



Community Coalition Resources, Exercises and Tools

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Community Coalition Event Planning Tools

Many end-of-life coalitions find it helpful to have ready-made exercises and tools that they can use in their communities without "re-inventing the wheel." The following resources can be easily modified and used to help your coalition plan and implement community events. These activities and tools come from actual events of community end-of-life coalitions. Launching your activities from these prepared resources can save your coalition valuable time and energy.

1. Community Event Examples

a. Group exercise 1: Compassionately Caring for Our Own— Elements of an Ideal Society

Once we accept the challenge that we can improve the way people die in our community, we are left to struggle with how to do it. We may find direction by starting with a picture of where we want to go – what would be ideal. This exercise helps us to reflect on how society should care for the dying and creates an action guide for the coalition.

b. Group exercise 2: The “Best Death” I Have Witnessed

Encouraging coalition members to share their experiences around death helps the group to see the value in hearing every person’s perspective and learn about “good” and “bad” dying experiences.

b. Life Decisions Community Education Series

Descriptions of presentations you can offer in your community.

c. The Future of Death: A Community Response to End-of-Life Issues

The brochure text for a conference on ethical issues and advance directives is provided.

d. A Kaleidoscope of Caring: Exploring the Palliative Arts

Health care professionals and members of the community want to learn more about complementary therapies. The agenda for a successful community conference is provided.

2. Event Planning Tools

a. Sample Conference Budget

A sample budget for coalition conferences and seminars is provided.

b. Conference Planning Timetable

c. Community Sign-up Form

Use this form to collect names of people interested in joining your efforts.

Group Exercise 1: Compassionately Caring for Our Own -- Elements of an Ideal Society

Have a facilitator lead a group discussion, allowing time brainstorming ideas for each question. At the next meeting, distribute the typed responses to the coalition and use them as a "target" during your strategic planning process, focusing on what needs to happen/change to reach the ideal you envision.

In an ideal society....

When and where would people start learning about death and dying?

How would death and dying be portrayed in media and popular culture?

What images would people have when they imagine someone dying?

What kind of care would be available to those entering the last phase of their life?

Who would care for those in the last phase of life?

How would health care providers know if a person didn't want heroic measures?

Who would advocate for those in the final stages of life?

What type of services would be available for those wanting information about the last phase of life?

Who would provide information to people so they could make decisions regarding end-of-life issues?

Who would pay for the care and services listed above?

What types of services would be available to family and friends preceding and following the death of a loved one?

Where would these services be delivered?

Who would pay for these services?

What allowances / benefits would employers provide for those caring for a loved one?

What allowance/benefits would employers provide for those who are grieving the death of a loved one?

What criteria would be used to decide who had access to end-of-life care and services?

What would be an ideal death for someone who didn't die suddenly?

How would society respond to people wanting to hasten their death?

Group exercise 2: The “Best Death” I Have Witnessed

If a coalition member has not witnessed the death of a close family member or friend, encourage them to share their perspectives on deaths they have heard about from friends or colleagues.

Take time to reflect upon deaths (overall end-of-life experience) of those close to you.

Of those, which, if any, was the best death?

Where did the death occur?

Who was there?

Did the person have pain or symptoms that could not be controlled?

Was the person conscious or unconscious?

Did everyone close to this person feel that it was a good death?

Did the person accept that he/she was dying?

What information or services could have made it a better death?

What, if anything, can you do to make sure that everyone you know experiences this kind of death?

The “Worst Death” I Have Witnessed

Take time to reflect upon deaths (overall end-of-life experience) of those close to you.

Of those, which, if any, was the worst death?

Where did the death occur?

Who was there?

Did the person have pain or symptoms that could not be controlled?

Was the person conscious or unconscious?

Did everyone close to this person feel that it was a bad death?

Did the person accept that he/she was dying?

What information or services could have made it a better death?

What, if anything, can you do to make sure that no one you know experiences this kind of death?

Life Decisions Community Education Series

The educational sessions listed below can be presented as part of a community education series or as individual seminars. Coalitions can work together to plan the sessions, identify speakers, find places to host the sessions and publicize the events.

Based on your experience doing programming in your community, you may find that the titles or descriptions might not work to attract people to the sessions. Alternative titles for each session are provided or may be developed to suit your situation

Before the Crisis Hits: Planning for the Unthinkable -- Part One

or

Planning Ahead – Making Your Wishes Known – Part One

Does your family know your specific wishes in the event of a sudden accident or terminal illness? Have you prepared yourself and your loved ones legally and financially for a critical healthcare crisis? Talking about these issues is never easy, but you will be doing yourself and your family a favor if you are fully prepared for the unthinkable. This session will address the legal, medical and financial considerations involved in end-of-life decision making.

Before the Crisis Hits: Planning for the Unthinkable -- Part Two

or

Planning Ahead – Making Your Wishes Known – Part Two

Part two of the *Before the Crisis Hits: Planning for the Unthinkable* presentation allows you to express your wishes about end-of-life care and decisions to your loved ones on videotape. Professionals will guide you through a series of questions to help you express your wishes to your family, health care surrogate and/or physician. The video will be yours to keep and share with anyone you feel needs to know your decisions regarding end-of-life care. Participants will also be encouraged to sign an advance directive at the session if they don't already have one.

Crisis Prevention in End-of-life Care: A Primer for Healthcare Practitioners

or

Decision Making in End-of-life Care: A Primer for Healthcare Practitioners

or

Advocacy in End-of-life Care: A Primer for Healthcare Practitioners

As healthcare providers, we all have a responsibility to be knowledgeable about the legal and medical implications of end-of-life care decision making. With increased utilization of advance directives that sometimes conflict the wishes of a healthcare surrogate, our job as patient advocate becomes challenging. Learn about your responsibilities and options available to you as a healthcare provider.

Relief of Suffering: Holistic Pain and Symptom Management

or

Holistic Pain and Symptom Management

or

Whole Person Pain and Symptom Management

This session will provide participants with information of the multi-dimensional effects of pain on the patient and family and the barriers to alleviating suffering. The session will examine total pain -- physical, social, psychological and spiritual -- and state-of-the-art assessment, treatment and interventions.

The Future of Death: A Community Response to End-of-Life Issues Conference Brochure Text

In 1997, the Project DECIDE coalition in Pinellas County, Florida presented the Future of Death Conference. The conference was so popular that registration was closed at 250 registrations and the conference was repeated several months later, again drawing 250 registrants. A template for the conference brochure is listed below with possibilities listed for the kinds of people who might lead the various sessions.

Advance directives offer all of us options about the care provided at the end of life. As health and human service professionals, lawyers, guardians and advocates we have a profound responsibility not only to ensure access to information about the options afforded by advance directives, but also to ensure that our care systems facilitate the execution of these directives if and when it is necessary.

What are the barriers to implementing advance directives?

How can we ensure that people make their wishes known before it is too late?

What do we do when the incapacitated patient's expressed wishes conflict with those of the family or legal caregiver?

This conference will explore these and other issues relating to the selection and execution of all types of advance directives and provide participants with tools to ensure that the wishes of those we serve are honored to the best of our ability.

Conference Objectives

Upon completion of this program, participants will be able to . . .

- Participate in community dialogue on end-of-life issues
- Discuss difficult ethical dilemmas surrounding end-of-life issues
- Clarify practice liabilities in care of the dying
- Outline methods to relieve pain and suffering at the end of life
- Define all aspects of advance directives and their appropriate uses
- Evaluate systems in your care setting in relation to advance directive laws and regulations

Who Should Attend

- Lawyers
- Guardians
- Administrators
- Nurses
- Psychosocial professionals
- Clergy
- Home health aides
- Case managers
- Physicians
- Medical office personnel
- Emergency response workers
- Long term care professionals

Conference Schedule

8:30 am	Registration and Continental Breakfast
9:00-10:00 am	Opening Session
10:00-10:15 am	Morning Break
10:15-11:45 am	Morning Concurrent Sessions
11:45-1:15 pm	Lunch with Panel Presentation
1:30-3:00 pm	Afternoon Concurrent Sessions
3:00-3:15 pm	Afternoon Break
3:15-4:15 pm	General Session

Agenda

9:00-10:00 am -- Opening Session

Perspectives on End-of-Life Care

Secretary of the Department of Elder Affairs

10:15-11:45 am -- Morning Concurrent Sessions (A-E)

A. After the Document is Signed: Bridging the Legal-Medical Gap

Attorney
Oncologist
Geriatric Nurse Practitioner

Do you know what happens after a living will is executed? What is the implementation process by different care providers? How can you, as a lawyer or guardian, help resolve conflict that may arise between family members regarding treatment decisions? This session will address these and other complex situations that arise after the document is signed, while examining the concept of moral persuasion in these cases.

B. Relief of Suffering: Pain and Symptom Management at the End of Life

Advanced Practice Nurse
Chaplain
Licensed Mental Health Counselor

One of the most pervasive arguments in favor of legalizing physician-assisted suicide is to relieve pain and suffering. This session will discuss common myths regarding pain and symptom control at the end of life. Multidimensional assessments will be discussed to illustrate how physical, psychosocial and spiritual pain and suffering can be assessed and addressed to achieve comfort for dying patients.

C. Advocating Defensively: A Clinician's Guide to Advance Directives

Professor of Law
Attorney

The term advance directive means different things to different people. This session will provide definitions for durable power of attorney, DNRO, living wills, health care surrogate and proxy. In addition, the advocacy role of health care providers will be discussed and examined in relation to managing personal and organizational liability while focusing on the needs of the patient/client.

D. Season of Opportunity-- Spiritual Care at the End of Life

Chaplain

Dying is not just a physical event. This interactive workshop will address the issues and approaches that are involved in effective spiritual care at the end of life. It will provide background and resources to assist professional and non-professional caregivers value and positively influence the spiritual dynamics of the dying process.

E. Providers at Risk? Capacity and Informed Consent

Healthcare Consultant

How do you define and evaluate capacity of patients and clients? During the last months of life, a person's capacity might change from one day to the next. Therefore, it is extremely important that our systems include a process to continually evaluate this sliding scale capacity to determine who will make care decisions. The session will also evaluate the relationship between capacity and advocacy.

11:45 am -- Lunch Served

12:00-1:15 pm -- Panel Presentation

Death by Design: Physician Assisted Suicide

Facilitator: Coalition Member
Panelists: Ethicist
Oncologist
Judge
Professor College of Public Health

1:30-3:00 pm -- Afternoon Concurrent Sessions (F-J)

F. When Systems Conflict: Advocacy/Law/Regulations

Guardianship Association
College Professor
Judge

Getting an advance directive executed can be a struggle, depending on the circumstances and care setting. This case-based session will examine potential dilemmas and identify relevant Federal and State laws and rules and regulations related to advance directives in various health care settings.

G. To Feed or Not to Feed: Nutrition and Hydration at the End of Life

Clinical Pharmacist
Infusion Nurse Manager

Some of the most difficult decisions caregivers make are in relation to nutrition and hydration. This session will focus on the advantages and/or disadvantages of artificial feeding and hydration, caregiver decisions and dilemmas, and comfort issues regarding nutrition and hydration at the end of life.

H. *When Should Palliative Care Begin? Avoiding Futile Care*

Professor, College of Public Health
Palliative Care Program Director

Many professional caregivers struggle with when to stop curative treatment in favor of palliative care. Recent national studies indicate that Americans are dying in intensive care units while receiving futile care that fails to improve the quality of their life. This session will explore the difficult process involved in the decision to begin palliative care as well as outline the dimensions of an aggressive interdisciplinary comfort care plan designed to provide dignity and comfort at the end of life.

I. *Conflicts at the Bedside*

Physician
Social Worker
Aging Group Representative

At times, acting in the best interest of patients /clients conflicts with organizational policies, personal beliefs and family requests. This case-based session will assist professionals to think through a variety of difficult decisions and provide a foundation for ethical and professional decision making.

J. *Bioethics Committees: What, Why, When, How*

Physician
Hospital Ethics Committee Member
Nursing Home Administer

Many organizations are investigating the feasibility of developing an institutional bioethics committee. This presentation will discuss the benefits of developing a bioethics committee, including what issues to consider in the decision making process, who to invite to participate and resources in the community.

3:15-4:15 pm -- General Session

Creating a Social Change Movement: Normalizing Death in our Community

State Hospice Association Leader

A Kaleidoscope of Caring Exploring the Palliative Arts

In 2001, the Pinellas Partnership for End-of-life Care coalition hosted a seminar on palliative arts and complementary therapies. The agenda is below. More than 100 individuals attended the all day seminar.

Seminar Agenda

Time	Session/Event	Presenter Organizations
8:00-8:30	Breakfast (provided)	
8:30-9:00	A Kaleidoscope of Caring	Hospice Program
9:00-10:00	The Power of Touch	Massage Therapist
10:00-10:15	Break	
10:15-11:00	Music Therapy: Healing for the Soul	Music Therapist
11:00-11:45	Musical Caregiving: The Healing Artist	Music Therapist
11:45-12:45	Lunch (provided) Presenting....	Hospice Program
12:45-1:45	Aromatherapy	Aromatherapist
1:45-2:00	Break	
2:00-3:00	Journaling/Life Review	Hospice Social Worker
3:00-3:15	Break	
3:15-4:15	The Healing Power of Humor	Hospice Social Worker

Sample Conference Budget
Cut, paste or modify to fit your needs

Revenue	
Registrations \$55 per person (@ ___ people)	
Registrations -\$30 per person (@__ people)	
Sponsor Revenue	
Total Revenue	
Expenses	
Brochure Printing & Mailing	
On-site Materials Printing	
Paper Products	
Food/Caterer	
On-site staffing	
Continuing Education Credits	
Speaker Fee	
Advertising/Marketing	
Art Supplies	
Total Expenses	
Total	

Conference Planning Timetable

This time line was developed as a guideline for people planning a conference or event. Your planning process will depend on the complexity of event, type of outreach/publicity planned and other factors.

Ideally, planning for conferences starts six to nine months prior to the event. However, your coalition may have less time to plan your event. Adjust the timetable and task list to meet your specific needs.

Task	Months/ Weeks Out	Completion Date
Select theme/Focus	6 months	
Identify target audience	6 months	
Contact potential sponsors	6 months	
Contact outside continuing education providers	6 months	
Draft budget	6 months	
Select dates/reserve rooms	6 months	
Contact and confirm speakers	5 months	
Brochure content & design	4 months	
Contact caterer	4 months	
Obtain mailing lists	4 months	
Reserve mail house	4 months	

Task	Months/ Weeks Out	Completion Date
Brochure to mail house	3-4 months	
Mail faculty packets w/ brochure	3-4 months	
Set up registration database	3 months	
Finalize menu with caterer	1-2 months	
Send confirmations and travel directions to participants	2 months / ongoing	
Recruit volunteers	2 months	
Rent tables, vans, etc	1 month	
Draft layout	1 month	
Go over layout with maintenance	1 month	
Draft detailed agenda	1 month	
Make signs	1 month	
Finalize volunteer schedule	1 month	
Review AV needs, order equipment if needed	3-4 weeks	
Print handouts, maps, final program	2-3 weeks	
Preconference meeting to go over final details	1-2 weeks	

Task	Months/ Weeks Out	Completion Date
Confirm final count with caterer	1 week	
Put together folders	1 week	
Print badges	1 week	
Print CEU certificates	1 week	
Print rosters	1 day	
Set up conference rooms	1 day	
Get parking signs, vests	1 day	
Put up signs, set up registration, etc	1 day	

Community Sign-up Form

The response form was distributed to participants at the Future of Death conference. It was used to create a list of people willing to work to improve end-of-life issues. You can invite respondents to your next coalition meeting or add them to your events mailing list. Modify the list below as needed.

End-of-life Coalition Mailing List

As we work to create a social change movement on end-of-life issues, we need involvement from all segments of the community. Please indicate below your ideas and areas of interest for mobilizing our community to think about end-of-life issues and engage everyone in the community in a comprehensive and ongoing discussion about end-of-life care.

My ideas/areas of interest for mobilizing our community to improve end-of-life care:

1. _____
2. _____
3. _____
4. _____
5. _____

Yes! I want to participate in a coalition on end-of-life issues

_____ Your Name	_____ Phone Number	_____ Email
_____ Organization	_____ Position	
_____ Address	_____ City	_____ Zip

Please complete this form and place it in an evaluation box. Thank you!