

On Our Own Terms: A Community Conversation About End-of-Life Care in Tompkins County

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Survey yields surprising results

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If you were terminally ill and assisted suicide was legal, do you think you might consider it? How likely are you to avoid speaking freely to loved ones about death and dying? Are you worried that your money won't last or your doctor may not adequately treat your pain? If you were terminally ill, where do you think you would want to die?

These are just a sampling of the provocative questions answered by hundreds of diverse people in a recent survey about end-of-life care in Tompkins County. Organized by a group representing nonprofit, campus and other interests, the "On Our Own Terms" survey offers a fascinating snapshot on an issue everyone must face. It is also filled with startling statistics on how many residents don't have living wills or health care proxies, or those who may avoid medical checkups because they are afraid the doctor will find "something serious." The data (from 688 people) will now be used to educate and promote dialogue among the various "death-and-dying" stakeholders."

Highlights of Survey Results

by Nina Miller, Hospicare and Betty Falcão, Health Planning Council

We are grateful to the more than 680 people who took time to share their views in the recent survey about end of life care in Tompkins County. We especially want to thank the *Ithaca Journal* for publishing the survey as well as the varied and powerful personal essays on experiences with death and dying.

The survey tells us a great deal about ourselves: where we would prefer to die, what our fears are, what we have done to prepare for death, what we avoid, what we need.

We often think of end of life care as being of concern only to seniors. Yet **more than half of those who answered the survey were less than 60 years old**; most of these were in their 40's and 50's. Clearly many of us are affected by death, even if it's not our own. We care about our parents; we talk with our friends about their parents; some of our colleagues are struggling with cancer; our neighbor dies of a heart attack.

These realities are challenges for those in the workforce as well as for those who are close to or in retirement.

The data also show that we're not quite sure how to talk about death. Almost everyone (646 people, 94%) said that it was very important to have realistic answers from their doctor. **Yet only 67 said they had talked with their doctor about their end of life care wishes.**

Similarly, more than 471 people said that they had a religious or spiritual orientation. Yet only 7 said that they had talked with their religious adviser about their wishes.

People overwhelmingly did not want their care to be a burden for their loved ones. Yet almost half of the respondents did not have a living will or a health care proxy. A recent study revealed that people appointed through health care proxies, that were clear about the wishes of their loved one, were better able to work through their grief after death occurred, freed from the burden of guilt about possibly making the wrong decision.

These apparently contradictory responses highlight the very mixed feelings that many of us have in talking about death.

Most people (74%) said that their first preference was to die at home. This mirrors national surveys. The strong second choice was to die in a hospice residence. The hospital was third choice, and nursing home was a distant fourth. How does this compare with actual place of death? In Tompkins County, figures from 1999 indicate that more people die in the hospital than anywhere else (208). Nursing homes are the second most frequent site (160), with home being the third (146 or 26%).

Almost half of the respondents (from many different religious affiliations) said that they would consider assisted suicide if it were legal. Another quarter said that they were not sure, with the last quarter saying that they would not consider it. Studies show that for many people this option is intermingled with issues about pain management, a wish for control of one's dying and possible undiagnosed depression.

Hospice support in the last months of life was also something that most people wanted. Yet too many people contact hospice only days before their death. Ninety-one percent state that physical comfort was pretty-to-very important when near death. Yet study after study has demonstrated that many people experience considerable pain as they approach the end of life.

The survey results are a rich source of opinion from people in our community. The same responses can mean different things to different people. After answering the specific questions, many people wrote additional comments and shared their ideas about what our community could do to improve end of life care.

Summaries of the responses had been posted on the Ithaca Journal website. Now, additional details are available through Hospicare and the Health Planning Council. (To preserve confidentiality, only group totals are shared.)

Death and dying will always be a part of life. **Talking about it and working together in our community can improve the quality of this time for both the dying person and their family and friends.**

When we filled out the survey, we realized that many of the items that would help us deal with our own dying, (making sure our family and friends know that we love them, having things settled with our families, fulfilling personal goals, our spiritual well-being) are the same as what we want in a good life. This helped us understand that these are things we can be doing right now - all through our lives - and not just at the end.

We hope the survey results will be, not an end, but a beginning; that they will help us talk with our physicians, our loved ones, our attorneys and our friends about how we want to be cared for, and where. We hope that various community groups, religious congregations, medical professionals and others will find that this information serves as a spur to enhanced services, honest conversations and clarification of personal values.

At the end of this report, we have included some graphs with survey results as the many other sets of information that are available.

Why and How We Developed the Survey

"Most Americans avoid thinking about death until they are faced with it in their own families. Nor has our "can-do" culture encouraged us to develop ways to deal with death. And the emphasis in medicine has been on preventing disease and keeping people alive. In 1900, the average age of death was 46. Today, it's 78. But that success has brought its own particular set of problems. In 1900, people died almost as soon as they got sick. Today, the average length of time a person is disabled before death is four years. The quality of life during that period is often heart-breakingly poor and financially ruinous." *Ithaca Journal*, September, 2000

But there are alternatives to this dreary scenario. Public television journalist Bill Moyers explored them in a four-part series, "On Our Own Terms: Moyers on Dying," in September 2000. (The Moyers tapes are available for loan through Hospicare, the Tompkins County Public Library, the Senior Citizens Council and the Office for the Aging.)

How a PBS series began new dialogue

In Tompkins, the series served as a springboard for a consortium to promote community discussions about death: "On Our Own Terms: A Community Conversation about Dying in Tompkins County." In discussion groups, book

clubs, lectures and other forums, people were thinking and talking about how we die, and how society might improve the quality of that experience at the end of life.

The *Ithaca Journal* played a role in fostering this important discussion. Community residents submitted articles about their experiences with death and dying that were published on Saturdays over an eight-month period. The *Journal* also published a community-wide survey that hundreds of area residents completed. With additional participation by the Office for the Aging, the Senior Citizens Council and the Health Planning Council, the survey was widely distributed and available online. In the end, 688 responses were received; people added more than 950 comments.

Local Consortium

The consortium was organized by Nina Miller, Director, Hospicare and their Board. More than sixteen organizations participated – a diverse cross-section of service agencies, professional health organizations, charitable groups, government offices, clergy, senior advocacy groups, institutions of higher education and residents from senior housing. These included:

- Hospicare (staff and board members)
- County Office For Aging
- Health Planning Council, Long Term Care Committee
- The Ithaca Journal
- Ithaca College Gerontology Institute
- Ithaca Memorial Society
- RSVP
- Kendal at Ithaca residents
- Mental Health Association of Tomp. Co.
- Finger Lakes Independence Council
- Cornell Applied Gerontological Research Institute
- Catholic Charities
- Human Services Coalition
- Cayuga Medical Center
- Senior Citizens Council
- American Cancer Society

Development and Distribution of the Survey

Terry Beckley, Ithaca College Gerontology Institute, contacted the Missoula (Montana) Demonstration Project which had conducted an end of life survey, with the leadership of the renowned Ira Byock (author of *Dying Well*). We received a copy of Missoula's survey entitled "The Quality of Life's End" which consists of 73 questions. We adapted the Missoula survey to better suit the needs of Tompkins County and whittled the number of questions down to 28. This was available from January 20 through March 31, 2001 in many places:

- The *Ithaca Journal*, on January 20th

- *Senior Circle* newsletter from the Senior Citizens Center and COFA in February
- Caregiver News, COFA in March
- Lisa Holmes, COFA, coordinated the development of an interactive on-line version of the survey, and carried it on COFA's website.
- Consortium members distributed paper surveys by hand and notices were posted in various locations throughout Tompkins County.

Using the Survey Results to Promote Conversation

Local agencies, religious groups, community organizations and elected representatives can use the data and accompanying commentary to better understand the end-of-life needs of Tompkins County residents, and to improve the quality of their experiences as they and their loved ones approach death.

Community agencies have many resources to offer local groups. These include a speakers bureau and confidential tabulation of surveys from your own group. Details about these are at the end of this report.

Some additional ideas include:

- Take the survey yourself to prompt your thinking as a springboard for talking with others; encourage other family members to fill out the survey as well. (The survey is included in the next section.)
- Continue the community conversation through a series in the *Ithaca Journal* with some of the comments. If anyone wants to write some articles, we would welcome this.
- Speak on talk shows, such as the Casey Stevens show.
- Organized a workshop on advance directives, such as what Hospicare did at the public library.
- Possibly have articles focus on three different stages that people go through: learning that they are dying, knowing what to do once they know they are dying, and after someone has lost a loved one.
- Organize the survey results (both tabulations and comments) to present to different audiences, including medical community, religious leaders, discharge planners, and community groups.
- Add the community comments to various materials: pamphlets, press releases, newsletter articles, grant applications, publicity for events/workshops, etc.
- Share comments about children with the Day Care Council and the schools.
- Using topics with a high volume of concerns to help design workshops; through COFA, Senior Citizens Center, ICGI (perhaps on pain management), physician seminar series, and others.
- Enhance awareness of depression along with pain management.
- Develop a resource guide to help advocate for dying family members; COFA is considering this.

- Increase publicity about and access to forms through adding advance directives forms and information to local web sites, including COFA, LTCS, Hospicare, CMC and other providers.

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Want local information about end-of-life care? You could contact:

- **272-212 Hospicare of Tompkins County.**

Comprehensive care for terminally ill patients and their families. Services provided in individual homes, in nursing homes and at their six-bed facility. www.hospicare.org

- **274-5287 Long Term Care Services of Tompkins County.**

Assessment of individual need and development and management of a plan for services, for all income and age levels, sponsored by Tompkins County. www.tompkins-co.org/dss/ltc

- **274-5482 Tompkins County Office for the Aging.**

Information and referral about long term care services, housing options, financial benefits, caregiver support groups and more. www.tompkins-co.org/cofa/

Original Survey and Graphs of Survey Results

A. The three-page survey starts on the next page. Feel free to copy if you'd like, just crediting that it came from the On Our Own Terms Coalition.

B. The charts on the following pages are from a power point presentation. We would be happy to send this to you. We could also tailor a presentation for your particular group.

Narrative Responses

The last three questions asked for narrative comments, if people wanted to add something. As you can see people added 971 additional comments. We've categorized the responses into the topics below. A sample of the individual remarks are on the next page.

Q. 26 - Are there any other factors you think are important to a "good" death? (421 total)			
37	Being pain free and mentally clear	19	Having caring and truthful physicians
31	Personal and emotional "peace"	18	Communication with family members/friends
30	Religion and spirituality	17	Living a good life prior to death
28	Having family present, not being alone	15	Societal acceptance of talking about death
28	"Quick" death, not prolonged death	10	Not wanting to fear death
26	Being in control, having choices	10	Legal assisted suicide
23	Support for others in dealing with one's death	9	Dying in familiar surroundings
20	Making peace with friends and family	7	Health insurance and access to medical care
20	Having wishes for after death respected	4	Knowing that children will be OK/cared for
19	Maintaining dignity	3	Being an organ donor
19	Having one's affairs in order	28	Miscellaneous

Q. 27 - What could our community do that might improve end-of-life care? (373 total)

76	Additional support and expansion of hospice care and Hospicare	15	Improve care in nursing homes and hospitals
27	Support for families and family caregivers	12	Improve working conditions and pay for aides
27	Increase awareness of available resources	11	Support physician-assisted suicide
26	Community education about end-of-life issues	11	Promote volunteer/informal assistance
24	Open communication about death	10	Availability of latest pain control techniques
22	Affordable housing/service options	5	Promote funding of current and new services
21	Educating professionals/physicians	4	Educating children about death and dying
19	Respect of individual needs and wishes	3	Religion
19	Enhance availability of home care	24	Miscellaneous
17	Promote economic justice – good care for all regardless of income		

Q. 28 – Do you have any other comments? (177 total)

45	Comments about raising this important issue for discussion, conducting the survey, and the Ithaca Journal series	7	Concern about implying a "right" way to approach issues surrounding death, such as through religious paths or by setting up expectations about a "right way" to die.
21	Strengths of local services, including: Hospicare, Kendal, Ithaca Memorial society, Home health care, Support groups	6	Improve availability of services
		3	Need for information to help advocate for dying family members – resource guide?
16	Concerns about local services	3	Promotion of organ donation
16	Promotion of continued public discussion of these issues	3	Comments about the power of religion and spirituality to comfort during one's dying
15	Concerns about high costs of long-term care, hospitals, funerals	9	
		1	Support for assisted suicide Disapproval of assisted suicide
12	Need for information/discussion about funerals, burial, other types of services, etc.	20	Miscellaneous

Sample of Individual Comments

A few of the more than 950

comments - Celebrating your life before you die, seeing people you love, accepting, not fearing death.

- I want to remain conscious, not spaced out on meds.

- Being alert enough to pray or hear a prayer and say goodbye.

- I believe that pain control and comfort are essential, if not to the person dying then to the family around that person.

- Being as much at peace as possible with what is being left behind; having time to say good bye OR having done a good enough job of that before death, that loved ones don't feel any additional shock and grief.

- To be at peace w/ God. Forgive and be forgiven by friends and family for what I have ever said or done to hurt others.

- It helps to have a faith that has sustained you through life and will when the end does come.

- Strong faith & positive attitude, being able to laugh

- Being cared for physically. Being "heard" by medical folks. Having loved ones around. Empathy.

- Making family/friends feel as comfortable as possible with my condition, making them comfortable visiting me.

- Not being alone - ever, not in the hospital room, not at home, not

- Not having to suffer. I have an exact picture in my head of the last time I saw a family member before they died of cancer. They had no idea how they looked because they were either unconscious or in so much pain they "didn't care".

-Not prolonged, with illness memories supplanting healthy ones for family and friends.

- Being in control of the decision of when to end ones own life through intervention of a second party or by choosing to end treatments.

- For me, the single most important factor is control. I want to be in charge; I don't want others taking over the process for me. That's what dying with dignity means to me.

- Perhaps info for families on how to support dying person and families of dying persons.

- Emotional as well as physical support for family, that you are prepared to die, the idea that I could die right now, and I am cool with it because everyone I love knows it, and I have lived life well.

- Emotional support for my children

- Lack of fuss - At my age, death is to be expected.

- Discuss end -of life issues for lesbian and gay people and their self-defined families

- Provide more services to assist home caregivers who often must care full-time for the dying person.

- Help make death a normal part of conversations.

anywhere - I don't want anyone to die alone.

- I don't want a funeral. I want a memorial party, and a cremation, I have spoken to my husband about these wishes.

- Knowing the truth from doctors. That has not been the case w/ some of the doctors my family had.

- Doctors who do not view all deaths as medical 'failures'

- Medical personnel need to know when "enough is enough".

- Maintaining "life" in any form without concern for quality is not acceptable.

- Having competent caretakers that are safe to have in your home. And regarding assisted suicide, there are a lot of medications to make people more comfortable. There's no need to rush death.

- A society/culture that accepts/celebrates death and ancestors, that encourages children and all ages to acknowledge death.

- When there is no joy left in life, only pain and/or I am incapacitated, I want to die promptly. A drug overdose will be fine.

- Furnish affordable services, especially for individuals that have paid taxes all their lives.

- Continue education, of medical community especially, re. adequate pain/symptom management.

- Increase pay and benefits to home-health care workers and other jobs dealing w/ terminally ill

- Hospicare is a wonderful service which deserves more financial support from local, state and federal government.

- Adequate resources, \$ in nursing homes where more people die (compared to hospitals and hospice).

- It would be good to raise the profile of hospice care, which I understand to be compassionate and high-quality.

- Have sufficient residential capacity to care for those who want hospicare.

Don't make people think that there is a "RIGHT WAY" to die.

That is just one more burden and worry.

Additional Details

Available Upon Request Through the Health Planning Council, 273-8686

(Results available in print, word, excel, and power point presentation)

Actual survey form - On Our Own Terms Survey (4 pages)

Totals of survey results, by ages under 60 and 60 and over (14 pages)

Ithaca Journal – End of Life Care coverage

Printed Survey results, articles and some personal stories. (15 pages)

Are there any other factors you think are important to a "good" death?

Detailed Responses to Question 26 (370 comments, 12 pages)

What could our community do that might improve end-of-life care?

Detailed Responses to Question 27 (331 comments, 12 pages)

Do you have any other comments?

Detailed Responses to Question 28 (159 comments, 6 pages)

Four-part PBS series "On Our Own Terms: Moyers on Dying"

Videotapes (each is 90 minutes) available for loan through Hospicare, the Tompkins County Public Library, the Senior Citizens Council and the Office for the Aging. Discussion Guide also available.

Speakers Bureau

Members of the Coalition are available to address and lead discussions about a variety of topics. These include:

- survey results, the whole survey or focusing on some part
- health care proxies
- the religious response to end-of-life issues
- talking with your family and doctor about your wishes
- finding long term care in our community.

Tabulating survey results from your own group

Your group could use responses from your own members to promote discussion of these issues. Members of your group could take the survey in either the paper or on-line form. The Health Planning Council could then

tabulate the results in an anonymous, confidential way. The HPC would give your designated representative a summary report of responses from your members.