

“So you’re going to die…” overview & talking points for a program series in Concord.

“So you’re going to die…” is a program series being held in Concord during October, 2018 co-sponsored by the Good Shepherd Institute in Newton and Death Nurse LLC of Concord.

The series deals with three related segments in the final arc towards end of life:

- making informed decisions for medical treatment in serious illness;
- caring for patients and families with serious illness and at end of life;
- caring for the deceased and the bereaved.

Each program opens with a short documentary film, followed by a guest speaker and audience discussion with Q&A.

Each program’s content is appropriate for patients and families currently facing any of these challenges, as well as for clinicians, caregivers, and the community.

The program’s purposes are:

- to provide attendees with accurate information and reliable resources for informed decision making and safe, effective, and compassionate care at each stage of the final arc towards end of life, and following death;
- to generate and support ongoing sustainable action for open discussion and credible education suitable for lay people, caregivers, and clinicians in ways that are directed by, and meaningful to, the communities in which they occur.

These programs are free and open to the public subject to space limitations, and require online pre-registration. All programs will be held at 770 Main Street in Concord. Tax-deductible contributions are welcomed to help offset program costs, and can be made to Good Shepherd Community Care, a qualified non-profit organization registered in Massachusetts.

<p>Donate online</p> <p>https://www.gscommunitycare.org/onlinedonations_pop.asp</p> <p>Donation Type: Other</p> <p>Supporting: So You’re Going to Die...</p>	<p>Donate by mail</p> <p>Good Shepherd Community Care 90 Wells Avenue Newton, MA 02459</p> <p>memo: So You’re Going to Die..</p>	<p>Donate by cash or check at the event.</p>
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October 2 - Caring for the deceased and the bereaved.

Topics: Caring for the deceased. What to consider in developing plans for the funeral and final disposition, including family-directed death care, home funerals, green burial, other options for final disposition, and how to work effectively with a funeral director. Ways to normalize open discussion about death. Resources for bereavement support for those who've lost a loved one.

Film: *Steelmantown* (2007), Transformer Films. Facing death and celebrating life at a “green cemetery” in southern New Jersey. *Steelmantown* tells three intersecting stories about the owner and developer of a green cemetery, the husband-wife owners of a funeral home, and the naturalist at the cemetery who is diagnosed with a serious illness. Their stories come together in this moving account of a way to care for the dead that’s currently considered “non-traditional,” even though it’s as old as history. <https://vimeo.com/131680248>

Speaker: Caitlin Doughty is a mortician, author, and death care activist who founded the death acceptance collective The Order of the Good Death. Her books ‘Smoke Gets in Your Eyes’ and ‘From Here to Eternity’ have been on the New York Times best-seller list. After earning a degree in medieval history, Caitlin moved to California, where she worked as a crematory operator, funeral director, and body-van transport driver. She subsequently earned her second degree in mortuary science. Unhappy with the state of the American funeral industry, she opened her own alternative non-profit funeral home in 2015, Undertaking LA, to help people help themselves - handle a corpse. Adapted from <http://caitlindoughty.com/about>

October 18 - Caring for patients and families with serious illness and at end of life.

Topics: Understanding available interdisciplinary clinical supports, including palliative care and hospice. The roles and responsibilities of members in the interdisciplinary clinical group, including nurses, physicians, social workers, chaplains, direct caregivers, and others. Anticipating, assessing, and addressing the multiple challenges of serious illness and end of life, including physical, psychosocial, and existential suffering.

Film: End Game (2018), Netflix. From Rotten Tomatoes - "Where will loved ones spend their last days? Who will be in the room? What feelings and secrets need to be shared with family before it is too late? Acclaimed Academy Award-winning filmmakers Rob Epstein and Jeffrey Friedman probe these questions and more in the context of two San Francisco Bay Area medical facilities on the forefront of creating new paradigms for end of life decisions with grace."

https://www.rottentomatoes.com/m/end_game_2018/

Speaker: Arden O'Donnell received her MSW from Smith College and her MPH from Boston University. She began working in palliative care with HIV/AIDS patients in Zimbabwe and Lesotho, subsequently in Social Work as a Pediatric Palliative Care Fellow at the Children's Hospital Boston, then as a member of the Dana Farber-Brigham and Women's Palliative Care Service. She recently ran a clinical trial with Akshay Desai, MD, MPH entitled, "A Focused Palliative Care Intervention for Recently Hospitalized High-Risk Patients with Heart Failure." Arden currently teaches at the Smith College School for Social Work, and is a doctoral student in the School of Social Work at Boston University. <https://www.bu.edu/ssw/profile/arden-odonnell/>

October 31 - Making informed decisions for medical treatment in serious illness.

Topics: Advance care planning. Understanding options for medical treatment in serious illness, including aggressive treatment, limited treatment, and treatment focused solely on comfort. Exploring and understanding values and beliefs to identify and articulate patient- and family-centered goals for care. Making informed decisions for medical treatment to achieve individualized goals for care.

Film: *Extremis* (2016), Netflix. This film follows Dr. Jessica Zitter and her team as they work with several different patients and families, each confronting severe health crises in the intensive care unit of an Oakland hospital. Individually and collectively, their stories highlight the challenges of understanding options and making literal “life and death” decisions under extreme pressure and in the face of uncertainty. This film shows how there are no easy answers or fanciful outcomes in such situations - just the difficult but essential process of talking honestly and doing the best we can. <https://www.netflix.com/title/80106307>

Speaker: Susan Block is a pioneering physician, teacher, and researcher in the field of palliative medicine and care at end of life. She is an Institute Physician in the Department of Psychosocial Oncology and Palliative Care at Dana-Farber and Brigham and Women’s Hospital, and Co-Director of the Harvard Medical School Center for Palliative Care. She is board-certified in internal medicine, psychiatry, and palliative medicine. In 2010, a Brigham surgeon showed up at her doorstep, told her that his conversations with very sick patients did not go well, and asked how he could do better. Atul Gawande subsequently said, “That conversation changed my life. She told me precisely what I could do differently next time, and it proved transformative—not just for me, but many others.” <https://www.dana-farber.org/find-a-doctor/susan-d-block/>

Top 10 FAQ's - "So you're going to die"

1 Why was this series developed?

Everybody dies, but almost nobody wants to talk about it. That's a problem, because you may get treatment in serious illness and at end of life that's not consistent with your beliefs, values, and goals. The result - confusion, distress, and suffering that could have been avoided; and futile efforts by clinicians that diminish rather than support your chances for comfort and meaning.

It doesn't have to be this way. It IS possible to confront serious illness and end of life openly and honestly. You can ensure that your beliefs, values, and goals are honored through one of life's major milestones; and that your comfort and meaning is supported in the broadest possible ways - physically, emotionally, culturally, and spiritually. It all starts with a few simple questions - What's most important to you? What are you worried about? What are your options? How can we help?

2 Who should attend these programs?

Anyone who's facing serious illness and end of life; anyone who might someday face serious illness and end of life; anyone who works with patients and families facing serious illness and end of life; and anyone. Note: Because of the subject matter, these programs are intended for adults.

3 What do you mean by, "...generate and support ongoing sustainable action..." as one purpose of these programs?

One program, or three, is a good way to begin addressing the problems identified above. But it's only a start. The most effective way to ensure that patients and families understand and get the treatment they want is with ongoing and sustainable actions that inform and support them, that reflect their goals, and that are based in the communities in which they live. These programs were designed to promote sustainable actions specifically in the town of Concord, Massachusetts. The specific actions of one community may be similar to those in another, or may they may be substantially different. We may share similar needs, but we may also have different approaches to addressing them, or in how we do so.

Our biggest hope is that this series will stimulate YOUR activism in this field, wherever you live!

4 Do I have to attend all of the programs?

We're glad for you to join us for one, two, or all programs. You may be more interested in one program, and less so in another. Each has value on its own.

"So you're going to die..." overview and talking points about the October program series in Concord.

5 Why do I have to pre-register?

Space is limited, so we need to make sure that we don't diminish the experience by overcrowding.

6 Why are the programs being held in a private home?

Two reasons. The series developer wasn't able to book the same venue for all of the programs because he went looking for one too late in the game. Presenting the programs in a private home allows the opportunity for a more relaxed and intimate discussion.

7 Will I be able to watch the programs later if I'm unable to attend?

We plan to record the program, and to make it available online and via social media - though probably in short segments. Each of the movies is available to view online at any time.

8 Can clinicians obtain credit for approved contact hours?

Yes, we have submitted program objectives for two (2) approved contact hours per program, for nurses and social workers. To obtain credit, attend the program(s) and submit the evaluation(s).

9 The programs are free? You're accepting donations?

Yes, and yes. Charging to learn about serious illness and death is probably the best way to give people a reason for not attending. So...free! Putting on these programs costs money, and though several private individuals and organizations have generously stepped forward, we need more help to cover all of the expenses. Whether or not you do, and how much, is entirely up to you. Also, too: no guilt if you can't or won't. We're still glad to have you.

10 Who's behind these programs?

The series was developed by Jerry Soucy, RN, CHPN at Death Nurse LLC, with support from the Good Shepherd Institute.

Jerry lives in Concord. He is an expert nurse certified in palliative care and hospice, and an activist through his independent practice, Death Nurse LLC promoting informed discussion and education for clinicians, caregivers, and the community about care in serious illness and at end of life. His 40+ years of nursing experience includes outpatient hemodialysis, specialty intensive care, and hospice. He was the primary caregiver for his wife, Jeanne, through her decline and death from Alzheimer's. He blogs about these and related issues at www.deathnurse.com

The Good Shepherd Institute is the educational arm of Good Shepherd Community Care, an independent, non-profit, non-sectarian provider of adult and pediatric palliative care and hospice. Initially founded as Hospice of the Good Shepherd in 1978, it's the original Massachusetts hospice serving patients in families in Newton and surrounding communities. www.gscommunitycare.org

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