



END OF LIFE COALITIONS

***A Manual for Building
Successful Coalitions Around
End of Life***

***A Project of the Coalition for Dialogue on Death and Dying
This project supported by The Project on Death in America***

A complementary video to this manual is available.

The Coalition for Dialogue on Death and Dying welcomes input and dialogue regarding issues surrounding death, dying, and bereavement in the Mid Coast region.

Michael J. Murphy, Ph.D.
Coalition for Dialogue on Death and Dying
c/o Hospice of Midcoast Maine
P.O. Box 741, Brunswick, ME 04011
Telephone: (207) 725-3602 or (207) 389-1579
Email: Hospice@Netquarters.net
www.cursitlibrary.com/coalition/

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I. BACKGROUND

Death is inevitable, but much of American culture strongly denies death until it occurs and then immediately moves to forget it once it has happened. A “conspiracy of silence” gets in the way of what should be the natural process of death, dying, and bereavement.

All too often, we hear on the consumer side, dying persons and their loved ones, that individuals fear dying alone, in isolation, dying in pain, having no control, not knowing what's going on, and being an economic and social burden on one's family. On the provider side, we hear of the health care professional's inability to deal with the dying process, admitted lack of updated skills and education, and concern with the breakdown in the relationship between health professionals and dying persons and their loved ones. Both groups are concerned that the very health care system itself does not enhance the care of the dying person nor is supportive of survivors. They, and health care administrators are concerned with financial barriers to care, the need to improve the system, and the need to work together towards developing social change relative to death, dying and the bereavement process.

Throughout the country, a number of initiatives have begun to look at how the status quo can be changed. There seems to be a collective consciousness that change is not only necessary, but can and must be achieved.

There is an ever-opening window regarding improving the process and, in its way, we are seeing and participating in the emergence of a social movement. A social movement can be described as an effort to solve collectively a problem that people have in common. Hence, it represents socially-shared demands for some change in the social order. This is what is happening through the country at the local, state and national levels. People are collectively gathering more information, getting educated, developing and converting constituencies towards changing the status quo in the area of death, dying and bereavement – and it is being done with passion.

II. THE USE OF COALITIONS

It is in light of this emerging social movement that the use of coalitions can be very effective vehicles for educating, mobilizing a constituency, and social change action. Coalitions are especially apt in the area of death, dying and bereavement as a means of changing culture, educating both consumers and providers and building a diverse constituency for change.

As part of a grant from the Project on Death in America, a project of the Open Society Institute, the Coalition for Dialogue on Death and Dying in Midcoast Maine developed this manual. The premise is that Coalitions have great promise in this area and that a “how to” manual would assist other groups around the country in replicating and adopting coalition activity to their local and state use.

In short, look upon this manual as an adaptable road map to help you mobilize your local area to address actions needed to improve the process at the end of life. A complementary video is available as well.

III. KEY CONCEPTS IN COALITION BUILDING

In order to get on the same page, some discussion of key concepts is warranted. Just what is a Coalition? A workable definition is: “Coalitions are organizations, social action groups and/or individuals that come together to exert influence by sharing resources and expertise.”[†] The key terms being come together and sharing. The intent being that there is

power in numbers and that the sharing of resources and expertise brings ownership and therefore commitment.

In their way, Coalitions are loosely developed collectives that may change over time. Ordinarily, a coalition is not a wedding for life or it may transform into another kind of vehicle. The constituencies of a coalition usually have a prime identification outside the coalition, but come together because they cannot do it alone. They collaborate because it is in their best interests to do so, it seems worth the effort, it enlarges their own sphere of influence, and it provides a united front and a social network for change.

The Purpose of a Coalition is to exert influence by sharing resources, expertise, constituencies and other power bases towards achieving commonly accepted goals. Further, in examining coalitions, key characteristics emerge. Toseland and Rivas[†] succinctly describe a series of key characteristics:

Leadership: often dedicated and charismatic individuals leading by consensus or vote.

Focus: building consensus for maximum influence

Bond: common commitment or interest regarding an issue.

Composition: loose collection of groups and individuals working together to achieve common goals.

Communication: formal or informal [patterns] depending upon the type of coalition.

A coalition regarding death, dying, and bereavement then, will begin with acknowledgement of the issue(s) and the need to work together, spurred initially by a small, and dedicated group of concerned citizens and activists focussing on forming a consensus, linked by the jointly perceived issue(s) to be addressed, and assuring that adaptive patterns of communication are always present.

IV. COMMUNITY APPROACHES TO CHANGE

How do coalitions make change? From the theory and practice field of community change, coalitions can avail themselves of any one or all three of the following approaches, depending on the coalition. Rothman, et. al.[†] describe these three approaches, which I contend "fit the process of coalition building, maintenance, and goal achievement.

Locality Development: presupposes community change effected best through broad participation at the local level in goal-determination action. This approach calls for a broad cross-section of citizens coming together in a self-help mode that collaboratively move towards group ownership. For the most part a locality development approach is concerned with Process Goals, that is goals that are oriented to system maintenance and enhancement and local empowerment.

Social Planning: presupposes a technical process of problem-solving regarding substantive social problems. This approach calls for data-gathering, analysis and implementing change based upon what the data implies. For the most part, a social planning approach is concerned with Task goals, that is the completion of a concrete task or solution of a delimited problem in a community system.

The Social Action approach presupposes a disadvantaged population segment that needs to be organized to make demands on the larger community for increased resources. This approach calls for a disadvantaged population, crystallizing issue(s), and organizing large numbers of people in a political way towards targets for negotiated change. This approach is concerned with either task or process goals to effect institutional goals.

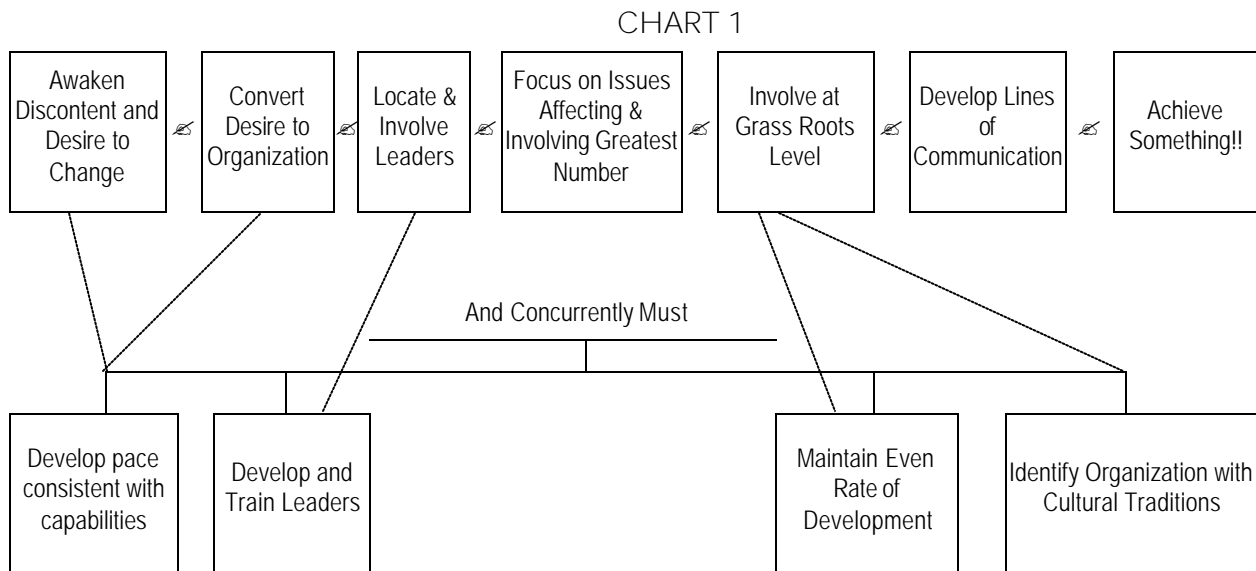
A group that wishes to effect change by developing a "community of concern" around death and dying may then utilize a locality development approach to be inclusive in its

membership (e.g. consumers, providers, institutions, etc.) It would continually be “nourishing the relationships.” A group wishing to effect change in a social planning approach might gather data on where do people die (community), in what location (hospital, at home, hospice, etc.). A group wishing to breakdown the barriers to receiving hospice care (admission protocols, lack of Medicaid benefits, etc.) might very well use a social action approach towards changing organizational or state policies.

An End of Life coalition, depending upon its particular vision, goals, etc., I contend, can use any and all of three approaches concurrently. It can involve various groupings in community building activities in a collaborative way, it can engage in needs assessments and problem-solving activities and it can move towards negotiated change efforts.

V. FUNCTIONAL CONTEXT OF END OF LIFE COALITION

There are a series of functions in the process of a coalition. Chart 1 is a graphic representation of coalition activity in a functional context



AWAKEN DISCONTENT AND A DESIRE TO CHANGE.

End of life coalitions usually start with discontent with the existing order of how things are (i.e. unempowered patients) and a desire to change the status quo. Individuals and organizations must come together to begin to voice their concerns and find some sense of commonality. There may be a range of issues initially identified by people coming from different places. A coalition begins then with a small group of people (initiators) that begin meetings to discuss, clarify issues and problems, develop a common language (especially needed in end of life groups to get by the ‘jargon’), find some things in common, and to begin to gather relevant information and outreach for other members. This is a typical locality development approach.

CONVERT DESIRE TO ORGANIZATION

This initial feeling of general unrest must now be refined and focused upon specific issues. There must be a conversion of the group/community's desire for change into a desire to organize. That is, some sort of a vehicle for change efforts must be formed to move from beginning activity to planning and action activity. In coalitions, this is somewhat looser than other kinds of organizations. Nevertheless, clarification of who's who, who does what,

clarification of roles and procedures are important to the process at this point. The coalition's structure sets a tone of business and seriousness to the purpose and, further, opens the opportunity of recruiting more members.

DEVELOP A PACE CONSISTENT WITH CAPABILITIES

Concurrently, in the beginning and growing stage, pace is important. There will be a natural movement to "do something now." But this is a beginning group and capabilities may vary. The members need to be on the same page. Moving too fast, when the membership is not ready, will lose members. On the other hand, experienced members will be frustrated by too much process. This is a dynamic process of balancing and education and of both process and task. The nurturing of the group, therefore, is important.

LOCATE AND INVOLVE LEADERS

Here is an ongoing activity directed towards locating and involving leaders who are identified with and accepted by relevant major subgroups, both formal and informal, in the community. In the initial and building stages, there is a need for a dedicated and charismatic individual(s) who can both attract and serve members. It is the ability to use both their own ideas as well as elicit and appreciate those of others.

DEVELOP AND TRAIN LEADERS

It is not enough to recruit leadership but such leaders' skills and content need to be developed as well. In the area of end of life, there may be leaders with great content knowledge, but other leaders may have skills and experience in attracting groups but may need to become better acquainted with content material about death and dying.

FOCUS ON ISSUES AFFECTING AND INVOLVING THE GREATEST NUMBER

An end of life coalition, in order to grow and be inclusive, must realize that it is the issues coupled with capable leadership that mobilizes people and organizations towards change. Mobilization involves conscious-raising. In working with the general public, community leaders, and relevant organizations, the attempt is to crystallize the issue(s) that will draw a constituency. This is an outreach effort that may call for: meetings with members of the general public and key organizations; talks and presentations to various community organizations, religious and civic groupings, framing and dramatizing the issue(s) through the media and holding public meetings. The aim is to dramatize the issues, encouraging groups to both feel a "community of concern" and a desire to join forces in action for change.

In many ways, the focus on the issues is the building of power. Look upon power as the ability to do something. In many end-of-life issues, there is a sense of powerlessness. An end of life coalition, then, strives for power to do something: to change the status quo. Power, in this sense, is a blend of education and constituency. The more people that are involved, the more positive the opportunities for positive change.

INVOLVE AT THE GRASS-ROOTS LEVEL

Coupled with the issue-focus is the need for an end-of-life coalition to actively involve the entire community. All too often, people are viewed as recipients of the change effort only. Both the locality development and social action approaches, call for active outreach, involvement, education, joint problem-solving, decision-making, and action by all levels of the community. In short, the grass-roots is viewed as a desired full active partner in the coalition.

MAINTAIN AN EVEN-RATE OF DEVELOPMENT

Because of a commitment to inclusivity, efforts must be taken to maintain a relatively even rate of development of the groups within the coalition. For example, health provider

groups may be very cognizant of problems of inter-referral of grieving survivors, or problems of continuity in services for the dying patient, and the like. But other organizations and individuals may not have the expertise and experience with such areas. They cannot be left behind, if the coalition wishes to bring concerted activity to make changes. The role of the coalition is to assure that groups do not get lost or go off alone rather than embracing a total coalition effort.

IDENTIFY ORGANIZATION WITH CULTURAL TRADITIONS.

At all steps in the coalition process, beginning with the core group, continuing its growth, and taking concerted action, the coalition must be aware of and strive to be representative and understanding of the full cultural diversity of the community. This calls for planned efforts to recruit members that will assure full-fledged representation and participation.

DEVELOP LINES OF COMMUNICATION.

For an end of life coalition to be successful, means of formal and informal communication must be developed and used. Such means as agendas, minutes, reports, joint education efforts, team-building, one-on-one conversations and group dialogues are all means of linking people and organizations together and improving the coalition's functioning as a whole. This takes an enormous amount of time but is deemed necessary to preserve coalition activities.

DO SOMETHING!

Coalitions will not survive without movement towards agreed-upon goals and objectives. Coalition members are always deciding whether being part of a coalition is worth the effort. If changes in the status quo are not attempted, the coalition becomes an exercise in process only. Coalitions have both process and task goals, and the concerted achievement of the task goals is the *raison d'être* of its existence.

A word here on whether to have staff or not in an end of life coalition. There is merit in organizational members lending their staff members to coalitions. Coordination becomes the issue. It is difficult to maintain coordination and continuity without a staff person fully dedicated to serving as an enabler, data-gatherer, coordinator, and advocate. Splitting roles affects energy. Simply, if there is funding available to hire staff, do it!

VI. CHECKLIST FOR END OF LIFE COALITIONS

Based on the above discussion, here is a checklist that can be used as a reference planning guide. It involves a series of coalition phases:

Phase 1. Initiation

- 1) What do people know and what do they need to know?
- 2) What is the real aim(s) for forming a coalition?
- 3) Is there a core group that can bring others to the table?
- 4) Is there an outreach strategy to involve new members? (or, who else should be involved?).
Inclusivity implies the use of collective imagination in recruiting members that are fully representative of the community including cultural diversity.
- 5) Has the group defined the action and target systems?
Action system: those individuals, groups, and organizations that participate in the change effort.

Target system: those individuals, groups, organizations that need to be changed in order to achieve the objectives of the change effort. In coalition-building, positive change tries to involve both systems in a productive manner.

- 6) Are new members brought up to date (continuing orientation)?
- 7) Has additional leadership been identified, recruited and trained?
- 8) Has the coalition arrived at a consensual vision and mission statement? Such statements serve as a focussing point and to mobilize people to get involved. It is not enough to discuss problems in end of life care: what is needed is a vision of what the community would like to have. A vision statement then is a picture of a desired future, it is bounded in shared values and sometimes starts with "We believe" A mission statement can describe an end-of-life coalition in terms of services, constituencies, roles and functions, etc. For example: "The End of Life Coalition is a community organizations with a commitment to respond to, serve, and advocate for the needs, interests, and empowerment of dying persons and their families, by providing support and new opportunities for their self-sufficiency and well-being."
- 9) Do we continually build capacity by education the coalition's members?
- 10) Do we engage in activities designed to inform, educate and involve the community (e.g. community forums, use of media, etc.)?

In sum, the initiation phase is designed to unfreeze individuals, groups, and organizations (focussing discontent and developing and training leadership, and involving people from every level of the community).

Phase 2. Establishing an Organizational Vehicle for Change.

Vehicle is an apt word here, because the coalition is trying to move towards action.

- 1) Has the coalition formed an adequate structure to carry out its work?

The best structure is one that is adaptive to the nature of the coalition's work, the characteristics of the membership, its size and complexity, and meeting the coalition's goals and objectives. It can be tight or loose, it can be hierarchical or not.

Phase 3. "Psyching Out" the Coalition's Arena.

A coalition engages in assessment activities in order to obtain complete information about the present state of end of life practices and services. Experience, past solutions, observations, looking at records and data secured from research, relevant information from other communities, all constitute popular sources of usable information. Such information has to be gathered and jointly analyzed so as to guide the coalition towards its next steps. The following questions may be asked:

- 1) Does the coalition and its members have an agreement on basic meanings, terms and issues?
- 2) Has the coalition jointly decided which methods for collecting data are applicable?

A needs assessment is a common technique in this regard; where an organization will collect data by such means as:

Primary Data: interviews with dying persons, focus groups of providers, community dialogues; Secondary Data: demographics of dying people such as age of death, ethnicity, site of death, cause of death; Assessment of Present Services: identification of the array of present services related directly or indirectly to end of life and what do they do, and are they working.

- 3) What information from other parts of the country is/are relevant to the coalition's work?
- 4) In analyzing the data, are there apparent relationships among the data?
- 5) Are all useable data being included, any reasonable sources of data being overlooked?
- 6) In the assessment of data, does it point towards recruitment of new members or point out new way(s) to organize the coalition?
- 7) Are the members fully informed and feel ownership of the gathered information and its analysis?
- 8) Has the coalition revisited its goals and restated them, if necessary, in light of this "psyching out" stage?

Phase 4. Action:

Given the building of the coalition, its maturing, development of an organizational vehicle, and its "psyching out" of the status of end of life care, the coalition then moves into the planned action for change phase. Note, action is already occurring. The very movement through the first three phases has produced change: development of a "community of concern," more positive inter-organizational relationships, a more educated public, and, possible other changes. This phase involves joint, problem-solving, decision-making and implementation. Again, a series of questions may be asked:

- 1) What individuals, groups, organizations need to be involved in the change effort (refer back to action and target system discussion)?
- 2) What assumptions regarding the future are being made in order to develop the plan for action?
- 3) Is the possible plan(s) in keeping with the coalition's mission, goals, and method of operation?
- 4) Is the proposed plan for action simple or complex?
- 5) Will it be readily acceptable to the coalition members and the community at large?
- 6) Does it have flexibility to adjust?
- 7) Has a carefully worked out time schedule been established?
- 8) Importantly, have the details of where, when, and by whom the planned action should be done, and put in proper sequence for its intended goals and objectives to be met?
- 9) Simply, has the plan been put in writing?
- 10) Has the plan for action been effectively dramatized and is it now being accepted in the community?
- 11) Has an adequate plan for monitoring and evaluating the action been effected and appropriate changes in activities made where warranted (i.e. the data collected to measure results)?

Phase 5. Institutionalizing the Effort

The plan for action is a moving stage in which a great deal of change activity takes place. Now the question is how to refreeze the changes so that the changes become institutionalized. That is, how to sustain the changes that have been made so that slippage will

not occur and that the impetus for improved end of life care will continue. A series of questions can be asked:

- 1) Have the desired changes been accepted and fully integrated into existing or new organizations?
For Example, a new admissions protocol implemented in a hospital favoring dying person's needs for access; a new state policy regarding eligibility for hospice care through Medicaid, etc.?
- 2) Have discussions been held to determine the future role(s) of the coalition?

Phase 6. Nurturing

This is, in reality, not a separate phase but emphasizes that nurturing must receive attention in all phases. Coalitions have their ups and downs, their surgings of vitality and activity, periods of reflection, and periods of conflict or uncertainty. The glue towards keeping a coalition moving is awareness of the primary task of building and maintaining consensus and focussing on the goals to be mutually achieved. "Turf" is normal and to be expected. "Quid pro quo" is appropriate in unsettled times. The key is to continue to nurture the boards of the coalition, the members' ideals, common goals, interests in the issue(s) and fostering the belief that in the coalition there is strength to get something done. Again, power is education plus constituency. Therefore, attention to representation, joint activities, and opportunities to participate is vital to the life of a coalition. Throughout the phases of the coalition, then, such tools as outreach, team-building, encouraging participation, developing formal and informal lines of communication, encouraging dialogue, and developing incentives for involvement and participation are the ways to keep members active, committed and happy!

VII. THE COALITION FOR DIALOGUE ON DEATH AND DYING: AN EXAMPLE

In late 1995, under the auspices of the Hospice of Midcoast Maine, a small group of individuals and organizations came together to discuss the cultural issues, barriers, and organizational issues surrounding death and dying in Mid Coast Maine (14 communities). It was spearheaded by the active leadership of the hospice president. The group, discontent with the way things were coupled with charisma and dedication, saw positive change as a vision of the future. Feeling that they, or the Hospice, could not effect change alone, the group moved to recruit new members. The beginning group grew to twelve organizations, and now has 36 active members, over 100 volunteers working on committees and has reached over 2,000 people through its activities. In short, it has become the change agent in the arena of end of life in Mid Coast Maine.

The Coalition collectively worked through a consensual series of activities over a prolonged period of time and developed a rallying statement:

"The Coalition is a growing 36 member organization composed of organizations and citizens with the purpose of serving as the catalyst and consensus body for identifying, assessing and discussing the culture, issues, programs, and potentially needed changes regarding death, dying, and bereavement in the Mid Coast Maine region."

The Coalition then formulated its goals to:

- ✍ Understand the region's diverse cultures of death and bereavement.
- ✍ Identify and assess the current system of care related to death and dying.
- ✍ Evaluate how well the system is working.
- ✍ Identify gaps in the system.
- ✍ Remedy gaps and effect change.

In its growth, the Coalition pointedly aimed at involvement of the total community: providers, consumers, institutions, community groups, businesses, unions, social and health agencies, volunteers, and the like, who were coming to the table for the first time. The action system was being formed. The Coalition then formed an organizational vehicle to carry out its purposes (see chart 2). Key leadership was recruited to an Advisory Committee that included area hospitals, major employers, insurers, institutions, and medical professions. It was adherence to the concept that those most able to make changes would be involved in a collaborative way.

The Coalition has received three year funding from the Project on Death in America (PDIA) and as a result was able to hire a coordinator and supportive staff. This served to add more focus to the Coalition's activities.

In order to find out what the state of end of life was in the region, the Coalition formed a number of committees. To achieve the above goals, but also to build organizational capacity, data was sought from a number of sources. From the consumer side: interviews were conducted with dying persons and their families; community dialogues were conducted throughout the area with diverse groups (e.g. church groups, unions, grieving adolescents, volunteers, civic groups, clubs, etc.); and two area-wide dialogues that combined consumers and providers. From the provider side: focus groups were held with providers of health care and support practitioners (e.g. physicians, nurses, social workers, support and service groups, clergy, police, EMS, and hospice volunteers); organizational analyses were conducted of the array of approximately 50 organizations that provide direct or indirect services around death, dying, and bereavement.

Survey instruments were designed to collect the data (see chart 3 for an example), display it in an understandable way and provide the means for analysis. Over 700 persons were involved in the process. In addition, secondary data was obtained relative to incidence of death, location, cause, etc. in order to provide a full picture of the present state.

All these activities were shared and discussed through the Coalition. For the most part, everyone was on the same page and both formal and informal lines of communication were in great use. The community was kept involved through planned Symposia, newspaper articles and electronic media, over 50 speeches to community groups, production of video-tapes, and the standbys of organizations: meetings, planned agendas, minutes, reports, team-building efforts, and the like. Individuals underwent training to become facilitators and became active emissaries to the general community.

In the two year process of obtaining relevant data, change has already occurred: two organizations have merged into order to form an organization that could serve people over an age continuum; guides to resources for the final months of life have been disseminated throughout the region as one response to the lack of knowledge and information about resources on the part of both providers and consumers; the beginnings of a Center for Death and Dying; and movement towards a Palliative Care Compact; are some examples of how change occurred throughout the process of coalition building.

A major action phase has now been initiated. On the basis of the findings of the two-year study, a document was produced: "A Call to Action: A Report to the Community on Life at the End of Life in Mid Coast Maine." This represents the plan for action by the Coalition. Armed with education and an ever-growing constituency, the Coalition has issued a call to action for positive change.

The document was worked through the entire Coalition, spurred by a Survey Committee, and the members took ownership. It then was presented to the community in a major Symposium and was duly reported in the media as well as being fully videotaped by Cable TV for future showings.

This document represented a new action phase. It recommended the creation of five task forces: Patient and Family Empowerment; Health Care Organizations; Providers; Economics of Care; and Community. It made a series of recommendations for task force involvement that would bring the area-community, general public, consumers, providers, and care-giving organizations together to mutually work on a series of actions to improve end-of-life experiences and the system.

The emphasis of future action is a collaborative effort based upon joint community problem-solving, overcoming barriers and resistance to positive change, and finding the means and resources to strengthen and change the system. It calls for activity on the part of the action and target systems, hopefully in a positive way.

An interesting point for this Coalition is its focus on building upon already existing assets. Rather than focussing on problems, the Coalition frames its approach on identifying and pursuing change efforts that represent opportunities for change (see Task Force Five: The Community).

This Coalition has utilized locality development, social planning and some social action approaches to change.

VIII. A FINAL NOTE

The use of a coalition around improving end of life care has great merit and provides a full community approach to change. Four principles to remember are:

- 1) Involvement. Coalitions will thrive on exerting collective influence to bring about change. Much thought must go towards achieving relevant inclusivity in recruitment. All levels of the community should be involved, and attention paid to diversity, action and target systems.
- 2) Collaboration. As noted, coalitions are dependent upon collaborative action that is based upon true joint community problem-solving, joint action to overcome resistance(s) to change, and joint sharing of resources and expertise. There is more of a chance with active collaboration than without it.
- 3) Assets to opportunities. As a positive twist to problem and needs formulations, consider building upon already existing assets. Working from strengths and the assessment of data: we know what we have, we know what we want, we identify what opportunities can be pursued to make the system and the process better. Building upon opportunities aids positive action and may decrease resistance to change.
- 4) Change efforts. Resistance to change is normal and can be viewed as a defense. Involving a full community in a coalition, discussing issues and efforts, getting educated, finding where the points of agreement are, developing more familiarity and trust, and working together for common goals – all serve to dispel much of the resistance to change. The very process itself is change, and proves rewarding to participants.

Finally, no one approach will work in the end of life arena. It has a complexity that calls for various efforts – the key is determining which fit the situation.

GOOD LUCK!!

Michael J. Murphy, Ph.D.

Charts and Sources

CHART 1

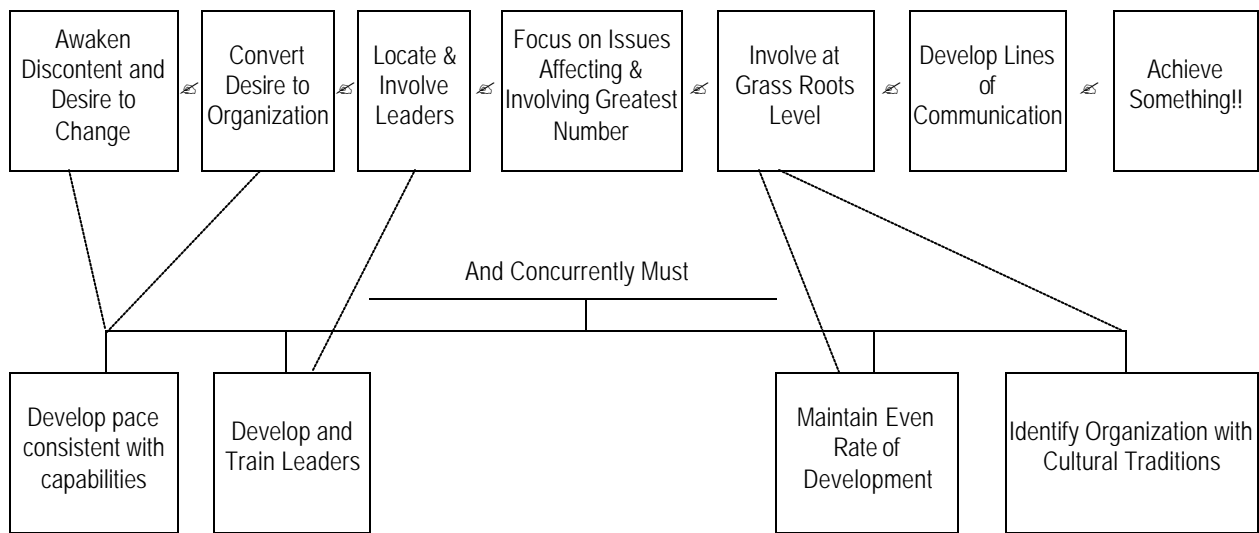


Chart 2

Coalition for Dialogue on Death and Dying Organizational Chart

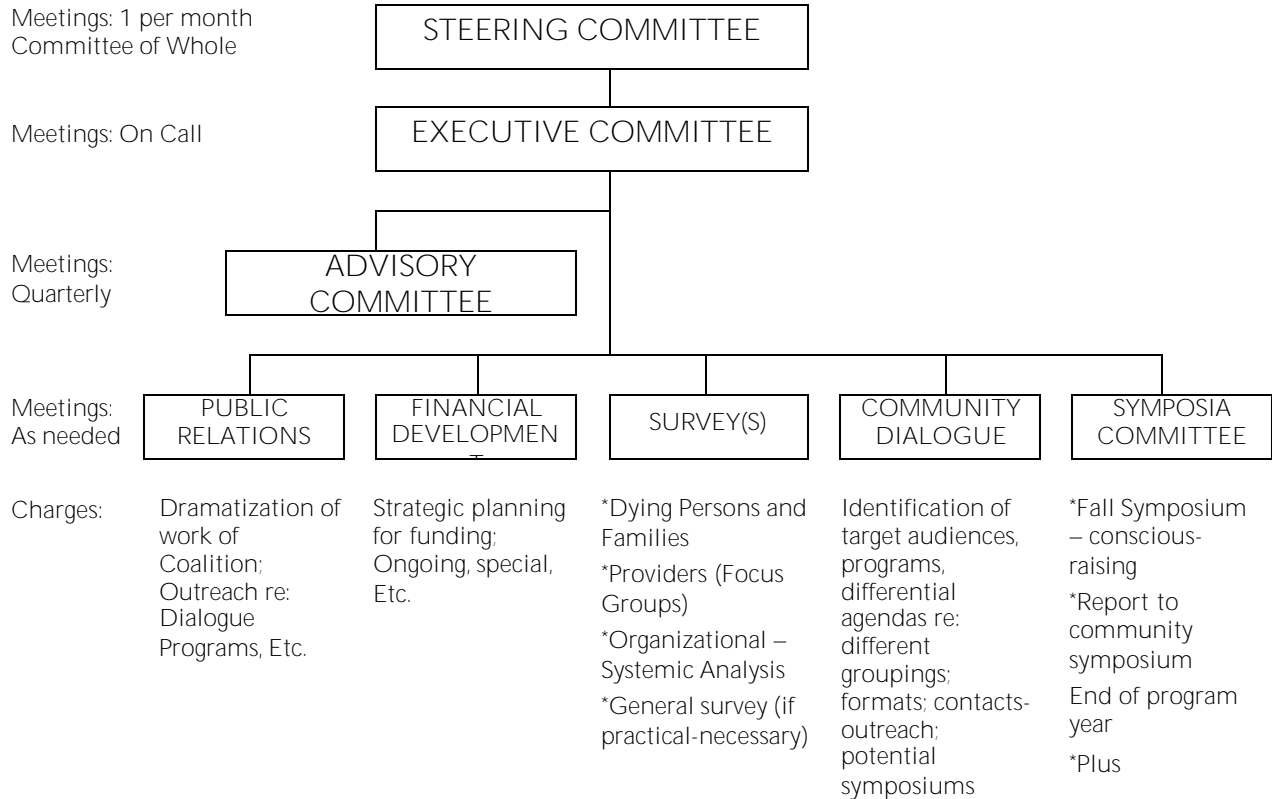


Chart 3

Guide: Interviews With Individuals Who are Dying.

When did you learn about your condition?

Who told you about your condition (and that you are dying)?

Tell me how that felt for you?

How did the rest of your family and friends learn of this? How did they respond?

How did the medical staff respond to you at the time?

Please tell me how you understand your condition today.

What are the most important things that concern you now?

Are there people that you can talk to about your concerns?

Do you find that you can talk to your family about your condition and about death and dying? Is that hard? How does that feel?

What kinds of help do you need now?

Who are the people or groups that you have found most helpful? What kinds of help do they provide?

What kinds of things that other people do are not helpful to you? What did you find least helpful?

Are there supports or assistance that you wish that you would like to have, but do not?

Tell me a little about how physicians have helped you or have not helped you deal with this situation? How about family? Clergy? Nursing staff? Friends? Neighbors?

If you had something you would like to change about this experience of dying that would make it better for other people, what would it be?

Task Force Five: The Community

- ? Initiate a community-wide Compact regarding palliative care;
- ? Initiate a community-wide integrated service delivery system;
- ? Establish a central access point for dying persons, their families, and providers;
- ? Develop community-wide education programs regarding death and dying;
- ? Encourage, develop, and implement grief and bereavement support in all relevant gathering places;
- ? Provide information and communications vehicles between delivery systems and the community;
- ? Provide information and referral aids for patients, families, and service providers.

† Referenced Sources

See: Toseland, Ronald W., and Rivas, Robert F., "An Introduction to Group Work Practice," 2nd Edition, (Boston: Allyn & Bacon), pp. 42-43.

Ibid., pp. 32.

For a Full discussion, see: Rothman, Jack; Erlich, John L.; and Trofman, John E.; editors, "Strategies of Community Organization," 5th Edition (Itasca, Ill.: F.E. Peacock Publishers, 1995), pp. 26-61.

COALITION FOR DIALOGUE ON DEATH AND DYING: STEERING COMMITTEE

John Norton, Chair	Bowdoin College
Gary Araujo	Hospice of Midcoast Maine
Marie Badger	Hospice of Midcoast Maine
Gary Bartlett	Brunswick School Department
Kathleen Brainerd	Navy Family Service Center
Robert Chadwick	Hospice of Midcoast Maine
Grete Chandler	Shoreline Community Mental Health
Lee Demers	Transitions
Deborah Demosthenes, R.M., B.S.N., C.R.N.H.	Community Health and Nursing Services
Robert Edson	American Cancer Society
John Farnham	Hospice of Midcoast Maine
Beth Finlayson	Freeport Community Services
Richard Gelwick, Th.D.	University of New England
Jessica Harnar	Coastal Economic Development Corp.
Nancy Herk	Brunswick Area Respite Program
Ruth Hoffman	Coalition for Dialogue Death & Dying
William Imes, Th.D.	First Parish Congregational Church
Kathleen Kaplan	University of New England
Sig Knudsen	55 Plus Center
Michael L'Abbé	Mid Coast Health Services
Juliana L'Heureux, B.S., R.N., M.H.S.A.	Community Health and Nursing Services
Peter Lindsay	United Way of Midcoast Maine
Jean MacDonald, Ph.D.	Coalition for Dialogue on Death & Dying
Craig McEwen, Ph.D.	Bowdoin College
Pat Murtaugh	L. L. Bean
Roy Nakamura, M.D.	Martin's Point Health Center
Ralph Perry	South Harpswell
Sophia Pfeiffer	Maine Bioethics Network
Laura Emma Ridgewell	Fisherman's Wives' Assoc.
Mary Louise Seldenfleur	South Harpswell
Jack Six, Ph.D.	University of Maine, Augusta
Edith Smith	Maine Funeral Director's Assoc.
Karen Taber, R.N., M.S., C.C.R.N., C.S.	Mid Coast Health Services
Kathy Vaden	Parkview Hospital
Jill Wallace	Merrymeeting AIDS Support Services
Arlene Wing, R.N.C., M.H.S.A.	Integra Group
Michael Murphy, Ph.D.	Coalition Coordinator
Michelle Drucker, M.Ed.	Consultant
Alfred L. Hipkins	Scribe