

CARP Advanced Directives Poll Report
February 8, 2013

KEY FINDINGS

For the most part members have not discussed end-of-life issues with their doctors but have done so with their families. In each case, however, the main topics of conversation were DNRs and treatment choices at the end of life. Doctors and families were equally helpful and proactive in this discussion.

The plurality of members have a DNR or an Advanced Directive and almost all have shared it with family. Spouses agree with each others' end-of-life wishes.

Members think cautious doctors and demanding family may be the reason DNRs are not honoured, and many would like a simple DIY DNR kit provided by government.

Members continue to strongly support legalized physician-assisted suicide, although they recognize there is a danger of guardians and caregivers abusing this. Members strongly consider it their absolute right to refuse treatment or nutrition if they wish.

Members say their provincial health systems are adequate at pain reduction and optimizing quality of life, but do a sub-standard job of easing grieving and avoiding unnecessary procedures.

Members are very concerned about burdening their family by becoming seriously or terminally ill, and they fear not having enough information about their options, but are less concerned with being emotionally prepared for death. They expect to learn about end-of-life issues from their doctor and from family (and CARP).

While members generally agree with CRA's plan to reduce costs by no longer indiscriminately mailing out tax forms, they are concerned that many seniors don't have access to the internet (where forms are to be downloaded) or that it was done without notice. Most think CRA should rescind the decision and either mail out tax forms or request slips for tax forms to all who filed by mail last year.

In the Ontario Liberal leadership race, members correctly predicted Kathleen Wynne would become premier, and they expect her to recall the legislature, make a deal with teachers and increase funding for home care.

The Conservatives continue to lead and the NDP and Liberals are exactly tied for second place.

Detailed Findings - End of Life

The majority of members do not plan to discuss end-of-life issues with their doctor (57%), although one quarter plan to in the future (28%). Just one tenth have already (13%).

Have you discussed the end of your life with your family doctor?

| | |
|---------------------------------|------------|
| YES | 13% |
| More than once | 5% |
| Once | 8% |
| NO | 85% |
| I will | 28% |
| No plans to | 57% |
| DON'T HAVE FAMILY DOCTOR | 3% |

In most cases, the topic of the conversation was a DNR order (42%), followed by discussing how wishes would be fulfilled (14%), what treatment options were available at the end of life (12%) and the issue of prolonging life vs just controlling pain (10%).

What was the primary topic of this conversation?

| | |
|---|-----|
| Do Not Resuscitate order (DNR) | 42% |
| Ensuring wishes are fulfilled | 14% |
| Treatment options at end of life | 12% |
| Pain control vs prolonging life | 10% |
| How to decide on end of life treatment options | 8% |
| Prognosis for an existing disease/condition | 5% |
| Doctor's role at end of life | 4% |
| OTHER | 5% |

The majority say their doctor was proactive and helpful (55%), while about a fifth found the doctor listened but was not proactive (21%).

How would you describe your experience discussing end-of-life issues with your doctor?

| | |
|--|------------|
| Doctor was very proactive/helpful | 55% |
| Doctor listened/was not proactive | 21% |
| We have a clear plan for the end of my life | 9% |
| Doctor dismissed my concerns | 3% |
| Doctor said it wasn't time to talk yet | 3% |
| Doctor gave me clear answers on treatment options | 2% |
| OTHER | 6% |

The majority of members have talked to family about end-of-life issues (61%), either a spouse (26%) or both spouse and children (24%). Of the one third who have not done so yet (36%), most plan to (22%).

Have you talked to family members about the end of your life?

| | |
|--------------------------|------------|
| YES | 61% |
| Spouse | 26% |
| Children | 11% |
| Both | 24% |
| NO | 36% |
| I will | 22% |
| No plans to | 14% |
| DON'T HAVE FAMILY | 3% |

Once again, the DNR was the primary topic of conversation (30%), followed treatment options at the end of life (20%), assigning a family member as designated decision-maker (15%) or deciding on end-of-life treatment (11%).

What was the primary topic of this conversation?

| | |
|---|------------|
| Do Not Resuscitate order (DNR) | 30% |
| Treatment options at end of life | 20% |
| Assign family member as decision-maker | 15% |
| Deciding on end of life treatment | 11% |
| Pain control vs prolonging life | 8% |
| Life expectancy | 6% |
| Eventual cause of death | 3% |
| OTHER | 7% |

One half say family was proactive and helpful in this discussion (49%), while about one fifth listened but were not proactive (18%). Some now have a clear plan for the end of their lives (14%) while others found family members unwilling to talk yet (11%).

How would you describe your experience discussing end-of-life issues with your family?

| | |
|---|-----|
| They were very proactive/helpful | 49% |
| They listened/were not proactive | 18% |
| We have a clear plan for my end of life care | 14% |
| They said it wasn't time to talk yet | 11% |
| Dismissed my concerns | 2% |
| Family is divided | 1% |
| OTHER | 5% |

Four-in-ten members have Advanced Directives or DNRs (42%), evenly split between each other and both. This incidence appears to have declined since the last time we asked, but it must be noted that the question was asked previously of a "living will" rather than an Advanced Directive, and members may have been unsure what a living will was, and if it was different from their last will and testament.

Do you have an advanced directive (living will) about care at the end of your life, or a Do Not Resuscitate Order (DNR)?

| | August 2010 | December 2011 | January 2013 |
|-----------------------|--------------------|----------------------|---------------------|
| YES | 63% | 64% | 42% |
| Living will/AD | 28% | 35% | 16% |
| DNR | 19% | 7% | 13% |
| BOTH | 16% | 22% | 13% |
| NO | 37% | 36% | 58% |

The vast majority have shared the existence of their DNR with family (92%), and most know the location (69%).

Does your spouse or family know where your advanced directive or DNR is kept, if they are aware of it?

| | |
|-------------------------------------|-------------|
| YES | 92%% |
| Aware/know where it is | 69% |
| Aware/don't know where it is | 23% |
| NO | 8% |

In most cases, spouses agree on their end-of-life directives (78%).

Are you and your spouse in agreement about advanced directives and/or DNRs for each of you?

| | |
|--|-----|
| Yes. We agree with each other's choices | 78% |
| I have made no plans | 12% |
| Don't agree, but respect each other's choices | 5% |
| Spouse has made no plans | 5% |

Members are evenly split on whether they want their DNRs followed exactly (40%) or whether they want the doctor to use judgment (42%).

Do you expect your advanced directive or DNR to be followed exactly as written, or would you want doctors to use their judgment if they thought there was a chance of recovery?

| | |
|---|-----|
| Doctor to use own judgment if hope of recovery | 42% |
| Expect doctor to follow DNR exactly | 40% |
| DNR is guideline only | 18% |

Members suspect DNRs are not honoured because of family wishes (23%), doctors' fears of lawsuits (13%) or the fact DNRs aren't enforced by law (10%).

Why do you think advanced directives/DNRs are often not followed or observed?

| | |
|--|-----|
| Family wishes trump DNR | 23% |
| Doctors afraid of lawsuits | 13% |
| Not enough legal force to DNRs/ADs | 10% |
| Patient's condition changes | 8% |
| No acceptance of limits to medicine | 6% |
| Doctors aren't quitters | 6% |
| Doctors don't listen | 4% |
| Hospitals and doctors lack trust | 3% |
| OTHER | 3% |
| DON'T KNOW | 25% |

The most common aid to getting a DNR would be an easy-to-use DIY kit from government (26%), followed by more public awareness in general (16%) and more information available online (15%).

What single factor would make it the easiest for you to set up an advanced directive or DNR for yourself?

| | |
|--|-----|
| Easy-to-use DIY kit from government | 26% |
| More public awareness | 16% |
| More information available online | 15% |
| Initiate through family doctor | 9% |
| Free medical/legal seminars | 8% |
| Required and enforced by law | 6% |
| Initiate during hospital/clinic visit | 2% |
| OTHER | 4% |
| DON'T KNOW | 15% |

Members strongly support legalized physician-assisted suicide (68%), and their support has not wavered over time (December 2011 - 70%).

If Canada had a comprehensive, government-paid system of effective palliative care and compassionate end-of-life care, would you support legalized physician-assisted suicide for the terminally ill?

| | December, 2011 | January, 2013 |
|-------------------|-----------------------|----------------------|
| Yes | 70% | 67% |
| No | 17% | 19% |
| DON'T KNOW | 13% | 15% |

The two biggest concerns about legalized suicide are abuse by guardians and caregivers (22%) or the fact that doctors may not agree on what is a terminal illness (12%).

If physician-assisted suicide for the terminally ill were legal in Canada, what would be your biggest concern?

| | |
|---|-----|
| Abuse by guardians/caregivers | 22% |
| Medicine not exact about what is "terminal" | 12% |
| Breeds culture of defeat/not fighting for life | 8% |
| Against it on religious grounds | 8% |
| Families may pressure for inheritance | 7% |
| Abused by the suicidal | 4% |
| Against it on moral (non-religious) grounds | 4% |
| Romanticizing "good death" will become trendy | 2% |
| NO CONCERNS | 25% |
| OTHER/DON'T KNOW | 8% |

Members say their provincial health care systems are generally good at reducing pain and optimizing quality of life in seriously or terminally ill patients (38%) but not at easing grieving (16%) or avoiding unnecessary procedures (14%). In most cases, however, members do not know how well their province does at each of these functions.

How well does the health care system in your province deal with reducing pain and suffering and optimizing the quality of life of seriously and terminally ill patients/with easing the grieving process for survivors/with avoiding costly and time-consuming treatments at the end of life that have little chance of success?

| | Reducing pain | Easing grieving | Avoiding procedures |
|------------------------|----------------------|------------------------|----------------------------|
| WELL | 38% | 16% | 14% |
| Very well | 7% | 2% | 2% |
| Well | 31% | 14% | 12% |
| NOT WELL | 25% | 38% | 35% |
| Not very well | 20% | 26% | 27% |
| Not at all well | 5% | 12% | 8% |
| DON'T KNOW | 36% | 47% | 51% |

The wide majority (75%) agree that it is their absolute right to refuse treatment or nutrition or resuscitation.

Do you consider it your right to refuse or discontinue treatment, refuse nutrition, refuse resuscitation and receive pain and symptom control that may hasten your death or are these just wishes that the doctors should take into consideration?

| | |
|--|------------|
| My rights must be upheld | 75% |
| My family may counteract my wishes | 8% |
| My doctors may counteract my wishes | 6% |
| Patients should have no say | 2% |
| OTHER | 2% |
| DON'T KNOW | 7% |

Members are very concerned about burdening their families at death (84%) and not having enough information when the time comes (73%), but are not as concerned with being emotionally prepared for death (49%).

How concerned are you that you wouldn't have enough information about treatment options if a family member became seriously or terminally ill/about burdening your family or friends if you became seriously or terminally ill/about not being emotionally prepared for death and dying?

| | Burdening family | No Information | Prepared emotionally |
|----------------------|-------------------------|-----------------------|-----------------------------|
| CONCERNED | 84% | 73% | 49% |
| Extremely concerned | 18% | 11% | 4% |
| Very concerned | 31% | 22% | 11% |
| Somewhat concerned | 35% | 40% | 34% |
| NOT CONCERNED | 15% | 23% | 49% |
| Not very concerned | 11% | 17% | 31% |
| Not at all concerned | 4% | 6% | 18% |
| DON'T KNOW | 1% | 4% | 2% |

Most members will learn about end-of-life issues from their doctor (36%) followed by family (14%). CARP is a source of information too (5%).

Where would you turn to learn about end-of-life issues?

| | |
|-------------------------|------------|
| Family doctor | 36% |
| Spouse/children | 14% |
| Religious leader | 8% |
| Lawyer | 7% |
| Social services | 7% |
| Media | 5% |
| CARP | 5% |
| Friends | 4% |
| OTHER | 15% |

Canada Revenue Agency

The majority agree with CRA's decision to stop mailing out income tax forms to all Canadians this year (54%).

The Canada Revenue Agency (CRA) has announced it will no longer mail out paper income tax forms. These forms will now be available on the internet for downloading, or at the post office for pick-up. This decision was made to save printing and mailing costs. Do you agree or disagree with this decision?

| | |
|--------------------------|------------|
| AGREE | 54% |
| Agree strongly | 16% |
| Agree | 38% |
| DISAGREE | 44% |
| Disagree | 22% |
| Disagree strongly | 22% |
| DON'T KNOW | 2% |

There is concern however, that many seniors don't have internet access (32%), that it was done without notice (19%), that many seniors don't trust the internet for financial matters (18%) and that many seniors can't get out to the post office (10%).

Which of the following would be the biggest obstacle to getting an income tax form if this decision stands?

| | |
|---|-----|
| Many seniors don't have internet | 32% |
| It was done without notice | 19% |
| Many seniors don't trust internet for finances | 18% |
| Many seniors can't get out | 11% |
| Few post offices/many being closed | 5% |
| Many seniors have internet/no printer | 3% |
| OTHER | 4% |
| DON'T KNOW | 8% |

The plurality think CRA should rescind the decision and mail out forms to all who filed by mail last year (40%), while somewhat fewer suggest CRA mail request slips for the forms to all who filed by mail last year (24%). One quarter don't think any action is necessary (24%).

What step do you think CRA should take to resolve this issue?

| | |
|---|------------|
| Rescind/mail forms to all who mailed last year | 40% |
| Rescind/mail request forms to all who mailed last year | 24% |
| Restore telefile | 5% |
| Apologize to tax filers | 2% |
| NO ACTION REQUIRED | 23% |
| OTHER | 3% |
| DON'T KNOW | 3% |

Ontario Liberal Leadership Election

CARP members correctly predicted Kathleen Wynne would win the campaign for Liberal leader and premier in Ontario (22%), and correctly predicted the second place finisher as well (Sandra Pupatello - 11%). The plurality don't know who they prefer for leader (43%).

ONTARIO ONLY A new Liberal leader will be chosen on January 26 in Ontario. This leader will become premier. Who of the following do you think would be most supportive of issues important to older Ontarians?

| | |
|-------------------------|-----|
| Kathleen Wynne | 22% |
| Sandra Pupatello | 11% |
| Gerard Kennedy | 7% |
| Eric Hoskins | 2% |
| NONE | 14% |
| DON'T KNOW | 43% |

CARP members agree the first task for the new premier is to recall the legislature (49%), followed by settling with the teachers (11%) and coming up with more funding for home care (10%). All these things have been promised by the new premier.

ONTARIO ONLY Which of the following do you think is the most important priority for the new premier?

| | |
|---|-----|
| Recall legislature | 49% |
| Settle dispute with teachers | 11% |
| More funding for home care | 10% |
| Urge federal government to enhance CPP | 7% |
| Freeze property taxes for seniors | 7% |
| Standards for nursing/retirement homes | 5% |
| Reduce/control cost of drugs | 4% |
| More action on elder abuse | 1% |
| OTHER | 6% |

Electoral Preference

The NDP (25%) and the Liberals (25%) are tied for second place, while the Conservatives have gained a few points (45%).



More than 1800 CARP Poll™ panel members responded to this poll between January 25 and 30, 2013. The margin of error for a probability sample this size is about plus or minus 2%, 19 times out of 20