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NEW JERSEY’S END OF LIFE CARE PLANNING

Public is comfortable with idea, but few are making plans

The Monmouth University Polling Institute and the New Jersey Health Care Quality Institute today released their third “Health Matters Poll,” a periodic survey of Garden State attitudes on health care related issues. The current survey, which examines planning for end of life care, found that most New Jerseyans have had some sort of discussion about their wishes for end of life medical treatment, but few have actually made specific plans.

Most New Jersey residents say they are comfortable thinking about the idea of getting older, including 45% who are very comfortable and 28% who are somewhat comfortable with the idea. Another 26% say getting older is something they would rather not think about. There are no significant differences in this comfort level by residents’ age, race, education or income.

Men (50%) are more likely than women (40%) to say they are *very comfortable* with the idea of getting older. That may be because men (53%) are significantly less likely than women (69%) to think about what will happen to them if they develop a terminal illness. Specifically, 6-in-10 New Jersey adults say they have thought about their own wishes for medical treatment if they had a disease with no hope of improvement that caused a great deal of pain. This includes 27% who have given it a great deal of thought and 34% who have given it some thought. Another 22% of New Jerseyans have not given it very much thought and 17% have given it no thought at all.

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"We know that end-of-life decisions and conversations are some of the most difficult and stressful conversations family members can have," said David L. Knowlton, President and CEO of the New Jersey Health Care Quality Institute. "It is encouraging that so many New Jerseyans are at least comfortable with thinking these issues over. The challenge now is to translate that comfort into a meaningful conversation and a written plan that fulfills their wishes."

New Jerseyans appear to start thinking about potential end of life issues after they turn 30. Less than half (48%) of state residents age 18 to 29 years old have thought about what they would like done if they were suffering from a painful terminal illness, compared to 60% of those age 30 to 49, 69% of those age 50 to 69, and 65% of those age 70 and older.

More than 6-in-10 (62%) New Jerseyans have discussed their wishes for end of life medical treatment with someone, but fewer than half (45%) have put those wishes down in writing, such as in a living will. White residents are more likely than black and Latino residents to have either had this type of discussion – 69% white and 55% black/Latino – or put their wishes in writing – 50% white and 35% black/Latino. Women (68%) are more likely than men (55%) to have had an end of life treatment discussion but they are not any more likely to have put their wishes in writing – 46% women and 43% men.

As may be expected, there are significant age variations in planning for potential end of life needs. Those age 70 and older (81%) or age 50 to 69 (75%) are most likely to have discussed these issues with someone, followed by 66% of those age 30 to 49. Only 27% of those age 18 to 29 have done the same. Also, 70% of those age 70 and older have put their wishes in writing, which declines to 52% among those age 50 to 69, 41% among those age 30 to 49, and 26% among those age 18 to 29.

“While nearly half of New Jerseyans say they have put their wishes in writing, there is some uncertainty whether it is written in a format that will be honored or even if family members know where to find those documents if the person was incapacitated,” said Patrick Murray, director of the Monmouth University Polling Institute.

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Most New Jerseyans say they would be very comfortable discussing end of life medical care planning with a family member (81%) or their doctor (73%). A majority (58%) also say they would be very comfortable having this discussion with a close friend. Those age 30 to 49 (65%) are the most likely to feel very comfortable having this talk with a friend, followed by 60% of those age 50 to 69, 55% of those age 70 and older, and 47% of those age 18 to 29. Parents of minors (64%) are also somewhat more likely than non-parents (55%) to feel very comfortable discussing end of life care plans with a close friend.

Fewer than half of New Jerseyans say they would be very comfortable having this type of discussion with a nurse or other non-doctor health professional (45%) or with a clergy member (39%). Parents are somewhat more likely than non-parents to be very comfortable with either a nurse – 51% parents and 42% non-parents – or a clergy member – 48% parents and 35% non-parents. Younger adults under the age of 30 (31%) are the least likely to feel very comfortable speaking with a clergy member about end of life planning, but there are few significant differences among other age groups – 40% age 30 to 49, 44% age 50 to 69, and 37% age 70 and older.

Just over half (52%) of New Jerseyans say they are very familiar with hospice care, which focuses on easing pain and providing emotional and spiritual support at the end of a person's life. Another 29% are somewhat familiar and 18% are not familiar with hospice care. Women (59%) are more likely than men (46%) to be very familiar with hospice care. Also, white residents (59%) are more likely than black and Latino residents (47%) to be somewhat familiar.

Most of those familiar with hospice care have heard about it from a family member (62%) while one-third (36%) of those familiar report actually knowing someone who received hospice care. Other sources of information for hospice care include friends (22%), doctors (13%), nurses (13%), TV or radio (9%), and newspapers or magazines (8%).

The survey also examined state residents' financial planning for end of life needs. Two-thirds of New Jerseyans say they are at least somewhat confident they will have the resources required to

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pay for any care they may need as they get older, but only 1-in-4 have started to save for those expenses.

Specifically, 27% of New Jerseyans say they have set aside money to pay for ongoing living assistance expenses including care in a nursing home or senior community or care from a home health aide. This includes 45% of those age 70 and older, 35% of those age 50 to 69, 22% of those age 30 to 49, and 14% of those age 18 to 29. There is a gap by income as well. Just 16% of those who earn less than \$50,000 a year have started to save for end of life needs, compared to one-third of those who earn \$50,000 to just under \$100,000 (33%) or \$100,000 or more (32%).

While few are currently setting aside funds for end of life care, most hope they will have the resources they need, although just 22% are very confident of this. The plurality (46%) say they are somewhat confident. Another 19% of New Jerseyans are not too confident and 11% are not at all confident that they will be able to cover their end of life care costs. About three-quarters of those who earn more than \$100,000 (75%) or from \$50,000 to just under \$100,000 (72%) are at least somewhat confident they will have these resources, while a smaller majority of those earning \$50,000 or less (58%) say the same. It's worth noting, though, that no more than 25% of any income group reports that they are *very confident* they will have the resources necessary to meet their potential end of life care expenses.

METHODOLOGY: The Health Matters Poll was conducted by the Monmouth University Polling Institute in partnership with the New Jersey Health Care Quality Institute from March 30 to April 1, 2014 with a statewide random sample of 803 adult New Jersey residents, including 601 via live interview on a landline telephone and 202 via live interview on a cell phone. For results based on the total sample, one can say with 95% confidence that the error attributable to sampling has a maximum margin of plus or minus 3.5 percentage points. Sampling error increases as the sample size decreases, so statements based on various population subgroups, such as separate figures reported by gender or party identification, are subject to more error than are statements based on the total sample. In addition to sampling error, one should bear in mind that question wording and practical difficulties in conducting surveys can introduce error or bias into the findings of opinion polls.

POLL DEMOGRAPHICS (weighted)

38% Dem	49% Male	28% 18-34	63% White
43% Ind	51% Female	40% 35-54	13% Black
19% Rep	32% 55+	15% Hispanic	9% Asian/Other

NEW JERSEY HEALTH MATTERS SURVEY APRIL 2014 – QUESTIONNAIRE

1. Would you say that the idea of getting older is: something that you'd rather not think about, or is it something that you're comfortable thinking about? [IF COMFORTABLE ASK:] Would you say you are somewhat comfortable or very comfortable thinking about getting older? [ITEMS WERE ROTATED]

26% Rather not think about
28 Somewhat comfortable thinking about
45 Very comfortable thinking about
2 (VOL) Don't Know/Refused

2. Before today, how much had you thought about your own wishes for medical treatment if you had a disease with no hope of improvement and you were suffering a great deal of physical pain? Had you given this a great deal of thought, some thought, not very much thought, or no thought at all?

27% Great deal of thought
34 Some thought
22 Not very much thought
17 No thought at all
1 (VOL) Don't Know/Refused

3. Are your own wishes for medical treatment in this kind of circumstance written down somewhere such as a living will, or not?

45% Yes
54 No
1 (VOL) Don't Know/Refused

4. Have you had a discussion with someone about your own wishes for medical treatment in this kind of circumstance, or haven't you done this?

62% Yes, have had discussion
38 No, haven't had discussion
0 (VOL) Don't Know/Refused

5. How comfortable would you feel talking to [READ ITEM] about planning for medical care you may need at the end of your life – very comfortable, somewhat comfortable, not too comfortable, or not at all comfortable? [ITEMS WERE ROTATED]

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	Very comfortable	Somewhat comfortable	Not too comfortable	Not at all comfortable	(VOL) Don't know
A family member	81%	13%	2%	2%	1%
Your doctor	73%	19%	3%	3%	2%
A close friend	58%	27%	7%	7%	2%
A nurse or other non-doctor health care professional	45%	32%	10%	10%	2%
A clergy member	39%	25%	10%	21%	5%

6. How confident are you that you will have the financial resources to pay for any care you may need as you get older? Would you say very confident, somewhat confident, not too confident, or not at all confident?

- 22% Very confident
- 46 Somewhat confident
- 19 Not too confident
- 11 Not at all confident
- 2 (VOL) Don't Know/Refused

7. Have you set aside money to pay for ongoing living assistance expenses including care in a nursing home or senior community or care from a home healthcare aide, or not?

- 27% Yes
- 70 No
- 2 (VOL) Have long term care insurance plan
- 2 (VOL) Don't Know/Refused

8. I'd like to ask you about hospice care, which focuses on easing pain and providing emotional and spiritual support at the end of a person's life. Are you very familiar, somewhat familiar, or not familiar with hospice care?

- 52% Very familiar
- 29 Somewhat familiar
- 18 Not familiar
- 1 (VOL) Don't Know/Refused

[NOTE: Question 9 was asked of those familiar with hospice care; n=689, m.o.e.=±3.7%]

9. How did you hear about hospice care? [NOTE: Results add to more than 100% because multiple responses were accepted.]

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62%	Family member
36	Know someone who had hospice
22	Friend or neighbor
13	Doctor
13	Nurse/non-doctor professional
9	TV or radio
8	Newspaper or magazine
6	Pamphlet or brochure
5	Work in the healthcare field
2	School or work
2	Clergy member
1	Hospital
1	Other
2	No answer

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