End-of-Life University Special Report:

Action Steps for Changing End-of-Life Care in Your Community



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Action Steps for Changing End-of-Life Care in Your Community

If you would like to help overcome the denial of death in your community and encourage open conversations about the end-of-life check out the suggestions below for how you can help. We all need to get involved!!

1. Complete your own Advance Directive.

Begin by making sure you have taken the necessary steps to make your own end-of-life wishes known. Complete a document such as **Five Wishes** or the Advance Directive form recommended in your state, which you can find online at **Caring Connections.** You can also register your wishes online at **My Directives** and use their new mobile app to update or share your documents.

Resources:

Five Wishes - <u>www.agingwithdignity.org</u>Advance Directives by State - <u>www.caringinfo.org</u>

My Directives: www.mydirectives.com

2. Have an End-of-Life conversation with your loved ones.

Begin by completing **The Conversation Project Starter Kit** to get your thoughts and preferences in order. This will help you plan how to get the conversation started.

Resources:

The Conversation Project: www.theconversationproject.org
(Article) Tips for Talking With Your Loved Ones About the End-of-Life
(Article) 5 Movies to Jumpstart Your End-of-Life Conversations

3. Start a Death Café in your community.

Consider starting your own **Death Cafe** - an informal gathering of strangers to talk about death and dying. You don't need to have any particular training to host a Death Cafe and there is no agenda for the meetings. Check out the Death Cafe website for their guidelines for starting a Death Cafe or attend EOLU's Virtual Death Cafe to learn more.

Resources:

Death Cafe: www.deathcafe.com

Virtual Death Cafe: www.eoluniversity.com/death-cafe

4. Plan a "Death Over Dinner" event.

Invite your friends and family for dinner and a conversation about death. The Death Over Dinner website has tools to help you plan your event including wording for your invitation and a selection of audio or written content for your guests to check out before they arrive for dinner. Start with this website and get the assistance you need to plan your event

Resources:

Death Over Dinner: http://deathoverdinner.org/get-started

5. Host a Film Screening and Discussion

Consider hosting a community-wide event featuring an end-of-life documentary film and discussion. You will need a place to show the film such as a local theater, college or high school, or a hospital that has a conference facility. See the websites below for information on acquiring the film for your screening. Find a local speaker or a panel of speakers to lead a group discussion about the end-of-life after the film.

Resources:

(Film) Death: A Love Story

(Film) Death Makes Life Possible

(Film) A Will for the Woods

(Film) Love in Our Own Time

(Film) Prison Terminal: The Last Days of Private Jack Hall

6. Host an End-of-Life Play and Discussion.

You can bring a play to your community that focuses on the end-of-life and use that event to stimulate a discussion group. There are some one-woman plays available that require very little set-up and staging. They can be hosted anywhere with a riser stage and audio equipment. Consider offering a play as a keynote event during a conference or a prelude to a special dinner.

Resources:

(Play) Waltzing the Reaper

(Play) The Death Monologues

7. Start an End-of-Life Book Club.

Create a monthly book club that meets in a local library or book store to read and discuss books about the end-of-life. There are dozens and dozens of excellent books out there that you will enjoy reading and that will spark fascinating discussions. Some books (like *What Really Matters*) feature a Reader's Guide you can use to lead your group discussion. Check out the Recommended Reading lists below.

Resources:

EOLU Recommended Reading: <u>www.eoluniversity.com/recommended-reading</u>

Seven Ponds Book List: http://www.sevenponds.com/multimedia/books
New York Life Foundation: http://www.newyorklife.com

8. Teach a "Five Wishes" Workshop.

Help people in your community complete a Five Wishes document by planning and facilitating a workshop to talk them through the process step-by-step. You might offer to do the workshop at a senior center in your community or at a local church. Aging With Dignity has guidelines on their website for facilitating a Five Wishes workshop.

Resources:

Aging With Dignity: http://www.agingwithdignity.org/host-a-workshop.php

9. Create a Multi-Day Event for your Community.

This will require a team of people and several months to plan, but you can garner a lot of attention for the subject of the end-of-life by creating a BIG event. Gather together various people from your community with interest in the end-of-life: hospices, funeral directors, death midwives, estate planners, hospitals, palliative care teams, social workers, chaplains, faith-based organizations. Utilize all the local resources in your community to put the event together - invite speakers on various end-of-life topics, host a Death Cafe during the event, have a film festival with end-of-life films, invite threshold choirs or musicians and artists to contribute. A similar event was held in Bellingham WA in 2014 - you can read more about it at the website mentioned below.

Resources:

The Art of Dying Exhibition and Conference: www.theartofdeathbellingham.wordpress.com

10. Volunteer for your local hospice.

Get hands-on experience with the end-of-life by becoming a hospice volunteer - and change your life at the same time! Find local hospices and learn what it takes to be a volunteer through Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO).

Resources:

Caring Connections: www.caringinfo.org

NHPCO: www.nhpco.org

11. Become an Advocate for End-of-Life issues.

Get involved on a policy level in your state and on the national scene. Find out what you need to know at the Hospice Action Network website (a division of the NHPCO) where you can get informed on issues and learn how to become an advocate.

Resources:

Hospice Action Network: http://hospiceactionnetwork.org

12. Teach a Death and Dying Class at your local college.

If you have credentials in the end-of-life arena, consider volunteering to teach a course in death and dying for your local community college. Young people are interested in death and dying and would benefit greatly from such a class. Consult the book *The Death Class* by Erika Hayaski for ideas and inspiration.

Resources:

The Death Class: http://thedeathclass.com

Tips for Teaching a Death and Dying Class in Your Community:

http://www.huffingtonpost.com/karen-m-wyatt-md/tips-for-teaching-a-

death_b_7066898.html

13. Become a Death Midwife.

There are many excellent training programs that can teach you how to help families with a dying loved one as a Death Midwife. You don't need to be a medical professional to get this education and get involved. Find a program that works for you

Resources:

Positive Passings with Suzanne B. O'Brien,

RN: www.suzannebobrien.com

End-of-Life Doula Certificate Program with Deanna Cochran,

RN: www.accompanyingthedying.com

Beyond Hospice with Donna Belk: http://beyondhospice.com

14. Become a Home Funeral Guide

You can assist families with planning and carrying out funerals and memorials at home. The National Home Funeral Alliance has resources for you to learn how to become a guide.

Resources:

National Home Funeral Alliance: http://homefuneralalliance.org

15. Encourage a local cemetery to become a certified green burial ground.

Green or natural burial results in minimal impact on the environment. Many traditional cemeteries could become certified for green burial if they were convinced that there was a need in the community. Get educated by the Green Burial Council and start a campaign to convince your local cemetery to get certified.

Resources:

Green Burial Council: http://greenburialcouncil.org

16. Start a Palliative Care Program.

If you live in a community that does NOT currently have a palliative care program available as an alternative for patients, it would certainly be worthwhile to get a program started. Studies have shown that patients who receive palliative care in addition to conventional treatment live longer and at reduced medical expenses.

If you are a doctor, nurse or hospital administrator you will already know some of the steps that must to be taken and who you need to talk to. There are resources below that can help you look at various models and determine the right one for your community. If you are a lay person you will want to get some local medical providers or nurses on your team, educate yourself about palliative care, and perhaps circulate a petition to show that

there is community interest in having palliative care available.

Resources:

California Healthcare Foundation: <u>How to Start a Palliative Care</u>

Program

Kaiser Permanente: Palliative Care Toolkit

Center to Advance Palliative Care: https://www.capc.org

NHPCO Virtual Event: How to Structure a Palliative Care Program

To start a petition go to:

Change.org: https://www.change.org/start-a-petition