Sandra North vividly recalls the night her mother died. After spending four years in a nursing home with advanced Alzheimer's Disease, her 89-year-old mother was rushed to a hospital because of difficulty breathing. In the emergency room, she was placed on a respirator. “She had tubes everywhere. I begged them to let her go in peace, but they wouldn’t listen to me,” says North. “When her heart stopped, a crash team rushed in to try to resuscitate her. In the process they broke her ribs. Finally they stopped trying and she died. The doctor said, ‘We did all we could,’ but she deserved a better end.”

North has filled out a living will and appointed a healthcare proxy. Still, she worries that her death will be no better than her mother’s. “How can I make sure things will be different?” she asks. As 80 million baby boomers prepare to care for aging parents, many are asking similar questions. So too are their parents.

These questions are the subject of Finding Our Way: Living with Dying in America, a 15-part newspaper series that will explore complex issues and endeavor to create a new culture in which we can be cared for as we near life’s end. Finding Our Way is a collaborative national education effort coordinated by Partnership for Caring, Last Acts, The Center for Advanced Illness Coordinated Care/VA HealthCare Network Upstate New York at Albany, and the Center for Death Education and Bioethics at the University of Wisconsin.

Each article in the series will be written by a leading expert in the field of end-of-life care and will include compelling personal stories and state-of-the art information, tools and resources. Importantly, Finding Our Way considers matters far broader than our last hours or even our last days or weeks. Finding Our Way shows us that how we die is determined, in large part, by how we live with dying.

Finding Our Way shows us that how we die is determined, in large part, by how we live with dying.

PfC Board Member Dan Tobin, MD, is the Finding Our Way Project Director and its chief architect. “More and more, we see death portrayed accurately and with sensitivity in TV...Continued on page 4
Dear Friends,

It’s a trend and we’re listening! By phone, letter and email, many of you are getting in touch. In fact, 8,000 of you completed the survey we sent out with the Winter 2000 issue of VOICES. It was a remarkable response and we’re very grateful.

The vast majority of your communications have been enormously positive, particularly about PFC’s new website (www.partnershipforcaring.org) and recent editions of VOICES. Best of all, you have been full of wonderful suggestions about how we can help you — our Partners — to advocate more effectively in both your personal lives and for others.

The Spring issue’s article, Compassion Sabbath: Improving Ministry at Life’s End, drew uniformly positive reviews and requests for advice about how programs like it might be started in your own communities. A number of you asked to see more on issues of religion and spirituality as they affect people approaching the end of life. We will provide this information with pleasure.

Another issue high on your agenda is family caregiving. Several asked for more information about the caregiving many of us will provide as, increasingly, those close to us live with debilitating chronic and terminal illness. In response to your suggestions, you will find a new column, “Caregivers Corner,” beginning in this issue of VOICES (see page 3). Let us know what you think about the column and, most important, what you’d like to see in it.

We’re particularly excited by your response to the survey questions asking how you might get actively involved to improve end-of-life care and caregiving in your own communities. We asked how you’d like to raise your voices to spread the word about what improvements are needed. We asked if you would be willing to demand that changes be made so that care becomes readily available for you, those close to you, as well as others in your community. Just about all of you who completed the survey volunteered to raise your voices — contacting legislators, calling friends, hosting meetings and distributing information.

Surveys continue to come in. To enable more people the opportunity to get involved, we’ve put a copy of the survey on our website. In our next newsletter, we’ll provide more details about the survey results. Even more important, during the next six months, we’ll get back to those of you who responded with ideas for actions you might take and materials to help you to take these actions. Together, we’ll raise our voices loudly — we’ll make a difference.

Thanks to all of you who have added your voices to Partnership for Caring: America’s Voices for the Dying. And, thanks to all of you who keep in touch. Please keep it up.

— Karen

Help people across the nation become strong voices for dying people and their loved ones. How? One action step at a time!

Promote Finding Our Way
This 15-week series offers a wonderful opportunity for our nation to learn about end-of-life issues and to affect change (see cover story). Make a difference and take one or many of these actions.

Launch a letter writing campaign. Write your local newspaper to ask that they run the series. Tell why you think it’s important for a comprehensive series on death and dying to appear in your paper. Let your paper know the series will be available without cost to all newspapers on the Knight-Ridder Tribune website beginning September 10. Ask family, friends and colleagues to write letters, too.

Contact local radio and television stations. Tell them about the series and encourage them to run companion stories.

Share. Do you have an end-of-life story? In your letters, offer to tell it to reporters.

Join a local forum or steering committee to help plan community events associated with the series. Call PFC to learn how.

Engage your friends and family in a discussion about the articles as they appear in your newspaper. Form an “articles club” or ask one of your community organizations to do so.

Let us know you raised your voice. Drop a note, e-mail or call (see box below) to tell us your action steps.

Nominate a Caregiver

Honor a caregiver. Caregiving newsletter’s Caregiver of the Year contest (see Caregivers Corner, page 3) offers a special opportunity to acknowledge a caregiver who performs these rewarding but stressful responsibilities. Pay tribute to someone you know — or to yourself — by making a nomination.
There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

— Former First Lady Rosalynn Carter

There are more than 25 million caregiving households in the United States. While caregiving for an adult family member or friend whose health status has deteriorated can be very rewarding, it is often stressful and hard work. In this column we acknowledge the rewards and difficulties and provide information about helpful resources as well as ways to advocate for better services for our nation’s caregivers.

Caregiver of the Year: Call for Nominations

Do you know a great caregiver or caregiving family? Caregiving newsletter’s Caregiver of the Year contest honors five caregivers each year. Anyone caring for an aging relative, friend or neighbor is eligible. Nominations are accepted annually from June 1 to October 1. You can even nominate yourself!

To nominate a caregiver for this award, simply write an essay describing how the caregiver meets the following criteria:

- Caregiver’s ability to complement caregiving responsibilities with his or her own needs and interests.
- Caregiver’s problem-solving techniques.
- Caregiver’s use of community services.
- Caregiver’s community involvement.

Winners will receive a certificate, prizes and a subscription to Caregiving newsletter, which offers support, information and opportunities to share concerns with other caregivers and ask questions of experts. The winners and their stories will be featured in the December issue.

For more information about the Caregiver of the Year award or Caregiving newsletter, visit www.Caregiving.com or call Partnership for Caring (800) 989-9455.

Stay Informed, Be an Advocate

A new website (www.CaregiversCount.com) was recently launched to educate, inform and empower family caregivers about activities in our nation’s capitol that could affect them. CaregiversCount.com features articles that focus on the most recent developments and initiatives in Washington and provides suggestions on how to effectively advocate for or against positions and programs. It also offers links to other sites of interest to caregivers.

Wit Screening a Huge Success

HBO Films, Partnership for Caring, and Last Acts held a screening and reception for the Mike Nichols film adaptation of the 1999 Pulitzer Prize winning drama Wit, which aired March 24 on HBO. Several members and representatives from more than 40 congressional offices attended. Other invited guests included PFC partners who live in the metropolitan Washington, DC area and Last Acts partners.

The response was so strong, a second screening was arranged to enable more people to preview the film. The film’s poignancy is beautifully expressed in the following letter to PFC Chief Operating Officer Garey Eakes (see page 8).

March 22, 2001

Dear Garey,

I just wanted to thank you again for inviting me to the screening of Wit. As I have no political clout, I was obviously invited for personal reasons, and I appreciate your thinking of me.

I’ve been thinking about the movie all morning, and wanted to share my thoughts with you. When I saw the play it was before Dan was diagnosed, and while I found it powerful, moving, and thought-provoking, it really didn’t affect me personally. Seeing the movie after having gone through the experience of watching someone I love die from cancer was a totally different experience.

The details in the movie were realistic and brought back lots of memories for me – Dan and I shared lots of popsicles and went through bottles of lotion. I can’t remember ever seeing a movie that portrayed the process of dying so vividly and graphically – it was true. I was particularly struck by Vivian’s comment about how fast the deterioration was at the end. Dan’s death was like that.

While I did not have to deal personally with the issues that the movie brought up – the lack of sensitivity of the medical profession, the use of experimental treatments, the importance of research vs. the right to die with dignity – they should be of concern to all of us babyboomers as we start to deal with the deaths of our parents and start thinking about our own mortality. I feel immense gratitude that Dan was able to die at home, with no medical intervention other than pain medications, surrounded by the love and kindness of those close to him.

And I feel immense gratitude for you and your organization for bringing the end-of-life care issue to our consciousness.

Thanks, Garey.

Robin Marc
NEWSPAPER SERIES SPOTLIGHTS LIVING WITH DYING IN AMERICA

Continued from page 1

Finding Our Way: Living with Dying in America

Look for these articles in the Knight-Ridder Tribune series to be published and distributed in newspapers this fall, beginning the week of September 10:

Living with Dying in America
by Robert Milch, MD, and Donald Schumacher, PsyD

It is Time to Talk: Conversations Near the End of Life
by Dale Larson, PhD

Widowhood
by Myra Christopher

Palliative Care: Managing Pain and Other Symptoms
by Russell Portenoy, MD

Planning for Care Near the End of Life
by Robert Bendiksen, PhD, and Bernard Hammes, PhD

Culture and Diversity
by LaVerda Crawley, MD

Spirituality and Faith
by Martha Rutland-Wallis, PhD, and Hugh Maddry, MDiv, DRE

Last Rites: Respecting a Life, Acknowledging a Death
by Thomas Lynch

Caring for Aging Parents and Partners
by Karen Orloff Kaplan, ScD, and Ira Byock, MD

Hospice: Comfort and Care
by Stephen Connor, PhD

Nursing Homes & Long-Term Care
by Len Fishman, JD, and Muriel Gillick, PhD

When a Child is Dying
by Joanne Hilden, MD, and Bruce Himelstein, MD

Unexpected Violence and Death
by Charles Corr, PhD

Living with Loss
by Marcia Lattanzi-Licht, RN, MA

A Vision for the Future
by Dan Tobin, MD

shows such as ER and Gideon's Crossing and this has a big impact on how the public views death. It seemed the timing was right to engage the public more directly in the wider issues and to provide the resources to help them gain control over their future,” says Tobin who also directs The Center for Advanced Illness Coordinated Care/VA HealthCare Network Upstate New York at Albany.

“This series offers a great opportunity to address an issue that affects everyone but is not often discussed in the media,” says Mike Duggan, Director of KRT News Service, Special Sections and Syndication. “I think our views on end-of-life issues are changing. My hope is to have as many people as possible read the series. If it is a success, I think it will lead to more attention to the subject by journalists in the future,” he adds.

Finding Our Way focuses on a broad range of topics that impact the way people live and are cared for near the end of life (see sidebar). For example, Dale Larson, PhD, Chair of the Department of Counseling Psychology at Santa Clara University, writes about It is Time to Talk: Conversations Near the End of Life. “For people with serious illness, the medical treatments and quality of life that lie ahead are largely determined by conversations they have with healthcare providers and loved ones,” says Larson. He discusses the types of conversations that are important, the barriers to having these often-difficult discussions and offers suggestions about ways to begin talking.

Another article considers the problems of Widowhood. “Widows and widowers are at greater risk of having significant health problems than are others,” says Myra Christopher, President of the Midwest Bioethics Center and the article’s author. She notes that bereaved spouses are often elderly men or women who have had the responsibility of being a primary caregiver. At the time of their loved one’s death, they find themselves alone and often physically and emotionally exhausted. “It is also important to remember, however, that not all widows are old,” adds Christopher. “In fact, there are a half million widows under age 45 in the US.”

Success Depends on Community Outreach

More than 350 community action coalitions nationwide are coordinating efforts to promote the series in their communities. “Although Knight-Ridder will make the series available to all newspapers across the country, each paper will make an independent decision about whether to run it. So, it is critical for consumers to write their local newspaper editors to let them know the issue is important to them and to ask that they run the series,” says Garey Eakes, PfC’s Director of Public Affairs (see “Take Action,” page 2).

“Widely read newspaper articles have had great impact in the past and have laid the groundwork for significant social change,” says Karen Kaplan, Partnership for Caring’s CEO. “We are honored to work with the very gifted writers on this project. And, we deeply appreciate the work of the community coalitions who will give life to these articles in their communities.”
Building on the momentum of the highly successful community outreach associated with last year’s PBS airing of On Our Own Terms, Moyers On Dying — which had an audience nearly 60% larger than the PBS prime-time average — the local coalitions hope to stimulate a similar response with Finding Our Way. For example, some of the coalitions are planning to:

- Urge local newspapers, TV and radio shows to develop local stories. Groups are offering to identify sources (both patients and experts), provide lists of local resources and even suggest potential advertisers.
- Involve local arts communities by staging art exhibits and special performances of the play Wit with ‘talk back’ discussions.
- Host community-wide discussion groups where residents can talk about the issues raised in the newspaper series.
- Encourage healthcare organizations to schedule “Grand Rounds” lectures on end-of-life care for professionals and informal brown-bag lunches where employees can discuss the series topics.

“Transforming our fear into positive and proactive action will help us see the opportunities for growth and closure at life’s end.”

to amaze me,” says Donna Bales, President of the Association of Kansas Hospices and Project Director of the Living Initiative for End-of-Life Care (LIFE). “So many groups are coming together and the support they give one another really helps. The power of grass roots efforts is incredible.”

The Next Chapters

The newspaper series and all the community action that surrounds it will not end the story for Finding Our Way. In the fall of 2002 an expanded version of the 15 newspaper articles will be published in book form. The book will serve as a text for a variety of courses on end-of-life care and will be available to consumers in bookstores throughout the country.

At the same time, the Finding Our Way: Living with Dying in America website will be launched. The website will offer course content free-of-charge to universities and

Continued on page 7
Partnership for Caring recently convened a summit on healthcare agency, sponsored by The Fan Fox and Leslie R. Samuels Foundation. Sixty-seven nationally known clinicians and advocates joined to create a blueprint for future activities that will improve the ability of healthcare agents to carry out their difficult responsibilities. Samuels Foundation grantees also exhibited information about their current healthcare agency projects.

Participants discussed ways to ease the emotional stress that accompanies making difficult end-of-life decisions on behalf of another. They noted that many agents are not aware of the kinds of decisions they will be called upon to make, so they don’t have the information they need. Likewise, healthcare providers often are unaware of the agents’ needs. And while laws grant agents decision-making authority, public policies need to build in more supports for that decision-making process. The blueprint includes several areas for study and development. A few examples include developing a “job description” of the roles and responsibilities of all parties involved in the process, suggesting policy changes that recognize culturally diverse ways of making end-of-life decisions, and developing a plan for a public health campaign about the appointment and effective use of healthcare agents. The blueprint will guide the Samuels Foundation in a second round of funding and provide direction to other efforts to change public policy, expand professional education and research, and engage the public in learning about the issues before a crisis occurs.
## Products

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- **Cardiopulmonary Resuscitation, Do-Not-Resuscitate Orders and End-of-Life Decisions. QA600 $5.95**
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- **Healthcare Agents: Appointing One & Being One. QA900 $5.95**
- **Medical Treatments and Your Advance Directives. Includes values questionnaire. QA400 $5.95**
- **The Physician-Assisted Suicide Debate: Understanding the Issues. QA800 $5.95**

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**NEWSPAPER SERIES SPOTLIGHTS Continued from page 5**

the general public — including the ability to download live lectures from experts using new “web-casting” technology. An interactive course may be taken for credit or non-credit through university extension programs. Universities also will be able to integrate any of the content found on the website into their own courses.

“...” says Tobin. “Transforming our fear into positive and proactive action will help us see the opportunities for growth and closure at life’s end.”

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PfC Names Chief Operating Officer

We are pleased to introduce M. Garey Eakes, JD, who joined Partnership for Caring in January as our Chief Operating Officer and Director of Public Affairs. He will be responsible for the day-to-day management of PfC operations and our communications efforts. This support allows CEO Karen Kaplan to spend more of her time advancing the PfC mission. “I hope that many of our Partners have an opportunity to get to know Garey and find out what an enormous asset he is for PfC and its mission!” says Kaplan.

Eakes brings a wealth of knowledge, experience and a strong public policy orientation to PfC. An elder law attorney for 16 years, he has been a forceful and effective advocate for older people and those facing long-term illness, disability and incapacity.

He was co-counsel for Michelle Finn in the Hugh Finn case from the initial trial through the Virginia Supreme Court appeals. This case drew national attention when the governor of Virginia intervened to prevent the removal of Finn's feeding tube. Hugh Finn was in a persistent vegetative state from a severe brain injury sustained in an automobile accident. Both the state Circuit Court and Virginia’s Supreme Court rejected the governor's petition and the feeding tube was removed. A bill was later passed by the state legislature to partially compensate Mrs. Finn for her expenses due to the action taken by the government to prevent withdrawal of her husband's life support.

As a frequent writer and lecturer, Eakes has been a guest on numerous radio programs and has been seen as a legal expert on Court TV, CSPAN, CNN’s Burden of Proof, and the CBS Evening News.

Eakes was a founding member of the National Academy of Elder Law Attorneys (NAELA) and served as President and Chair of its Board of Directors. He has been honored as a NAELA Fellow. In Virginia, Eakes formed a statewide coalition of Alzheimer’s advocates and served on the Board of the Alzheimer’s Association, Northern Virginia Chapter. He also served for the past two years on the Partnership for Caring Board.

“I had a long-held desire to move from one-on-one representation to a position where I could fully devote my energies to effect change for many. Partnership for Caring is the opportunity to work where my heart is,” says Eakes. “I look forward to developing deeper public involvement in raising expectations for care at life's end.”