



DYING FOR CARE

Towards Quality End-of-Life Care

English Language Version (English Language Transcript)

Video briefing for health policy, health delivery system, clinical and community leaders

Running time 16:50 (with credits)

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DYING FOR CARE – TOWARDS QUALITY END-OF-LIFE CARE

English Language Version (English Language Transcript)

INTRODUCTION

In September 2005, a cross-section of leaders deeply knowledgeable about Hospice Palliative Care sat down with award-winning director Stephen Hall to share their reflections on a range of issues and challenges associated with transforming care for those experiencing progressive chronic illness and imminent life-limiting illness. *Dying For Care* is a 16 minute video briefing organized as a collage of those ideas. Within this narrative are images of people who have graciously opened their homes, hospital and hospice rooms to share imagery of their commitment to live well until end-of-life and other visual imagery that reminds us of the diversity of the populations for which we are accountable in Canada. This video briefing has been designed as a catalyst for local health policy, system delivery and clinical leaders - to stimulate and support dialogue on emerging issues and understandings about transforming care for those experiencing a life-threatening and life-limiting illness.

FIRST SCREEN UP

In 2003, 226,000 people died in Canada.

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By 2015, some 300,000 people will die annually.

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Canada remains poorly prepared for this emerging reality.

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To help system leaders and clinicians transform care,

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Hospice Palliative Care leaders share reflections and insights they have learned.

Dr. José Pereira - My personal experience was as a family physician in rural Manitoba in 1993. I was in my office, and on one particular day, a young man came into my office with his wife. He was in his mid forties, and it was the first time I had seen him in my practice. He sat down in front of me, and he looked very uncomfortable, and said to me that he couldn't live life like this anymore. He was living in severe, severe pain because he had metastatic colon cancer. And I vividly remember feeling extremely uncomfortable with the situation. And looking back, my discomfort was because I had never received any education in the area... And I asked him what he was on for pain, and he said that he was on morphine and on very small doses. But I knew no better so I said "I'm sorry I can't increase your morphine because you'll become addicted." And I remember him looking at me, getting up, and he began to cry and he said to me "I hope one day, as physicians, you can better look after us," and he walked out of the office.

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DYING FOR CARE

Towards Quality End-of-Life Care

Dr. Larry Librach - ...I had a young man who was 28, who, I found his cancer, and it was a very malignant cancer. He was absorbed by the cancer system. At that time, you know, you referred it to the oncologist and then you never heard about the patient ever again. Well I didn't hear about the patient until I was in my office and I got an urgent call from his wife, saying that they had just discharged him from the hospital and he looked terrible. I had no information about what was happening to him. I saw him and he was in absolute agony. Here was this vigorous young man, who was bald he had lumps all over him, and he was in agony. What I found out was that they had fractured his neck in the ambulance ride home. And so for me it was easy; I gave him a shot of morphine although I wasn't sure how much to give him, sent him back to the hospital and six weeks to the day later, I got another phone call from his wife saying they had discharged him again, and I found him in absolute agony in his home. He had had no pain control for six weeks... I gave him a shot of morphine and my hands were shaking

as I was thinking about giving him another shot of morphine because I was told morphine was dangerous and was I going to kill him. And as I loaded up the syringe, he died in front of my eyes. Well that was a Friday afternoon, I was absolutely decimated, and then on Monday I went to the College of Family Physicians annual meeting and the first speaker was Dr. Balfour Mount, and the first thing he said, I'll remember it forever, was that "People do not have to die with pain." And it was like the heavens opened up, it was my epiphany...

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These stories continue to play out every day, in communities across Canada

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they reflect systems that do not support long periods of progressive illness,

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or enable coordinated and comprehensive care.

Sandy Johnson - We as Canadians value our health care system and I think we believe that our health care system will be there when and if we ever need it for end-of-life care. We believe that the system, the programs, the policies, the health-care professionals have adequate training and that the system is properly resourced so that if we ever need it then it would be there for us. And I say if we ever need it, because I think that we as a society like to think that death is an option.

Sharon Baxter - I think the biggest misconception of Canadians is that they think those services are going to be out there, and it isn't until they come into contact with the health care system that they find that they aren't there. So they may not be able to get a palliative care bed in a long-term care facility, or they may not be able to get a residential hospice if there is no residential hospice in their community because they are only in a few of the provinces, and they don't necessarily get all of the home-support programs that they need in place to be able to do that.

Dr. Harvey Chochinov - The fact is that you might receive poor quality care, the person delivering care might deliver less than adequate care, and yet both parties feel that, well, death is difficult, death is painful, suffering is inevitable, and therefore, optimal care is never really provided.

Dr. Frank Ferris - Do you really want to wait until you're dying before I communicate effectively with you, before I manage your pain effectively? I don't think so.

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In 2002, the consensus-based CHPCA Model to Guide Hospice Palliative Care was released in Canada.

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This model holds that hospice palliative care is appropriate for any patient and family living with a life-threatening illness

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due to any prognosis at any age and when they are prepared to accept care.

Maryse Bouvette - Palliative care is not a place, it's a philosophy. It doesn't mean the wallpaper on the wall; it doesn't mean you know that special room with the flowers... But it's an attitude, it's an approach to care, it's a philosophy of care and it can be done everywhere.

Sharon Baxter - It isn't about the space, it's about having the physician, and the nurse, and the social worker, and the pastoral care, and the supports that you need as a family to be able to deal with this and that's what it's about.

Dr. Frank Ferris - We're actually talking about therapies to relieve suffering and give people the capacity to live their life to the fullest they possibly can, while they fight their disease. And, if they happen to get to the point where they're dying, that they'll die safely and comfortably, and their family around them, and they'll be able to complete their business, and close their lives, and that there will be people there to support their families afterwards. But the focus isn't on dying; the focus is on living, because most people want to live. And we can help them do that.

Patricia Porterfield - It's as if you had a pair of glasses, and one lens was really focused on the biomedical model that you want to do the very best health care for this person. So you want to do the best symptom management and just provide excellent health care. But the other lens is focused on the fact that this is also the person's human journey. And that living and dying is a natural phenomenon... And then we need to put this pair of glasses on and keep these lenses in focus in order to have a good, clear picture of what hospice palliative care is trying to do.

Dr. Frank Ferris - To me it's the concept of anticipating what's going to happen, planning for it, managing it, and walking with the families. And they do completely differently than those who don't get that kind of supportive care.

Wendy Wainwright - To really care well for the dying, there needs to also be a focus on wholeness and healing, and on the person. So if you will, it's rather than focusing on illness... which happens to be attached to a person, it's really starting from the place of the person, who happens to have an illness.

Dr. Jose Pereira - Often, when they hear the word palliative, they think this is the end. We're in the last few days or weeks of our lives, and it's very frightening. And I think one of the most important messages that we have to try to convey to the public is that palliative care is not just about dying. It's not just about the last few days or weeks of life. Palliative care is about improving the quality of life for anyone who has an advancing, progressive illness. But it can be many, many months and sometimes even years before the death. Palliative care is about celebrating life. Palliative care is about improving life.

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A failure to care for the seriously ill and dying reflects the limitations which permeate a health care system

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excellent care for those with progressive illness and the dying reflects a system's core strengths.

Sandy Johnson - If we are ever at a point in our lives when we might consider that we could possibly die some day, then we think we have control of when and how that happens. So we don't prepare ourselves, we don't do anything to talk about it with our families, to prepare for its eventual coming for us, we don't understand what's available for health care services, we don't focus on it, we don't deal with it because we think that we're going to control when it happens.

Harvey Chochinov - It's not something that usually becomes, you know, part of regular conversation. It is something that we know it's hidden in the corner, it's on the periphery, and that's pretty much where we want to keep it. Periodically things happen in our lives that bring it from the periphery into our more central focus of vision, and when that happens, I'd say one of the problems we have is that we know too little, and we expect too little. And, that's a dangerous combination.

Larry Librach - There's this myth around that if you talk about dying it somehow makes people live less. You know it reduces hope. And as one of my colleagues says, "Well, so if you get another couple of months, what are you going to do with it? What's the hope behind that if there's no cure?"

Sharon Baxter - Many years ago, they felt that you don't tell people that they're dying. Now I think we've finally convinced people that it is their right to know, but we don't always tell them they're dying early enough.

Frank Ferris - You know, so many people think that you have to go to a lovely place, and die in a lovely place... I mean the scenario I like to describe is the old mansion with grandmother in the window, the lovely vase of flowers beside, the family all around, her arms across her chest, lovingly surrounded by her family is hospice palliative care. I think the chance of most of us dying in that way is pretty slim.

Maryse Bouvette - The health care professionals, they are trained to cure. And so we're not well skilled to face this other end of life, which is death. In the last 40 - 50 years, we've learned one way of dealing with health, with the disease, with life, and with death. We've looked at death in a very specific way, so now we have to unlearn that.

Dr. Romaine Gallagher - So, many of us went into medicine to save people. So, for some people, it's really their own emotions, our own thoughts and feelings that we bring with us that may stop us from sort of seeing palliative care as a successful end to an illness.

Dr. Jose Pereira - Death represents a failure for health professionals. Therefore, because it's a failure, we walk away from it. I think that the other challenge is that we're never trained; we're never educated on how to engage someone who's dying or their family. And so because of that, if you're not sure how to do something, if you're not comfortable doing something, you don't do it. You walk away from it.

Shane Sinclair - One of the challenges is that we do have a false dichotomy in my mind between living and dying and I'd like to see that sort of merge where we're providing good palliative care for example, not only to people who are in their last stages of life but palliative care as a philosophy is embraced by all fields of medicine and it's something that is incorporated into every aspect of the care that we give.

Dr. Romaine Gallagher - We have curative or disease modifying therapy up to a point, and then we have the introduction of palliative care. That is why palliative care is always associated with

dying. And I even see lots of us, like if it's not our other colleagues, it's us! We are part of the problem because we say words like "when is the patient palliative? Oh, this patient is palliative," whereas we should be saying "When can someone benefit from palliative care services?"

Frank Ferris - It's getting the word out to people that they should begin to expect that they can ask for all those issues to be addressed by their health care team. And I think that's a huge shift. Now many people say to me "Oh, well we don't want to use the palliative care word, because that means the death service." And what I say to those folks is, is that I don't care what the word is, it's the, as part of your health care, as you as a Canadian, don't you want me to address the issues that are getting in the way of you living from day to day, so that we can do the best possible therapy for them as well.

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We are experiencing an increase in progressive illness and expected death

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how we address these issues will have a significant impact in the confidence of Canadians

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to know that systems and services will be there when they and their families need them.

Romayne Gallagher - Physicians should be hard wired to care, and they should be hard wired to provide whole-person care. And that may be cure, that may be disease modifying, that may be palliative. If that were the way they saw things, then I think we could work very cooperatively right from the start.

Larry Librach - When I first started in palliative care, we were seen as hand-holders. It was that denigrating sort of way of looking at palliative care. On the other hand, I don't think we should be going all the way to say that the essence of palliative care is pain and symptom management.

Sharon Baxter - There is an education piece that needs to happen with health care providers that aren't palliative care specialists. I think we need to do a better job of telling oncologists, and HIV and AIDS programs, and all these other programs, people that are dealing with seniors as they're aging, with heart disease, that what hospice palliative care can do, what it should be doing, and why you would want to refer those people to those programs early enough.

Larry Librach - We can actually reduce the costs to the system and utilize resources better, so I don't think that it's an either or

Romayne Gallagher – What we really need to get through to people is that palliative care can benefit them throughout their illness.

Dr. Jose Pereira - The important thing is to view palliative care as an integral part of the health care system. Palliative care is not just this small, specialization that's set aside. And when a patient is now dying, they get moved to a hospice or to a palliative care unit. Palliative care is an approach that's integral within the health care system. And so if all of us are practicing the good principles of palliative care, it becomes integrated.

Larry Librach - Compared to where I was in 1978, when I started in palliative care, to now, in the last five years we've seen a tremendous increase in those ques and I think we're not only coming of age, I think we're creating that niche and are starting to convince others around better care for the dying.

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In the end, the systems and supports that we help create today,

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are the ones that will help us live well during progressive illness and at end-of-life.

Hospice Palliative Care leaders (in order of appearance)*

José Pereira, MBChB, DA, CCFP

Chair in Palliative Medicine,
University Hospital (Cantons of Vaud/Geneva),
Lausanne, Switzerland

S. Lawrence Librach, MD, CCFP, FCFP

Physician Leader,
Canada's, Educating Future Physicians in Palliative & End-of-Life Care (EFPPEC) Project
Toronto, Ontario

Sandy Johnson

Executive Director,
Hospice Saint-John & Sussex
Saint John, New Brunswick

Sharon Baxter, MSW

Executive Director,
Canadian Hospice Palliative Care Association (CHPCA)
Ottawa, Ontario

Harvey Max Chochinov, MD, PhD, FRCPC

Canada Research Chair (CRC) in Palliative Care
University of Manitoba/Cancer Care Manitoba
Winnipeg, Manitoba

Frank Ferris, MD

Principal Developer/Lead Author,
CHPCA Model to Guide Hospice Palliative Care
San Diego, California

Maryse Bouvette, BScN, MEd, RN

Co-Chair,
National Working Group on Education for Formal Caregivers,
Canadian Strategy on Palliative & End-of-Life Care
Ottawa, Ontario

Patricia Porterfield, MSN, RN

Clinical Nurse Specialist,
Vancouver Coastal Health Region
Vancouver, British Columbia

Wendy Wainwright, MEd

Member, Board of Directors
Canadian Hospice Palliative Care Association (CHPCA),
Victoria, British Columbia

Romayne Gallagher, MD, CCFP

Co-Chair,
National Working Group on Public Information and Awareness,
Canadian Strategy on Palliative & End-of-Life Care
Vancouver, B.C.

Chaplain Shane Sinclair, PhD(C)

Hospice & Palliative Care Service,
Calgary Health Region
Calgary, Alberta

* Producer's note: For production value purposes, where a HPC leader has multiple local and national leadership roles, the national leadership role has generally been listed in the credits of this production.