as memorials and funerals are delayed; Discuss counseling interventions to support these grievers.

## **PROGRAM OUTLINE**

### **INTIMACY AND SEXUALITY DURING ILLNESS (75 MIN)**

- Humans are both inherently relational and sexual beings. Intimacy is a deep personal and loving relationship with an emotional closeness and may or may not have a physical component. Sexuality encompasses the totality of behaviors and attitudes that influence sexual orientation and expression. This includes capacity for and strength of sexual feelings and behaviors, sensitivities about sexual feelings and behaviors, and gender identification. While sexuality is based on biological drive, it is also influenced by emotional, psychological, social, and spiritual mores, attitudes, and beliefs.
- Intimacy and sexuality needs exist, in one form or another, throughout the life cycle. Research shows that while terminally-ill patients retain sexual and intimacy needs, these desires often are unacknowledged by professional caregivers, their families, friends, and informal caregivers. End-of-life care professionals can assist by sensitively providing education about the ways these needs may change and how they can be addressed during advanced illness. Professionals should be aware of their own biases and knowledgeable about the personal, psychological, and institutional barriers that inhibit patients, informal caregivers, partners, and families from fulfilling intimacy and sexuality needs. Such barriers include an illness' effect on body image (weight loss, hair loss, mastectomy, for example); health considerations (such as fatigue, pain, medical equipment, weakness, nausea, side effects of treatment or medication, heart malfunction due to arousal); and psychological factors, including grief and depression.
- Caregivers who have an intimate or sexual relationship with a patient may also be affected by caregiver stress and fatigue, anticipatory mourning, or change in partner roles. As hospice aims to care for the family unit, information and/or counseling should be offered to caregivers who experience duress due to a diminishing ability to experience intimacy or sexuality.
- There may be additional barriers to intimacy and sexuality for those persons who define their sexual orientation as lesbian, gay, bisexual, transgender, questioning or asexual. Healthcare provider organizations should develop, review, and if necessary, revise policies, methods of communication, intake forms, and other materials that demonstrate inclusivity and respect for a patient's sexual orientation. End-of-life professionals should work from a patient-centered approach, and again, be aware of their own perspectives and biases.
- End-of-life professionals should routinely assess patients' advance care plans, as well as their sexual and intimacy needs and histories. There are tools such as the Ex-PLISSIT, BETTER, and ALARM models that can be useful in meeting these goals.
- Some patients and families report a different, or even increased intimacy, in the face of serious illness. Hospice and palliative care providers may find varied complementary therapies, such as meditation, massage, and pet therapy, useful in enhancing these opportunities and assisting patients in meeting intimacy needs.
- Spiritual and religious beliefs often address issues of sexuality and intimacy. End-of-life professionals should assess the ways that a client's spirituality can complicate and/or facilitate the expression of sexual and intimacy needs.
- While all individuals share intimacy and sexual needs, in certain populations these needs may raise profound ethical, legal, and practical issues for professionals and organizations providing end-of-life care. End-of-life professionals should review institutional policies in order to strike a balance between preserving these basic human needs while offering adequate protection for patients.
- While all individuals share intimacy and sexual needs, in certain populations these needs may raise profound ethical, legal, and practical issues for professionals and organizations providing end-of-life care. End-of-life professionals should review institutional policies in order to strike a balance between preserving these basic human needs while offering adequate protection for patients.

### **INTIMACY AND BEREAVEMENT (45 min)**

- When a partner dies, a bereaved person may experience the secondary loss of intimacy and/or sexual expression. Bereavement professionals should assess these needs and be aware of barriers that might inhibit bereaved individuals from addressing such needs or addressing them in ways that are destructive.
- Intimacy and sexual needs also may be interrupted when a child dies. Bereavement professionals should assess the ways that a child's death affects parental intimacy and sexuality and develop sensitive interventions that offer education and resources to assist parents in regaining an intimate relationship.

- Survivors of suicide or other trauma often may find it difficult to regain trust necessarily for healthy intimate and sexual relationships. Professionals should be sensitive to the barriers that exist for survivors of suicide and/or other trauma and support clients in acknowledging these obstacles.
- Discussions about sexuality and intimacy can create tension and cause discomfort in bereavement professionals. Professionals need training and supervision from colleagues, employers, or universities as they struggle with the skills and ethical sensitivities inherent in such discussions. In addition, individuals and their respective organizations should teach and model effective approaches to self-care.

## CONTINUING EDUCATION

This program is available for 2.5 credits of continuing education. CE credits are available to the registered participant online (after completing the course). One CE certificate is included in the cost of registration. Additional certificates (if selecting more than one board) are \$10 each. A complete list of board approvals for this course is posted to HFA's website (at [www.hospicefoundation.org](http://www.hospicefoundation.org)).

## COURSE COMPLETION REQUIREMENTS

Participants must view the entire 120-minute program (online-streaming video) and read the selected book chapters (available in PDF format). Partial credit is not awarded. Participants must also complete the entire CE process online, before the CE deadline (1 year after purchase of course). In order to go online, two codes will be issued to you and verified online; a Site # (same as your Order/Invoice #) and the Course Code (provided in your CE instruction sheet). 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\*). Participants 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>).

\*A complete list of board approvals is posted on HFA's website at [www.hospicefoundation.org](http://www.hospicefoundation.org).

## EXPERT SPEAKERS

**Carrie Arnold, PhD, FT, MEd, RSW, CCC**, obtained a Bachelor of Arts (Honours) in Psychology, a Master of Education (Counselling), both from the University of Western Ontario, and a Ph.D. (Psychology) from Saybrook University. She is a Certified Canadian Counsellor with the Canadian Counselling and Psychotherapy Association, is registered with the Ontario College of Social Workers and Social Service Workers and is an approved service provider with the First Nations and Inuit Health Branch of Health Canada. Dr. Arnold provides psychotherapy to adolescent and adult clients in the areas of grief, loss, and trauma. Her publications include articles on issues related to the experiences of adolescent girls, attachment and loss, and an edited volume entitled *Understanding Child and Adolescent Grief: Supporting Loss and Facilitating Growth* (Routledge).

Additionally, Dr. Arnold has launched The Grief and Loss Research Lab at King's University College. Current research interests include the use of photo narrative with the bereaved, as well as medical assistance in dying (MAiD). Dr. Arnold is currently an assistant professor, thanatology, at King's University College at Western University.

**Alua Arthur, JD**, is a death doula, attorney, and the founder of Going with Grace, an end of life planning organization that exists to support people as they answer the question 'What must I do to be at peace with myself so that I may live presently and die peacefully?' From private end of life consultations to online coursework to train death doulas, she is tirelessly committed to bringing awareness to death and dying and passionately believes considering death can inspire the way we live.

**John Cagle, MSW, PhD**, is an Associate Professor, University of Maryland School of Social Work with a substantive interest in improving care at the end of life. As a translational health services researcher, his efforts have focused on identifying effective models of care and support for dying patients and their families – and implementing those models into routine clinical practice. His research is informed by nearly a decade of clinical

work as a hospice social worker. Dr. Cagle completed his PhD from Virginia Commonwealth University where his dissertation thesis explored the needs and experiences of informal caregivers of advanced cancer patients.

After being awarded his doctoral degree in 2008, he trained as an NIA-funded postdoctoral fellow at the University of North Carolina at Chapel Hill, Institute on Aging as well as the University of California, San Francisco, Division of Geriatrics. His current research examines disparities in care at the end of life, psychosocial barriers to pain management, and improving palliative care outcomes in long-term care settings. His research has been supported by a number of public and private entities, including the Hospice Foundation of America, the National Palliative Care Research Center, the John A. Hartford Foundation, the National Institute on Aging, the Agency for Healthcare Research and Quality, the National Hospice and Palliative Care Organization, and the Foundation for Care at the End of Life.

**Kenneth J. Doka, PhD, MDiv**, is Senior Bereavement Consultant to HFA and recipient of the 2019 Lifetime Achievement Award from the Association for Death Education and Counseling.

He serves as editor of HFA's *Living with Grief*<sup>®</sup> book series and its *Journeys* bereavement newsletter. He is a prolific author, editor, and lecturer; past president of the Association for Death Education and Counseling (ADEC); and a member and past chair of the International Work Group on Death, Dying, and Bereavement (IWG). In 2018, the IWG presented Doka with the Herman Feifel Award for outstanding achievement in thanatology. He received an award for Outstanding Contributions in the Field of Death Education from ADEC in 1998. Doka is an ordained Lutheran minister and a licensed mental health counselor in the state of New York. This is Dr. Doka's 27<sup>th</sup> year of involvement with the *Living with Grief*<sup>®</sup> program.

## **MODERATOR**

**Frank Sesno**, is Director of Strategic Initiatives at The George Washington School of Media & Public Affairs. He is an Emmy Award-winning journalist and creator of Planet Forward, a user-driven web and television project that highlights innovations in sustainability. Inspired by his mother's experience with Hospice, Mr. Sesno has hosted the Hospice Foundation of *Living with Grief*<sup>®</sup> program for 10 years. Mr. Sesno's diverse career spans more than three decades, including 21 years at CNN where he served as White House correspondent, anchor and Washington Bureau Chief. He has interviewed five U.S. presidents and thousands of political, business and civic leaders — ranging from Hillary Clinton and Israeli Prime Minister Benjamin Netanyahu to Microsoft founder Bill Gates and broadcast legend Walter Cronkite. He has won several prestigious journalistic awards, including an Emmy, several cable ACE awards, and an Overseas Press Club Award. Mr. Sesno is a member of the board of trustees at Middlebury College, a member of the National Advisory Board for the Poynter Institute, a member of the Council on Foreign Relations and a board member at the National Council for Science and the Environment and at AmeriCares.

## **REVIEWER**

**Pamela Kushner, MA, MD, FAAFP**, *Clinical Professor Family Medicine*, University of CA Irvine

**Lynda Shand, CHPN, CNE, RN, PhD**, *Associate Professor*, Mercy College

## **BIBLIOGRAPHY/REFERENCES:**

### **Other organization's websites:**

Association for Death Education and Counseling [www.adec.org](http://www.adec.org)

### **Peer-reviewed journal/resource:**

Morrissey Stahl, K. A., Bower, K. L., Seponski, D. M., Lewis, D. C., Farnham, A. L., & Cava-Tadik, Y. (2018). A practitioner's guide to end-of-life intimacy: Suggestions for conceptualization and intervention in palliative care. *OMEGA-Journal of Death and Dying*, 77(1), 15-35.

Simpson, P., Wilson, C. B., Brown, L. J., Dickinson, T., & Horne, M. (2018). 'We've had our sex life way back': Older care home residents, sexuality and intimacy. *Ageing & Society*, 38(7), 1478-1501.

Thys, K., Mahieu, L., Cavolo, A., Hensen, C., Dierckx de Casterlé, B., & Gastmans, C. (2019). Nurses' experiences and reactions towards intimacy and sexuality expressions by nursing home residents: A qualitative study. *Journal of Clinical Nursing*, 28(5-6), 836-849.

**Textbook:**

Acquaviva, K. D. (2017). *LGBTQ-inclusive hospice and palliative Care: A practical guide to transforming professional practice*. New York: Columbia University Press.

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**CONFLICT OF INTEREST**

Planners (Panelists and Reviewers) disclose no conflict of interest relative to this educational activity.

**FOR QUESTIONS, COMMENTS, OR ADDRESSING GRIEVANCES  
PLEASE CONTACT**

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