



ADVANCE CARE PLANNING: POLICY, LEGAL AND PRACTICAL DIMENSIONS

Invited Panel Discussion

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Conversations on Caring (Vol 2) learning resource set

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Suggested Process and Learning Objectives for Problem-based, Small Group Learning and Local Staff/Professional Development Learning Circles

INTRODUCTION

Conversations on Caring, Volume 2, is a learning resource which has been prepared from previous Pallium Project professional development events. These events are the *Monthly Continuing Professional Development (CPD) Audio-conference Program* series. The *Monthly CPD Audio-conference Program* series was supported in 2005 and 2006 through a contribution from Health Canada's, Primary Health Care Transition Fund (PHCTF) as part of Primary Health Care Renewal in Canada. The views expressed in these sessions do not necessarily reflect the official policies of Health Canada or the employing organizations of members of the Pallium Project's, Community of Practice. These materials have been prepared as "reminder resources" for participants to the original sessions and as learning resources to support small group learning, either for local staff/professional development or as part of pre-service health science education courses in Canada.

The MP3 audio files and audio CDs which accompany this series have been post-produced from the original event in order to provide essential information and enable use, generally within 1 hour time blocks. This enables their ready use within "Brown Bag" lunch series, pre- and post-shift staff/professional development sessions, as the basis for staff meetings which are periodically dedicated to problem-based, issue-driven learning, or as an occasional "audio-book" alternative to listening to a radio (e.g., rural, home care visits). Each of the sessions has been based on topics which practicing Registered Nurses have identified as important to improving practice and service locally as part of a 2005-2006 audio-conference series entitled *Improving Care in Our Communities*. While program-developed and organized principally from a nursing process and case-management perspective, sessions reflect the inter-professional and trans-disciplinary perspectives of both the Guest Resources/Invited Panelists and the local participants, many whom reflect a diversity of perspectives of social workers, spiritual care providers, primary-care physicians, hospice/palliative program volunteers and others.

SUGGESTED PROCESSES – LOCAL, SMALL GROUP LEARNING

1. Prior to session - Designate someone as a meeting convener/facilitator – the convener's duties are to book/ensure a suitable quiet space for meeting/learning, a playback unit capable of playing audio CDs or MP3s (or have an Audio CD of the session you are using converted from the MP3 if you do not have the 12 AudioCD format set) and a written transcript for each participant (choosing a space with a whiteboard or a flip chart is ideal).
2. Prior to session - Review the transcript prior to the session, noting why this particular session was chosen, and take notes for introducing the key local issues which are relevant to the session content.
3. During session – Introduce the session, linking to the notes as to why this particular session is relevant to local context and circumstances (i.e., discuss why this topic at this time for this group of participants/learners).
4. During session (at session introduction) – Participants should be encouraged to take notes about things discussed in the session that they would like to discuss following the playback of the session.
5. Following playback – Convener should facilitate a "round table" style debriefing (or other semi-structured method) to enable participants to discuss their comments, perspectives and ideas arising from the session.
6. Following playback – For those comments and ideas which contain ideas for practice change, service and other quality improvement, the convener or another designated recorder should note these on the white board, flip chart or other means (designated note taker). The convener should commit to the group how specific actionable items generated from the session will be followed up upon (e.g., share with management; link to improvement process, etc.).

SUGGESTED LEARNING OBJECTIVES FOR THIS SESSION

By the end of the session the participant should be able to discuss all or part of the following:

- The role and importance of Advance Care Planning (ACP), especially for progressive and life-limiting illness.
- The two major approaches to Advance Care Planning in Canadian jurisdictions.
- Recognition that roles and functions in Advance Care Planning have different labels in various jurisdictions.
- The legal complexity and plurality of Advance Care Planning legislation in Canada.
- Recognition that Advance Care Plans and Level of Care forms do not have the same status in Canadian law.
- The importance of supported dialogue and progressive conversation as a communication methodology for enabling Advance Care Planning within families.
- The importance of having systems which support communication within the health care delivery team, particularly in multiple-shift environments and across settings of care (e.g., hospital, home, hospice, long-term/continuing care, etc.).
- The importance of completing Advance Care Plans prior to life-threatening, crisis situations.
- The health and wellness value of Advance Care Plans in supporting healthy bereavement processes for survivors.

INVITED PANELISTS

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Moderator
Jacquie Peden, RN, MN

Original Air Date – May 25, 2006

JACQUIE PEDEN

I'm pleased that you're able to speak to us today, Janet. Can you tell me, what is your recent involvement with Advance Care Planning?

JANET DUNBRACK

Yes. Thank you very much Jacquie, and hello everyone across Canada. I have recently completed a report for Health Canada on behalf of a community-based Public Information and Awareness Working Group, which is part of Canada's strategy for palliative and end-of-life care.

The purpose of the report was to look at clarifying advance care planning terminology across the country because each province tends to use different terminology to mean similar things. In other words, an advance directive may be described as a Personal Directive in one jurisdiction, as an Advance Care Plan in another, as a Power of Attorney for Personal Care in a third jurisdiction.

So, we wanted to compare the terminology, but we also decided to drill deeper and talk to volunteers, family members, and professionals in the health sector, the social sector, which is non-governmental organizations and consumers, and the legal sector. So, I spoke to 56 people across Canada in these different sectors and drew together their experience with advance care planning.

In terms of my own personal background, I'm a former Executive Director of the Canadian Palliative Care Association. And before that I worked extensively in palliative care involving HIV/AIDS. And I started off as a volunteer in palliative care many, many years ago. So, palliative care is really the background that I come from in this discussion.

I'd like to first give an overview of what's happening across Canada - some of the major issues that people are looking at. The issue, as you may be aware, is growing in importance. The media coverage given to the *Terry Schiavo* case in the United States and the *Nancy B* case in Canada have really made people aware of this.

The Canadian Hospice Palliative Care Association reported that after extensive media coverage of these cases, they received an enormous number of calls from people asking

about how they could prepare an Advance Directive because these issues have caused them to really think about their own personal situations and whether they wanted to leave wishes (i.e., express) wishes for their care if they become incapable of giving informed consent.

Another factor, of course, is that our population is aging and older people are starting to think about what kind of care we would like and being able to express our wishes while we're still capable. The Canadian Hospice Palliative Care Association this year chose as the theme of National Hospice Palliative Care Week - which is the first week in May - Advanced Care Planning and the theme they focused on was raising consumer awareness - raising public awareness - their slogan is *My Living, My Dying: Informed, Involved and In-Charge - Right to the End!* Next year they plan to focus on raising awareness among professionals, specifically, healthcare providers and in the third year they may use the theme for Hospice Palliative Care Week to develop resources that both consumers and professionals can use.

Joan Rush, who's another of the panelists, will be talking in detail about legislation across Canada. I just wanted to say that all the provinces and Yukon have some form of advance directive legislation, and Joan will go into that in more detail.

I wanted to say that even if a person has only - is only - able in their province to name someone to make decisions in their place rather than leave legally binding instructions - in all provinces - decision making that's made on behalf of a person does have to take into account their known wishes and if those are not known, whatever is known about their values, beliefs and principles. And if those are not known, the principles of acting in the person's best interest are used as a guide to decision making by the family and by healthcare providers.

The people I spoke to identified key factors in successful advance care planning from the viewpoint of both the patient and the family and the healthcare providers. The most important thing is communication between the patient and the family, and preferably while the person is relatively well, before a crisis happens so that the family has the dialogue in a relatively non-threatening, non-crisis situation.

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So that they have time to reflect, so that the person who's making their advance directive has time to think about what they would like in terms of care, what they want to express, who they might want to name to make decisions in their place if they wish to do that. And it takes time as I'm sure that Sue Grant will point out later when she talks about her experience.

Secondly, communication between the patient and the family and the healthcare team is also very important, not only with the Family Physician, if a person has a Family Physician, but also the healthcare team that's involved in their care. It's important to have trusting, respectful communication between the patient's family and the healthcare team in order for advance planning to work well.

And the third type of communication that's essential is communication within the healthcare team itself. So many people working in healthcare told me that not all members of their team were on the same page necessarily with respect to advance directives. When shifts changed, often information was not passed on or if a patient is transferred from one care setting to another, often the advance directive doesn't follow them. So, communication within the healthcare team, the various members is very important as well.

Generally, what people I talked to said is that people want to talk about advance care planning, although it can be a fearful topic for people to think about potential illness and dying. Generally people, if they're supported in having that kind of communication and discussion, are quite eager to have that kind of discussion.

Another factor that comes out as very important in success is having systems that work. Systems within the healthcare setting or the healthcare system that support the communications process. Good communication systems to ensure that all staff are aware of the advance directive. Systems to ensure that there is an awareness of the advance directive when the patient moves between care settings. Quebec right now is looking at a new policy of continuum of care and asking people to think about advance directives quite early in their diagnosis of something that may be a potentially life threatening illness.

When I spoke to family members who had been family care givers and how had spent sometimes years helping to provide care for somebody, particularly with a degenerative disease, most reported that they had peace of mind and a more peaceful bereavement when they had had the discussion with the patient over time about what their wishes were and when they felt that they had done all they could to respect the patient's wishes.

Those family members I spoke to said that they were now encouraging their adult children to do their advance directive while they're healthy rather than being caught in a crisis situation where the person's capability to give consent or even to make an advance directive may be in doubt.

So, these family members all said, "having been a caregiver myself, having seen how helpful the advance directive was, having seen how important it was to know my spouse's wishes, for example, "I'm now encouraging all my friends and my family to do advance directives while they're still able and still relatively healthy."

The resource list that was provided to you gives web links to all the legislation in the provinces and in the Yukon and to consumer resources which have been developed by provincial governments and by the Yukon to help walk people through the process and help them to start thinking and reflecting on this.

JACQUIE PEDEN

Joan, can you tell me what your recent involvement with advance care planning is?

JOAN RUSH

It's relatively recent compared to all the other panelists, although most of my legal career has been involved with life and disability insurance. Actually, I was unfamiliar with the concept of advance directive as are many lawyers and certainly most of the general population until a couple of years ago when I joined an ethics committee at the B.C. Cancer Agency.

I found regular expression of concern that the legislation was inadequate and there was, in short, the problem of advance directives in British Columbia was not being dealt with. No one knew what an advance directive was. It led me - my interest in health law in general - led me to return to school to complete a Masters of Law in Health Law and Ethics and I made advance directives the subject of my thesis. And so I've spent some time studying it now for a couple of years.

JACQUIE PEDEN

Can you tell me then, what are the differences in legislation around advance care planning across Canada?

JOAN RUSH

One of the things I think I'd like to refer everyone to - I can certainly discuss this, but Janet actually prepared this rather nice list or summary sheet of advance directives. One of the things that is particularly clear from this nice list is that there are differences in the type of advance directives that can be made in the different provinces.

The law of advance directives evolved creating two forms - either an Instructional Advance Directive, which is more commonly known as a Living Will - I had heard of living wills but not advance directives I want to add - and a Proxy Advance Directive. And the provinces have divided in their opinion on whether or not people should be entitled to have the power to create Instructional Advance Directives. And so a number of the provinces don't actually provide for it in legislation.

Although arguably, the common law of Canada does recognize our Instructional Advance Directives and healthcare providers not only are entitled to - but in their codes of ethics - ethically agree to abide by Instructional Advance Directives.

In my opinion the more modern Advance Directive legislative schemes are found in primarily, with the exclusion of British Columbia, are found in the western provinces and in P.E.I. and Newfoundland. But Manitoba - is probably the best leading example - and Saskatchewan and Alberta all have both the ability for the people to choose whether to write an Instructional or a Proxy or a combination of both. There are minimal restrictions on execution, particularly in Manitoba.

But a number of provinces have been hesitant. In Nova Scotia, notwithstanding a report by their Law Reform Commission recommending that more modern legislation be put in place it is still proxy legislation only. New Brunswick, it says on Janet's list proxy directive only. To be perfectly honest I have questioned whether or not the *Infirm Persons Act* really constitutes Advance Directive legislation as compared to simply legislation allowing others to agree to certain types of medical care but not necessarily withdrawal of life-sustaining treatment.

JACQUIE PEDEN

Can you explain the difference between the two, the Instructional and the Proxy and how does that impact the person at the front line working in those specific provinces?

JOAN RUSH

An Instructional Advance Directive can be both an oral or a written instruction directly from the individual to healthcare providers. So, it can be a statement of what you would wish or not wish. It can be taken down, either can be written out by the individual or perhaps recorded by the healthcare provider. But it's an indication of what a person would wish to consent to in the event of their future incapacity to give personal instructions.

That's why, Janet, with respect, I would distinguish the *Nancy B* case, because I think that *Nancy B* and *Ciarlariello*, and other cases are very settled law that people who have capacity such as *Nancy B* did, are entitled to refuse medical treatment. Our law absolutely respects that to the extent that in *Nancy B* and in *Rodriguez*, which commented on *Nancy B*, it would be considered a Battery for a healthcare provider to, which is both a criminal and potentially civil offence, to insist on providing healthcare treatment if a person has refused it.

The difficulty arises when healthcare providers are faced with trying to interpret instructions once a person has become incapable. And the initiatives I think that Fraser Health and other of your provinces have begun are helping people to create instructions that are reflective of their wishes, but that can easily be interpreted by the healthcare professionals, and by family members, that can be discussed and amended and revised – be reflective of people's wishes.

JACQUIE PEDEN

And the Proxy?

JOAN RUSH

So, a Proxy is an appointment of another person to give consent to treatment. In the *Substitute Decision Act* in Ontario - it's an appointment of a substitute. British Columbia calls that a Representative. The person can be called, in Alberta, as Janet mentions it's an Agent; Saskatchewan - a Proxy; Quebec - a Mandatory; New Brunswick - an Attorney for Personal Care, and, of course, Personal Care does not in the legislation specifically go into withdrawal of life-sustaining treatment. That's why I think it's a bit questionable.

But nevertheless I think it's being interpreted by healthcare professionals there to constitute an appointment of a Substitute. But, as you can see on her list, there's a Substitute Decision Maker, Guardian, Proxy, Attorney for Personal Care - many, many names, in B.C. - Representative, given to a person who this individual has appointed and said to the healthcare system "In the event of my incapacity I would like you to seek your direction from this individual with respect to my choices, and they will decide on my behalf."

JACQUIE PEDEN

Can you tell us if there are any other common legal issues?

JOAN RUSH

I think that healthcare professionals are perhaps unfamiliar with the degree of problematic law facing them because, for the most part the medical profession, in sort of every level of whether it's physicians, nursing, social workers, generally have adopted ethical statements that confirm the approval of Advance Directives. And having read all of those when I initially began my research and looking at a couple of the cases that absolutely confirmed that individuals' statements of their direction to healthcare providers should be followed - that the ethical statements are extremely clear and convincing - and it seems there should be little argument as to whether or not advance directives would be followed. So, I couldn't understand what really is the problem here, until I looked at the law.

And I wanted to make a quick comment on an article that was in yesterday's *Globe and Mail* in the Social Studies section. It's called *American Patrol*. The same thing is applicable here though in Canada. It said recent U.S. legal notes ... "Mary Wolford, 80, has made it perfectly clear what her final wish is and it is written in ink", reports the Associated Press. In February, the Decorah, Iowa woman had "Do Not Resuscitate" tattooed on her chest. I'm guessing this means she didn't trust either a necklace or a bracelet for fear someone might remove them. "However, having her last desire emblazoned on her chest has raised some legal issues. Some U.S. medical and legal experts doubt that the tattoo would be binding in the Emergency Room or in the Court."

Now, as lawyer, I have to ask you - and you are all healthcare professionals - why is that? Why would we doubt that a tattoo placed by someone 80 years old, to make sure her wishes are known, would be doubted by the legal professional and by the medical profession? But the reason it becomes very clear when you look at the law.

I studied both the U.S. law and the Canadian law, and I won't get into the U.S. because it's just too amazing. But in the Canadian law I think you should know that on a plain reading - Jocelyn Downey who writes from Dalhousie out of Nova Scotia, makes this point clear as well. The criminal law on a plain reading still makes healthcare providers criminally responsible for death if they withdraw life-sustaining treatment.

Notwithstanding many, many calls for amendment to the legislation, the criminal law still implies that it is a criminal act to withdraw life-sustaining treatment, notwithstanding a person's Advance Directive to do so, and it's quite complicated by the fact that medical professionals, especially physicians, are entitled to determine in cases of futility that health treatment can and should be withdrawn, and yet this is all confused by the criminal law.

The provincial legislation - as you have heard and as Janet has so ably put together in her list here - creates, I think, a great deal of confusion in that the legislation is not at all consistent across the provinces notwithstanding the supposed uniformity, accessibility and portability of the *Canada Health Act* and the idea that we supposedly have equal access to medical treatment and care across the country. Notwithstanding all of that the legislative process is different province by province and the case law, while seemingly clear in its statement, is not exactly on point.

The two most forceful cases - one dealt with provision of a blood transfusion to a woman who subsequently regained Competence but she - that's the *Malette v. Shulman* case - she had refused it and the court upheld her right to do so. And although they charged a minimal fine to the healthcare professional and one - I think, who's not of her religious group could probably argue it seems like it's the logical thing to do - to keep an otherwise healthy woman alive. Nevertheless, maybe she feels that, you know, eternal damnation is perhaps not sufficiently remunerated by the \$20,000 award she won.

But, at any rate the courts said at the Court of Appeal level in Ontario, no, if she's decided that she refuses to have - to give consent to have a life-saving blood transfusion, she's entitled to do so. That case was further upheld in an even more strongly worded case, *Fleming v. Reid* - also Ontario Court of Appeal - also considered a very important Appeal court in this country. And ... it seems clear but the legislation, the case law as far as legislation is varied, the criminal law is against you and there's no limitation of liability. It's a very difficult area.

JACQUIE PEDEN

Sue, I know that you recently been involved with developing a model of Advance Care Planning in Fraser Health. So can you tell us a little bit about that project?

SUE GRANT

You can probably understand why when you listen to Janet, and in particular when you listen to Joan on the specifics of the law, why Fraser Health elected to focus on conversation - on encouraging people to have conversations around their end-of-life wishes. Early on in our process, discovered a model of advance care planning, *Respecting Choices*[®] - based out of La Crosse, Wisconsin - the Gunderson Lutheran Hospital there - and we have modeled our particular initiative on that model - *Respecting Choices*.

We focus on encouraging people to have conversations about what wishes they might have around healthcare; just around these and some of their goals for living well in their last months or days or weeks of life. To have those conversations with the people they love and with their healthcare providers. And so we wanted to ensure that this could not only happen, that people could have these conversations, and we would facilitate that with some kind of education. But also we realized certainly from the *Respecting Choices* folks that it's really important to create a system that would allow someone to bring their wishes forward to the healthcare system, either verbally or ideally certainly in writing, to be able to bring your advance care plan to a healthcare provider and have that advance care plan accessible when you really need it when decisions are being made.

One of the things with advance directives - it's been found when they've done studies in the (United) States - that advance directives often don't make a difference in the care and they found that the reasons they suggest for that is that they're often not available, they're outdated, they're not ... they're too specific or they're too broad and they're often not associated with the conversations with the people that mean the most.

So, Fraser Health has really sort of leapt into the fray but we've tried to actually steer clear of trying to talk about making a specific form a requirement at all. Actually, we provided some educational materials. We have a workbook on our website which is referred to in the information that was sent out. So, we're starting to see a real - I would say it's a, grass roots response to this. It's just so heartening to hear the positive response from people who we've been doing public education on request with seniors' groups and the Rotary Clubs. People want to have this conversation! They want to know how to do it. They find it often an awkward topic to broach and they really welcome the support that Fraser Health's been able to give to them.

When I say “we” our particular model is being successful because there are so many people on the front lines and certainly people like my colleagues - the medical leader Doris Barwick and my director Carolyn Tayler - who have really just come on board and championed this at every level. And that’s, I think, why it’s actually been successful.

JACQUIE PEDEN

Have you ... So you’ve noticed a difference in how Advance Care Planning is done or how it’s received?

SUE GRANT

I’ve noticed as various people who are trained in being able to communicate the information about advance care planning, go out and talk to the public and they come back with these stories of people saying, “Oh I want my sister to hear about this. Can you give me some more copies of that workbook and the information?”

People are wanting to sit down and talk about it. We’re receiving that kind of response and where we’re having some of the most heartening response is in our residential care settings, where we’ve actually helped people have these kinds of conversations. People who have really wanted to have a voice and they actually have been able to make their wishes known.

We found situations where people have said “You know if anything happens to me, I want you to do absolutely everything you can to keep me alive.” And when we’ve actually gone to the chart and looked on what the orders are - the person’s been ordered DNR – Do Not Resuscitate. In fact the conversation has never happened. The person says “No, no, my doctor never talked to me. Nobody ever talked to me.”

So, just to be able to say, you know, it’s not just to say “don’t resuscitate me”, it’s to say “do resuscitate me. I want everything possible done”. Yesterday one of our facilitators told me a story about a group she spoke to and she said it was very interesting - a lot of couples were in the group. It was a seniors’ group at a church. It was just really interesting how one person would say - the husband would say - “Well, my wife would want everything done. I’d have everything done for her”, and she’s saying, “Well, dear no I wouldn’t.” It’s because we don’t really talk about it frankly, we often don’t know what people really close to us would really want.

JACQUIE PEDEN

I think that it’s sometimes really difficult for a healthcare provider to actually introduce the topic or to actually talk about this. Have you got any suggestions? It seems like what you’re doing in Fraser Health is doing some education about it and then you’re getting that opening. But if someone’s at the bedside working in Hospice Palliative Care, what are some of the ways that they could introduce the concept about Advance Care Planning?

SUE GRANT

You don’t need to call it Advance Care Planning. You can introduce the topic by saying, “Have you thought about what you might want ...” especially depending on where they’re at in the trajectory of their disease or even - say if a person was totally healthy and you’re actually interviewing a healthy person or talking to a healthy person - have you ever thought, first of all, of what gives your life meaning, and then how sick would you have to be? If you were very sick, how sick would you actually have to be for you to say, “Life would not be worth living for me?”

These kinds of conversations, they’re not “one off” conversations. They’re conversations that happen over time. Even the formal conversations that we might have with people who have indicated they want to sit down and they would like some help to have the conversation and they’ve got their family with them. Even those formal conversations - they take two or three sessions to actually have the people get out what really matters to them.

JACQUIE PEDEN

Can you just talk a bit about how the role of Advance Care Planning actually is important in managing decline and death?

SUE GRANT

I’ll tell you that my father died last year and a couple of months before he died he was really wanting to talk about this, but he had a couple of lines that he said and that’s kind of where it stopped with my mother. Even being in this role that I’m in I just found it hard to bring it up and so I had a friend who had information on advance care planning - was able to come and talk to my dad and he just wanted so badly to actually put these thoughts down. The thoughts that he wrote down were not as significant as what he said. But when he actually wrote that down, it was interesting how that document - it was a workbook - he kept that with him. He at one point said to me, “Sue, is it alright if I keep that on the coffee table. Do you think that would look odd if I just kept that advance care planning document?” I said, “Well, no. That’s just fine. It’s your coffee table and ...” But it was almost evidence for him that he still had some control and we found that too.

One very moving story about a man who had a conversation with his sister who had been dying over a series of months with Multiple Sclerosis and she was able with a facilitator and the brother to talk about what she wanted and they wrote it down and she made an Advance Care Plan. And a couple of weeks after her death he came back to the care facility and said to the staff, (to the staff nurse there), he said, “Do you see this workbook?” He said, “You know what? This has been my strength. This is my sister.”

It certainly can’t be underestimated and when I talk to people - and there’ll be people in our audience today who do a lot a work with bereavement counseling - but when I

talk to people who do that they say that a huge bulk of their work is around the guilt that surviving family members and friends have around “did we do the right thing for mom or dad or for my husband?” And when that guilt has been sort of worked through, because beforehand when they’ve had the conversations about “are you sure that’s what you want dad?” “Yeah, that’s what I want”, and it’s written down. It’s huge!

JACQUIE PEDEN

There’s two questions that were faxed in from participants - Pat Tichon from Dauphin/Parkland RHA in Manitoba, and her question is, “Please provide direction on the purpose of marking true and valid copy dating and signing the copies that are made from the original. Who should receive the original? Who should receive the copies?” That’s her first question; and, “Is it necessary to have the individual or substitute make her sign the advance care plan?”

JANET DUNBRACK

This is Janet. I can’t answer the first part of the question because I don’t know the technicalities of how the forms are processed in Manitoba. I can provide an answer to the second part of Pat’s question which, according to the Manitoba legislation, an Advance Directive has to be written, signed and dated. But there is no requirement in the Manitoba legislation that the person who’s named as the proxy sign the form.

JANET DUNBRACK

There is in some other provinces, but not according to what I was able to find out about the law in Manitoba.

JACQUIE PEDEN

So, I guess the other thing she’s just asking is can you make copies and is that what ... and who should receive the original copy and who should receive the copies?

JOAN RUSH

I think that what this really ties to is probably more policy that has to do with the practical mechanics of making sure people who need to know, do know. And probably the dating and saying true and valid copy and so forth, indicate that this is maybe the most recent or the only document that was made by the individual. But it’s beneficial, of course, that the doctor has the Advance Directive... if family members have an advance directive. And so, I think - as Janet said - it’s not in the legislation of Manitoba, but individual hospitals, I suppose, may make it part of policy. It would ... So perhaps when Pat comes on the line, she could clarify why the question arises. Is it perhaps a requirement?

JACQUIE PEDEN

The next question comes from Bonnie Wood from New Westminster, B.C. What she’s saying is “capacity assessments to be sure that the person is a Capable adult so that the advance directive will be considered a valid statement of preferences for future medical care.” I’m not sure ... Oh, should Capacity Assessments be done?

JOAN RUSH

I’d like to comment on that too for Bonnie. In the Canadian law an Advance Directive must be made by a capable adult. So the person is not able to create an Advance Directive for their subsequent care if they’re already found to be Incapable. I guess Bonnie’s question is so when you look at a document, how do you know if the person was Capable or Incapable when they wrote it? In general - under Canadian law - a person is assumed to be Capable. So, under Representation Agreement Act, under the Healthcare Consent Act of British Columbia here, people - adults - are presumed to be Capable unless shown to be Incapable.

JACQUIE PEDEN

Operator, I wanted to open it up for questions from participants.

OPERATOR

Our first question comes from Whitehorse.

JAN LANGFORD (Participant, Whitehorse)

It’s actually from Jan Langford, but I am in Whitehorse, Yukon. A bit of a question; a bit of a comment for Joan on the types of advance healthcare directives. I think it’s a bit simplistic to say there’s Proxy and Instructional. And I see in Yukon that we have a Proxy and an Instructional directive. Our legislation’s fairly new so we have a lot of debates around which way to go on this, and under the Yukon legislation a directive must appoint a proxy, but you can also set out your wishes or your instructions.

The big difference is the onus is on the proxy to when they’re providing a valid consent to the person’s healthcare when they’re no longer capable it’s up to the proxy to carry out those wishes and the onus is not on healthcare providers. And we did that for a couple of reasons. One is we thought that family proxies were in much better position to carry out the wishes. They’re probably in a better position to know the person, to interpret those wishes.

And we felt that it was a lot of responsibility to put on healthcare providers in all situations to carry out the wishes. Especially since a lot of these advance directives are not always clear about exactly what the person wants. I think just labeling directives as Proxy or Instructional the way that you’ve done it on the chart is a little simplistic just from the kind of discussion we had in the Yukon and feel like the opportunity that people have here is to both name a proxy and set out their wishes which will be respected. Any comments from that?

JOAN RUSH

I think, looking at the Yukon legislation right now - and a Proxy means a person appointed in a directive to give or refuse care for the Maker. It is true that your Proxy, of course, is considered the person who would carry out the wishes, so the wishes of the Maker can be expressed or might not be expressed. They may simply appoint a Maker

or a Substitute Proxy. But, I think the difference is as compared to, let's say Manitoba for example - or any of the others who have the two different types - in the Yukon, a person cannot simply put down their instructions and expect that healthcare providers would be able to follow them in future and, of course, you could... let me just continue for a sec.

The reason I think that it becomes an issue certainly in the research that I did, as I looked at many, many studies. There is quite a significant population - and Fraser Health confirms this as do many other jurisdictions - where people actually don't easily have another Substitute to appoint. They perhaps have lost their family members. Maybe they never married. They married but didn't have children and their spouse has passed away. And they actually ask healthcare providers sometimes if they would be willing to act as a Substitute because there isn't anyone to appoint. So, it seems an unfortunate restriction.

And in some cases too, there are some individuals who want to appoint or make their wishes known but don't want to appoint their spouse. I think some healthcare providers feel that way- that they don't want to put what they perceive to be a potential burden on a family member or spouse to actually be the one to say "yes, withdraw the treatment".

And thirdly, some people believe it is an entirely private issue between themselves and their medical professionals and, as is all healthcare direction to medical professionals, is to be maintained in confidence. So, you've got a variety of consequences but where not everybody has a substitute to appoint.

JAN LANGFORD

But I think there are other mechanisms, at least in our legislation, for allowing people to express their wishes and if they don't appoint someone then another substitute physician carries those wishes out. I certainly see your points on that.

OPERATOR

We'll take the next question. It's coming from Halifax.

DR. STEPHANIE CONNIDIS (Participant, Halifax)

Hi, this is Dr. Stephanie Connidis. I have probably an observation followed by a request for some comment. The first observation I have is - that although advance care directives being more than CPR - I just wanted to talk a bit about CPR that is offered to a population that perhaps it wasn't intended - and that, is CPR when it was first developed - it was decades ago - was meant so that people providing care intra-operatively would know whether to resuscitate somebody who arrested on the table. And this has then been extrapolated to all populations and yet there isn't any good evidence to say that the utility of offering CPR in certain populations is actually that - is actually providing any added benefit. I was wondering if you could comment on that?

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JANET DUNBRACK

This is Janet. That's a very interesting comment. I had so many people tell me when I did my research that people watch *ER* (i.e., television series) and they expect medical miracles. And they expect that whatever emergency care they receive will be like *ER*. And of course, in 100% of cases - or 99% - it will work and they will come back to normal living. Well, so many healthcare providers pointed out that that's really not the case.

And I must say that the Yukon, in particular, in the Consumer Guides that the Government of Yukon issues, really goes into the details of what's involved in CPR, intubation and so on. These kind of interventions that may happen in case of cardiac or respiratory failure, so that people really have a more realistic sense of what's involved. In response generally to your observation I would say that many, many healthcare providers said the same thing and said really people expect a medical miracle. It's just not there.

JOAN RUSH

Could I make a comment to you - it's Joan - and maybe Sue wishes to too. But it's one issue I think that's been on my mind about this. Healthcare providers, I think, are now considered to be a potential sort of angels and gods that you can create such miracles and are held to an enormously high standard for doing so it seems to me. And as a consequence the suggestion that you would, as healthcare providers, be offering people an opportunity to refuse treatment that might otherwise be completely curative, sounds as though you are doing someone out of a terrific opportunity for a longer, happier, healthy life. And that is the impression given by some of the people who are ardently opposed to advance directives generally.

I just have to comment on what's happened in British Columbia because I think it's applicable to all of you as healthcare providers. The suggestion for modernized advance directive legislation that would acknowledge that there's no requirement but simply allow people to voluntarily make an advance directive that has been very greatly opposed. Special interest groups, and including Trial Lawyers' Association, oppose it. One of the suggestions made was that the health authority named in their letter appeared to be promoting Advance Directives in order to reduce healthcare costs.

Now, they are talking about you folks! I mean, this suggestion is that the healthcare authorities want to refuse treatment that would otherwise be beneficial and life sustaining because you have some cult, as it's referred to - in truth, in materials in the United States as a culture of blood - that you are out to kill. And I think it's a very, very sad and terrible accusation made against healthcare providers who are in general, I mean, ethically, morally and legally committed to doing everything they can to better the lives and welfare of their patients.

But that's the argument and that's why I think to a great extent advance direct legislation, especially Instructional Advance Directive legislation, is opposed (i.e., by those opposed). It's a belief that you will refuse to offer care. If I could make one tiny comment of my personal suggestion for you it would be as healthcare providers that you become active in encouraging modern legislation that recognizes choice and patient autonomy and ensures that you're not liable for following a patient's choice. But to leave it as is, the only people trying to influence the legislation are people who are giving doctors and other healthcare providers a very bad name.

JANET DUNBRACK

I just add my Amen to that.

DR. STEPHANIE CONNIDIS

Can I just ask this one more comment?

DR. STEPHANIE CONNIDIS

The other thing I think is interesting in terms of that balancing act of ethical and personal autonomy case law and criminal law is the fact that if I have a patient and I do not or their directive is to not resuscitate, I have to document that fully in the notes and in the orders. However, this speaks well with criminal law, if there is nothing that says that has to be documented that they want a full code and in many instances - and especially with the nursing staff and the other staff - it's cruel to resuscitate somebody and yet nothing has to be written in the chart with respect to that. And that's just an observation that I think really does reflect on the criminal law.

OPERATOR

Our next question comes from Edmonton.

SHARON (Participant, Edmonton)

This is Sharon. I'm a palliative nurse, just a question regarding the criminal law. I may have documented it wrong but some of you indicated that the criminal act or the criminal law indicates that it's a criminal act to withdraw life sustaining care. So my question would be if a person who was near death because of cancer or whatever co-morbidities they have - if you have not started the CPR you were thus not withdrawing.

Secondly, if you have people who have chosen not to continue with therapy, radiation, or ALS patients who have chosen to have their ventilator be removed, are those all those also considered criminal acts they have chosen independently to stop further treatment, so that's two questions. If you could clarify the criminal law and, number two, how does not initiating the CPR equate into withdrawing life-sustaining measures and if people choose not to pursue chemo, radiation or have a ventilator removed, if that's a criminal act?

JOAN RUSH

Two things I guess I should differentiate between right now. People choose as in they are still capable and they're giving their instruction to you from them not to initiate chemo, etc. They have an absolute right to do so. Our law absolutely upholds consent to treatment as falling within the rights of the patient and you must follow that.

But let us assume for a moment this patient had become incapable and now you have to make a decision. Do I begin a course of treatment or not? And ultimately, I think that the medical/healthcare professionals would always typically decide if there was no Advance Directive, they will provide whatever medical treatment looks like it would be in the best interest of the individual. And choose not to provide something that appeared to be not in the best interest.

Now - going back for a moment to the criminal law - on a plain reading it is true that despite these many requests by every Law Reform Commission, the Senate, Private Members bills from the 1970s onward, to amend it and modernize it, to ensure that there's no legal liability to healthcare providers who withdraw for, either based on an advance directive or for palliative reasons. It hasn't been amended and that's the theory of a culture that pursues euthanasia.

Nevertheless, in our criminal law - our constitutional system - the provinces are the ones who would pursue legal action. So, while the law is a federal law, it is prosecuted provincially and for the most part the provinces have determined they would follow the sort of ethical position of the medical profession. However - I mean everybody knows that they're on a bit of a knife edge when they do that - B.C. is the only province that's actually created a written policy explaining when and why it will not pursue prosecution. The rest of the provinces leave it unspoken but it's sort of the right thing to do.

There have been cases where provision of potassium chloride - arguably for what the healthcare providers have suggested is a palliative reason - has been prosecuted but overdoses of morphine have not been. And the law is on this tenterhook and if you read - I was going to read a little excerpt from the Supreme Court of Canada in the *Rodriguez* case - where he looks at that issue where were we willing as a society to accept assisted suicide? The answer was no, but do we think it is appropriate to prosecute palliative measures where, for example, an overdose of morphine may cause death. The answer was "We will not. We don't ... We think that is done for a reason to reduce pain and suffering. We won't prosecute." But it's still ... it still sits out there as a bit of a knife edge over, you know, a sword of Damocles over the head of the medical profession.

JANET DUNBRACK

This is Janet. Joan, it might be interesting to point out too, for the questioner, that a lot of the provincial legislation protects healthcare providers and substitute decision makers from liability for the decisions they make, and often treatment is defined in provincial legislation as including withholding and withdrawing treatment. But, Joan, maybe you would like to make the distinction between protection from liability in provincial legislation versus the *Criminal Code*.

JOAN RUSH

Because our criminal legislation is Federal, the provinces can only protect you from civil liability. So, the provincial protection will only be for a court case brought by a family member or someone else, not a criminal action. Not all of them provide it and some of them don't provide it in the same legislation, so some are very unclear. Manitoba provides protection. B.C. does not, in the *Representation Agreement Act*, but it does in the *Healthcare Consent Act* if decisions are made in good faith. Similarly, I think, Ontario divides it, which again makes a healthcare provider a little jittery that in the one Act that tells them you can go ahead and follow this instruction, doesn't in the same piece of legislation protect them from liability. They have to turn to other legislation.

So, my personal view - I came from a background of many years of life and disability insurance law - where there's quite uniform legislation across the country. But I really believe that it would be beneficial to the provinces to have quite uniform legislation that provided immunity and provided these protections.

SHARON

At this point have there been any civil cases that you were aware of that have ... where a family has not agreed with a physician ordering Do Not Resuscitate or anything else for that matter?

JOAN RUSH

The *Jantzen* case in Ontario I think is a good example of this. (*Jantzen v Jantzen* [2002] O.J. No. 450). Mrs. and Mr. Jantzen had been married a dozen years, they had children, by everyone's estimation it was a happy marriage. They were relatively young. He had not made an advance directive. At any rate though one would assume his wife would be his substitute. And certainly they have the same hierarchy of substitute decision making that many of the provinces do. B.C. does as well under our *Healthcare Consent Act*. And his wife is logically the person who would make healthcare decisions for him in the event of his incapacity.

He was in a terrible accident and his position was probably similar to that of Terry Schiavo in terms of his mental sort of injuries and so the doctors recommended to her that the life support that he was on (intubation) should be withdrawn and his wife agreed. His family members, his

siblings, who are from a different province, they were from Quebec, they objected. And so they came to the medical professionals in Ontario and said, "no, don't do this."

And the wife - Mr. Jantzen's wife - was respectful of their concern and agreed to delay the decision for another month at which point the medical care providers said, "The only thing we can sense for him is discomfort." I'm sure I'm not saying anything the healthcare providers, as I understand it providing artificial food and nutrition, is not always without complication. And there was no hope of Mr. Jansen ever recovering any life, really.

And so his siblings objected but his wife after a month said "I do not wish him to suffer any longer. I would like you to withdraw the treatment." His siblings went to court and brought a civil action. So, she was forced - I mean, can you imagine the trauma when you think it through of a wife now having - to go to court to defend your actions - in doing what you think is best for your spouse. But at any rate the judge thought that she was the appropriate guardian and her decision should be followed and hoped that the family members would be as respectful of her position as she had been of theirs and not appeal the decision and in truth they did not.

But therein lies the problem. If he had actually created a directive - that "if I'm in a situation where the best medical knowledge available says there's no chance for me to recover, I would not like to be maintained alive on artificial food and nutrition," now they would be in a position to legally follow it and not have to stand aside and let court action take place.

JANET DUNBRACK

Joan, this is Janet. If he had also created an Instructional or an Advance Directive naming his wife as the legal proxy, would it have been simpler as well?

JOAN RUSH

Well, you see, that's why I kind of wonder about it because she effectively was the legal proxy under the legislation. But there was still an opportunity for the doctors to be subject to litigation and so her decision was still subject to a court action. Where if it's his decision I suppose that maybe there could be ... I think they would be in a much stronger position to follow it. But again, these are issues that I suppose we'll see work their way through the courts. The court cases that have been heard so far in that province, in Ontario, have been very strong to defend the previously made instructions of individuals.

SHARON

Even if a person has a Do Not Resuscitate, because it's provincial, people that disagree can still civilly take healthcare professionals to court despite there being legislation that one can have an Advance Directive or a Personal.

JOAN RUSH

Well, now that's a different story. You see a Do Not Resuscitate order is within the sole purview of the medical profession at this point in time. And so that's not an Advance Directive. You should differentiate between the two. A person can request a DNR, in which case the DNR is put into their Advance Directive, but the ability to make a DNR order at this time in Canadian law is within the purview of the medical profession. So, it would not be subject - I think - to being overturned by a civil court action unless someone could show that the medical professionals were not acting in good faith in having made the DNR order.

OPERATOR

Our next question comes from Whitehorse. Please go ahead.

ELAINE SENKPIEL (Participant, Whitehorse)

Thank you very much. It's Elaine Senkpiel from our continuing care facilities here in Whitehorse and I have a question about process. We currently complete advance directives with our residents in care and also/or resuscitation and care form if that's their choice.

One of the questions that's come up is whether we should be automatically sending copies of those forms to the hospital for the hospital chart in the event that the person might go to hospital in the future and do that on an automatic basis. I wonder if anyone in the audience has experience with that, and how, and could comment on if that works or not. Currently what we do is keep the original on our resident's chart and send a copy to the hospital each admission that they go for.

One of our questions and concerns is whether we would be able to keep the hospital chart adequately updated on a regular basis to have the most current form on their record. So, does anyone have any comments or experience with that in terms of the process?

SUE GRANT

But I think it's really important for the hospital - the Whitehorse hospital would have a wonderful opportunity - to create a system there for supporting advance directives, having a green sleeve which we use. It's a green page protector and having that on the old chart and then every time the person comes back into acute care, there is this reconnect with them to say, now, is this the most current? But at least it's right there in your face and it's on their chart all the time at the hospital. We're having some care facilities saying that they would like to look into having a green sleeve for their charts in their facilities that is in residential care as well. But certainly if you wanted to talk more about this, you could email me and we could get together and we could talk about how we've done it.

JANET DUNBRACK

Jacque, this is Janet. I do have a comment because I think Ms. Frankfeld is talking about levels of care forms. Is that right?

ELAINE SENKPIEL

Yes, that's right.

JANET DUNBRACK

Which is not equivalent to an Advance Directive necessarily and there's some legal concern that the legal status of those levels of care forms is doubtful. So you might want to look into whether you would like to have people actually getting involved in advance directives because the level of care form is not the equivalent, legally speaking, of an advance directive.

ELAINE SENKPIEL

And we're talking about both forms. Some of our clients do complete Advance Directives more than not. The others complete a level of care form.

JANET DUNBRACK

Yeah, so there is some concern by lawyers across the country that levels of care forms are being misinterpreted as Advance Directives. They should just be aware of that.

JACQUIE PEDEN

Okay... Thanks for clarifying that Janet. I think this was a really good session, and I'm glad that we had the expertise of the three of you to be able to answer the questions.

The take-home messages today are there appears to be a strong agreement among healthcare providers across Canada that open, ongoing communication is a vital factor in successful advance care planning which results in the person's wish - person's, patient's wishes - being respected to the extent possible and in a satisfactory experience for the family and the healthcare providers.

Although discussions about advance care planning between healthcare providers and patients must be improved, the greatest impediment to effective advance care planning is the law, and good Advance Care Planning is the process of personal reflection following by action. Healthcare providers have an obligation to create a system that will both assist individuals with the Advance Care Planning process and ensure advance care plans are honored.

I'd like to thank Janet, Joan and Sue for joining with us today. This is the end of this session. We look forward to connecting with you on June the 22nd when Louise Cadrin, a music therapist, and Bev Foster, a music educator, will discuss Music at the End-of-Life.

URLs Referenced in Audioconference Session

(Current as at event date of May 2006)

(Janet #1-5; Sue #6)

1. Dalhousie University Health Law Institute End-of-Life Project: Advance Directives <http://as01.ucis.dal.ca/dhli>
2. Ian Anderson Continuing Education Program in End-of-Life Care, Module 4: End-of-Life Decision Making – pdf download: www.cme.utoronto.ca/endoflife/Modules/End-of-Life%20Decision-Making%20Module.pdf
3. University of Toronto Joint Centre for Bioethics – Online - Living Will. French and Italian versions also online: <http://www.utoronto.ca/jcb>
4. *A Guide to Advance Care Planning*. Province of Ontario – developed as part of the provincial Alzheimer’s Strategy: English: www.citizenship.gov.on.ca/seniors/english/advancecareguide.pdf French: www.citizenship.gov.on.ca/seniors/french/advancecarefr25.pdf
5. Canadian Hospice Palliative Care Association. Site has materials for National Hospice Palliative Care Week. This year’s theme is Advance Care Planning: My Living, My Dying: Informed, Involved and In Charge – Right to the End. www.chpca.net
6. Advance Care Planning in Fraser Health: <http://www.fraserhealth.ca/HealthInfo/AdvanceCarePlanning/Default.htm>

As of August 2006, Health Canada has published the report documents to which Ms. Peden and Ms. Dunbrack refer in the session transcript at the following locations:

Advanced Care Planning – The Glossary Project: Final Report (English)

http://hc-sc.gc.ca/hcs-sss/pubs/care-soins/2006-proj-glos/index_e.html

Planification préalable des soins - le projet sur le glossaire : Rapport final (Français)

http://hc-sc.gc.ca/hcs-sss/pubs/care-soins/2006-proj-glos/index_f.html