



***Means to a Better End:
A Report on Dying in
America Today***

**Action Guide:
Seize the Opportunity!**

**Embargoed until
November 18, 2002**



***Means to a Better End:
A Report on Dying in
America Today***

**Action Guide:
Seize the Opportunity!**

**Embargoed until
November 18, 2002**

Contents

Purpose of *Means to a Better End: A Report on Dying in America Today* 3

Why This Action Guide? 3

Preparation for Release of the Report: A Good Offense Is the Best Defense 3

Interpreting *Means to a Better End*: The Messages 3

Overall Messages 3

Messages from the Measures 4

The Role of Local Efforts 4

Develop a Media Plan About Your Local Efforts 4

Develop Messages 4

Develop Media Savvy 5

Promoting *Means to a Better End*: Media and Policy Strategy 5

Media Relations 6

Washington, D.C., News Conference 6

Video News Release 6

Media Kit 6

Webcast 6

Policy Communications 7

Follow-Up Following Release of the Report:

Keep Your Eye on the Ball 7

Play with the Data: What's Behind the Numbers? 7

Further Action to Focus Attention on Change 7

Activities for Consumer Organizations 8

Reference Materials 8

Questions? 8

Purpose of *Means to a Better End: A Report on Dying in America Today*

Last Acts' new report, *Means to a Better End: A Report on Dying in America Today*, is a state-by-state analysis of the availability and use of good end-of-life care. The report is the first of its kind. In addition to the eight measures that constitute a state-by-state report card on the conditions of dying in America today, *Means to a Better End* also gives an accounting of what the *Last Acts* community is doing to improve the situation, and makes important recommendations for further action. Its publication is accompanied by a survey that captures current public attitudes and beliefs about death and dying.

The biggest barrier to attracting and sustaining press interest in end-of-life care issues or the public engagement process is that most reporters, producers and editors use their own criteria to evaluate whether or not a story is potentially of interest to their readers. These criteria include novelty, shock, conflict, confrontation, new data, celebrity involvement, symbolism, trends, humor, actions, and kids.

— From *Reforming End-of-Life Care in Your Community, Making Our Voices Heard: A Guide to Public Engagement (Community-State Partnerships in End-of-Life Care, 2000)*

Last Acts designed this report as a vehicle to gain visibility and provoke action on end-of-life issues. The results are intended to create a wake-up call that will draw the attention of the media, policymakers and the public to the continuing urgent need to improve end-of-life care. Used thoughtfully, *Means to a Better End* and the survey that accompanies it can be powerful tools for your own efforts to show off successes and focus attention on the need for more improvement in care and caring near the end of life.

Why This Action Guide?

Last Acts is releasing *Means to a Better End* along with the survey results at a news conference on November 18, 2002. *Last Acts* Partners and Rallying Points coalitions are receiving this Action Guide ahead of time so that they can prepare to respond to media inquiries about the report and be ready to take the initiative in actively promoting solutions to media and other policy audiences. *Last Acts* cannot release the state-by-state results to Partners and coalitions before the actual news conference without risking “leaks” and thereby jeopardizing media interest. The media are interested in “news” and news needs to be new.

If you are reading this Action Guide, you are probably affiliated with a *Last Acts* Partner or an end-of-life coalition. No

doubt, you understand the serious deficiencies in care for dying patients and their families, you are familiar with the barriers that make change such a challenge and you know that action is needed in order to improve end-of-life care in the United States.

Even with that depth of understanding, the ratings and the data in *Means to a Better End* may leave you surprised and disappointed, perhaps even angry. You know about the enormous resources and efforts of talented people that have been devoted to making improvements. The report may cause you to worry that the task is impossible, that all the hard work has failed to make significant progress, or that the public will believe your group has had no impact.

This Action Guide was created to help you see the entirely different and more productive messages that can and should be drawn from the data. It also describes some ways you can use *Means to a Better End* to promote the importance of end-of-life care and draw attention to the good work being done to improve that care.

Preparation for Release of the Report: A Good Offense Is the Best Defense

Interpreting *Means to a Better End: The Messages*

You are in an excellent position to use *Means to a Better End* to explain your work to the media, local legislators, other policymakers and the public. Burness Communications, as part of the *Last Acts* communications team, has created an extensive media relations plan to promote the report. It includes a series of messages that you can use as-is or tailor to the special circumstances of your group.

Overall Messages

- Americans have, at best, only a fair chance of finding good care at the end of life.
- Although hospice care is considered a “gold standard” for end-of-life care, usage from state to state varies from 4.9 to 42 percent—more than an eight-fold difference.
- Most states can cite examples of excellent care and progress is being made to promote quality care within their borders. However, from a national perspective, there is a long way to go to build health care and policy environments that consistently support outstanding care.
- Because of the many shortcomings in the care of dying patients, coalitions have formed across the country to act as advocates for improvement. Their records of achievement are impressive.

- Public policy changes, better health care financing and increased consumer demand are essential to improving end-of-life care. Other needs include more and better-trained professionals, supportive practice environments and more extensive research.
- The United States is at a crossroads—a better system of end-of-life care is urgently needed now, or we risk leaving our steadily increasing elderly population without the care they need.

Messages from the Measures

- 1 General:** Our rating system creates a statistical portrait, not a perfect measuring tool.
- 2 State advance directive policies:** Some states' laws include language or procedures that confuse or inconvenience citizens and make it harder for them to express their preferences or to designate appropriate surrogate decision-makers.
- 3 Site of death:** Where one dies—in a hospital, a nursing home or at home—depends on where one lives, and the health care resources available there. Research has shown that these availability factors outweigh patient preferences. Over 70 percent of Americans want to die at home. Only about 25 percent do so.
- 4 Hospice:** The average length of stay in hospice has dropped to well below the 60 days considered necessary for maximum benefit from the program. In fact, dying people commonly have the support of hospice care for less than a week. For some, it is only for a day or two.
- 5 Care in hospitals:** Though the number of organized palliative care programs in hospitals is increasing, they are not yet the norm and are difficult to reimburse fully with current payment mechanisms. Funding for these programs has to be pieced together and often relies on donations and private grants, raising questions about their financial viability.
- 6 Care in Intensive Care Units:** Nationwide, 28 percent of Medicare patients who die are treated in ICUs in their last six months of life. The rate varies widely, even within individual states. A high rate of ICU care for dying people suggests heavy use of technology, perhaps at the expense of attention to comfort or against expressed treatment preferences.
- 7 Pain in nursing homes:** According to research, pain for nearly half of the 1.6 million Americans living in nursing homes is under-assessed and under-treated.
- 8 State pain policies:** All states have laws addressing the use of controlled substances. Some are effective, but others create formidable barriers to good pain management.
- 9 Supply of trained professionals:** Palliative care training for the nation's physicians and nurses lags far behind the

needs of the aging U.S. population. This is true for those still in school as well as for the hundreds of thousands of professionals already in practice.

The Role of Local Efforts

Means to a Better End presents an important big-picture perspective on the provision of end-of-life care in the United States, using eight measures selected to reflect key elements of palliative care. *Means to a Better End* does not track or measure the successes or trends of a wide variety of state and local efforts and initiatives to improve end-of-life care because data for them are not available. Many state and local efforts are described in *Means to a Better End* in a section called “Momentum for Change.”

Local reporters may try to relate the results of *Means to a Better End* to their state or local community and to efforts and projects that may be under way. Many of you may be worried that low state grades will reflect poorly on your own efforts. They do not. The following messages can help you refute and deflect that perspective:

- 1** *Means to a Better End* looks at the big picture. It does not evaluate or pass judgment on individual programs and efforts or progress.
- 2** There are islands of excellence in a sea of mediocrity. Many people are doing wonderful work to improve the quality of end-of-life care. As a result of these programs and efforts, A+ care is available in many places, but far from universally. People in each and every state need to continue working in order to ensure that consistently excellent end-of-life care is available everywhere.
- 3** Yes, improvements are needed and change is difficult. *Means to a Better End* shows just how serious the problems are and why our organization has been working so hard! Ensuring consistently excellent end-of-life care throughout the United States requires both a state and a national commitment to plan for and finance that care.

Develop a Media Plan About Your Local Efforts

Means to a Better End is a hook to attract media attention. It alerts reporters to problems that exist. It also gives you the opportunity to point out that people in your community care about quality end-of-life care and to focus attention on the nature and extent of local efforts to improve that care. Seize it!

■ Develop Messages

Build on the messages listed above, but refine them so that they are specific to your local needs. Your precise messages will vary based on how your state ranked in the report and the sorts of local efforts that have been conducted, are under way, or are planned. It is important to be positive and to make the best of any situation without sounding defensive. Seizing the opportunity means being prepared either to “make hay” or

“make lemonade!”

If you have success stories to tell, this is an opportunity to highlight the improvements you have made in the context of how far there is yet to go. If your efforts are just beginning or are still in a planning stage, this is an opportunity to promote the importance of your work. If you are just getting organized, this is an opportunity to attract additional people to join your fledgling efforts. If you have tried but been unable to attract funding, this is an opportunity to draw attention to your plight and the fact that you are seeking financial support.

Don't be afraid to acknowledge the challenges in the overall end-of-life environment. Change is always tough. In this case, it requires grappling with issues that are still cultural taboos. Try to use individual stories as well as the demographic context to convey your message. Emphasize the increasing importance of end-of-life issues as the boomers age and the elderly live longer.

■ Develop Media Savvy

Your efforts will be most effective if you are informative and able to provide supporting materials and additional sources. Make your messages concise and clear. Be cooperative and sensitive to reporters' deadlines. Avoid saying “No comment” and never argue with a reporter. Be honest, even if it means admitting to limitations in your program. Reporters respect truth-tellers and regard them as continuing valuable sources.

The following concrete ideas can help you craft your message and prepare to be a savvy media resource:

Before you pick up the phone to call a reporter:

- 1 Identify any communications people within your organization and enlist their help.
- 2 Designate a person within your organization to coordinate with *Last Acts*.
- 3 Select one or more spokespersons for your organization and rehearse them—particularly around tough questions. Work with the key messages provided above. *Last Acts* can help you tailor them to your needs. Contact Mollie Katz at (301) 652-1558 for assistance. In addition, a list of Frequently Asked Questions and suggested answers has been created for your use. To request a copy, contact Sonja Gerald at (301) 652-1558 or sgerald@businesscommunications.com.
- 4 Create a list of your organization's activities and efforts. Be sure to emphasize any results. Have the list available to refer to as you speak to reporters.
- 5 Create a succinct account of your plans, goals and the difficulties you've overcome or encountered—or both.
- 6 Be prepared to thank your financial supporters and to credit people who have been essential to your efforts.

Longer-term tips:

- 1 Create a list of health care providers and other experts and suggest that reporters who are covering end-of-life care in your state contact them. Be sure the list includes correctly spelled names, job titles, e-mail addresses and phone numbers. Continually update this list.
- 2 Identify local patients and families who are willing to speak to reporters about their experiences with end-of-life care.
- 3 Prepare a list of key media contacts. Pay attention to the news, to what is covered and by whom. Which reporters cover health issues and which cover the elderly? Watch bylines. Set up a system to track media outlets and reporters. Develop and cultivate your list over time. It's OK to start small.
- 4 Contact reporters to keep them informed about developing news related to end-of-life concerns and offer insights on issues of importance in your community. Even if they don't write about you whenever you call, you will become a trusted resource for future stories.
- 5 Request an editorial board meeting with your local paper to discuss *Means to a Better End* and the work you're doing. Editorial boards may respond to the message that the country is at an important crossroads with respect to end-of-life care. A small, diverse delegation from your group may be most persuasive.
- 6 Ask someone affiliated with your local media to join your local end-of-life coalition.

Promoting *Means to a Better End*: Media and Policy Strategy

Regardless of the ratings that your state received, your efforts to promote *Means to a Better End* will help to advance the overall goal of improving end-of-life care in your

People working on end-of-life issues can look to changes in expectations about childbirth to inform and focus their efforts. “How women give birth in the United States has changed dramatically in the past 30 years, primarily because women demanded a different experience from their healthcare providers. Doctors had become so focused on using modern medicine to make childbirth safer and more comfortable that the human element got lost. Birth became a medical event without a support circle for the laboring woman to help defuse anxiety and discomfort. It wasn't until women began to voice discontent with their birthing experience and search for another safe but more fulfilling method of birthing that things began to change.”

— Robin Richman, M.D., a nationally recognized expert in women's health policy

community and throughout the country. *Last Acts* has developed a multifaceted approach including materials, messages and suggested activities in order to make it easier for *Last Acts* Partner organizations and state or local Rallying Points coalitions to reach out to the media and policymakers.

Media Relations

■ Washington, D.C., News Conference on November 18, 2002, with phone-in option for reporters based outside Washington

On behalf of *Last Acts*, Burness Communications is planning a news conference to announce publication of *Means to a Better End* along with the survey results and review the findings. *Last Acts* Partners, public policy groups and other advocates will be invited to attend this important event. Many reporters who cover end-of-life care, aging and health will be invited to attend in person. Burness will also invite reporters outside the Washington, D.C., area to participate via telephone using a toll-free number.

What You Can Burness has prepared a one-page media advisory that *Last Acts* Partners and Rallying Points coalitions can use to urge local media to participate in the news conference by telephone. Contact Sonja Gerald at (301) 652-1558 or sgerald@burnesscommunications.com to request a copy. If your local media contacts are interested in the story but are unavailable at that time, Burness will work with you to arrange individual phone interviews with spokespersons following the event.

■ Video News Release

Home Front Communications, a professional video news release (VNR) production company, will produce video materials that will be offered via satellite to local television stations nationwide. The video package will consist of a brief written background, interviews with key national spokespersons and silent video that local stations can use to create their own customized story.

What You Can A separate one-page advisory containing the satellite coordinates that stations will need to download the VNR is available to *Last Acts* Partners and Rallying Points coalitions in advance so that you can pitch the story to your local television stations. For a copy, contact Sonja Gerald at (301) 652-1558 or sgerald@burnesscommunications.com. Your local station is most likely to be interested if you can offer local spokespersons, patients or locations where they can videotape to supplement the VNR material that they download.

■ Media Kit

Burness is producing a media kit that will be distributed at the Washington news conference. It will be available on the *Last Acts* Web site (www.lastacts.org) in the Media Center. The kit will include:

- A news release*
- A copy of *Means to a Better End**
- A copy of the national survey results*
- An agenda of speakers at the news conference and their biographical information
- The names and credentials of national experts who are prepared to field questions about each of the eight measures included in *Means to a Better End*
- Fact sheets containing state-by-state results.*

What You Can

Download copies of advance material from the Partner Home of the *Last Acts* Web site for your organization and become familiar with the contents. Let local reporters know that the media kit findings of the report and national survey can be found on the *Last Acts* Web site on November 18, 2002. Supplement your pitch with names of local palliative care practitioners, coalition leaders, hospice leaders, and patients and families who can provide a local angle to illustrate the key messages. Help local journalists make this a state or local story by creating and providing your own factsheet, news release, expert contact list or other reference materials that focus on the specific work you have done. Feel free to use *Last Acts* materials as models for your own releases. They can also be used in combination with your own material to give journalists both a national and a state or local perspective.

■ Webcast

The Robert Wood Johnson Foundation® will Webcast the Washington news conference, offering access to the event on its own Web site (www.rwjf.org). Contact Burness at (301) 652-1558 for information about when the Webcast will be available and how to locate it on the site.

What You Can

The Webcast is a good tool for local outreach to your own staff, board and members and to policy leaders who may be able to influence end-of-life care. It is not recommended for media relations purposes because it will be regarded by the media as “old news.”

Policy Communications

Last Acts will use media coverage of the data to attract the in-

*To be posted on November 18, 2002, at 11:30 a.m. EST at the start of the news conference

terest of national and state policymakers. You can alert your federal and state representatives to the report and provide your name and number to their staff for follow-up. Be sure to highlight the “Recommendations” section of the report as it includes a list of specific actions recommended for policymakers.

Follow-Up After Release of the Report: Keep Your Eye on the Ball

Play with the Data: What’s Behind the Numbers?

With the benefit of time for reflection, many positive results could arise if you convene a group to review the measures, analyze the ratings and brainstorm ways to use the findings for planning purposes. After reflection, you may find it helpful to:

- 1 Consider whether the scores, be they high or low, represent the reality of what is going on in your community.

• • •

EXAMPLE Your state may have gotten a good grade because it has a provision in its laws that permits an out-of-hospital DNR order. However, members of your coalition may know that the provision has not been widely publicized or used. People are frequently dismayed to discover that their advance directives and health care proxies are of no effect when the ambulance arrives. This could be an area for further attention and work.

• • •

- 2 Break state-level numbers down to reflect conditions in local communities, if possible.
- 3 Think about other measures that might contribute to a fuller understanding of the status of end-of-life care in

The Partnership to Improve End-of-Life Care in Utah used negative ratings in a very positive way when they learned that Utah ranked among the lowest in the nation in managing pain in nursing homes. The data source was a research letter by Joan Teno, M.D., published in 2001 in the *Journal of the American Medical Association*. The partnership responded promptly by convening a meeting of stakeholders. Given the shocking results, the stakeholders came. After initial defensiveness and disputation about the validity of the data, the group came to a consensus that they could be doing a better job of managing pain in nursing homes. The result has been considerable work and unusual cooperation to launch a pilot project with enormous potential for important change.

your state or community. Promote the collection of data about those measures. Surveys might be a good way to generate local data on certain questions, such as, the preparedness of clergy to deal with end-of-life concerns.

- 4 Consider whether the ratings might motivate new players to become involved in end-of-life issues, then approach them about participating with your coalition.

• • •

EXAMPLE The Alabama end-of-life coalition, Alabamians for Better Care at Life’s End, finds it helpful that their coalition includes representatives from community and civic organizations; churches, clergy and funeral directors; health care professionals; professional schools; the Alabama state government; health care facilities; and the hospice community. Other coalitions have found it helpful to include a media representative in the coalition.

• • •

- 5 Consider whether the ratings suggest a need to expand your coalition to include representatives of various racial, ethnic and cultural groups within your state. Such an expansion could make your issues more meaningful to a wider range of people or help make the health care system more responsive. Helpful information is available from the *Last Acts/Rallying Points* National Resource Center on Diversity by calling toll-free at (866) 670-6723.

Further Action to Focus Attention on Change

You can use *Means to a Better End* to focus attention and encourage allies from health, aging and other fields to:

- Promote public understanding that patients and their families have choices about the care given to serious, life-threatening illnesses.
- Increase recognition of the elements of quality palliative care, including the necessity of respecting racial, ethnic and cultural differences.
- Convey the value of advance care planning in preventing the need to make difficult decisions at a time of crisis.

Action Steps that others around the country have used successfully:

- 1 With a partner, organize a town meeting or other community forum about the findings. Perhaps a workshop with your local AARP chapter or Area Agency on Aging might be possible. Meetings that are held at senior centers and events that include some sort of live or video presentation followed by discussion usually attract the largest audiences. Invite local health care leaders. A trained facilitator is often an important part of an effective program.
- 2 Identify key legislators to contact with the report, survey results and media coverage. If you can, interest one legislator and legislative aide in helping you arrange an in-

service training program about end-of-life care for the other legislators' aides and staffers. Attendance is likely to be highest if the training is short, is located right in their office building and occurs soon after the report is released.

- 3 Work with your local library or bookstore to create an exhibit and host a related discussion group.
- 4 Join your local Rallying Points coalition campaign and take advantage of Rallying Points' many technical assistance resources.

Activities for Consumer Organizations

Consumer membership organizations and coalitions of consumer organizations can play a special and very important role in focusing public attention on end-of-life issues even though improving end-of-life care may not be the organization's primary goal. There are many opportunities to help patients and families understand that they have choices about the care given to serious, life-threatening illnesses, and to convey the value of advance care planning in preventing the need for difficult decisions at a time of crisis. The following examples can be accomplished relatively easily and yet contribute to the overall effort:

- 1 Link to the *Last Acts* Web site (www.lastacts.org) from your organization's site. Visit the *Last Acts* site for end-of-life publications and resources, and include these in mailings to your membership.
- 2 Include articles on end-of-life topics in your organization's publications, magazines and e-mail newsletters.
- 3 Join an end-of-life coalition in your area, or if none exists, start one. The Rallying Points Web site (www.rallyingpoints.org) lists hundreds of coalitions across the United States and includes information to help new coalitions get started.
- 4 Urge local professional associations of doctors, nurses, pharmacists, social workers, clergy, attorneys and financial planners to join your local end-of-life coalition.
- 5 Help your members identify the stakeholders in the community, and encourage them to convene a group to discuss end-of-life issues.
- 6 Encourage your local hospital to establish a palliative care unit, or support an existing unit.
- 7 Reserve time at your organization's conferences and meetings for speakers on end-of-life topics.
- 8 Hold an advance care planning drive among your membership.
- 9 Order *Helping Employees Deal with End-of-Life Issues: A Tool Kit*, *Last Acts'* comprehensive guide to developing an eldercare program in your workplace.

- 10 Hold a fund-raiser for your local hospice.

Reference Materials

- *Convening Town Hall Meetings*, by the Rallying Points Regional Resource Center at The Hospice of the Florida Suncoast, 300 East Bay Drive, Largo, FL 33770. For a copy, send a request to kathybrandt@thehospice.org.
- *Starting and Maintaining a Successful End-of-Life Coalition*, by the Rallying Points Regional Resource Center at The Hospice of the Florida Suncoast, 300 East Bay Drive, Largo, FL 33770. For a copy, send a request to kathybrandt@thehospice.org.
- *Media Tips for Last Acts Partners: A Guide to Effective Media Relations*, prepared by Burness Communications, June 2002. Available by contacting Sonja Gerald at (301) 652-1558 or sgerald@burnesscommunications.com.
- *Using Qualitative and Quantitative Data to Shape Policy Change*. State Initiatives in End-of Life Care, Issue 1, June 1998. Available at www.lastacts.org or at www.midbio.org.

Numerous *Last Acts* publications can be obtained online: Go to www.lastacts.org and click on *Last Acts* Activities, then click on Publications in order to get to a list of publications in reverse chronological order, most recent first.

For a list of state pain initiatives: Go to www.aacpi.org and then click on Initiatives.

Questions?

If you have any questions or need further information about national or state-level media relations, please contact Mollie Katz at Burness Communications, (301) 652-1558, mkatz@burnesscommunications.com. Policy-related questions or requests for information should be addressed to Ben Milder at Burness Communications, (301) 652-1558, bmilder@burnesscommunications.com.

For information about forming or joining a community coalition, visit www.rallyingpoints.org.

**We're here
to help you.
Use us!**

Last Acts National Program Office
1620 Eye Street, N.W.
Suite 202
Washington, D.C. 20006-4017

www.lastacts.org

Phone: (800) 341-0050

Fax: (202) 296-8352