



**CHPCA/APCA NEW PROJECT IN AFRICA:  
PALLIATIVE CARE DELIVERY FOR PEOPLE  
LIVING WITH HIV/AIDS IN AFRICA:  
EMPOWERING MEN TO  
REINFORCE THEIR ROLE AS CARE GIVERS**

**Background**

Early in 2006, a new and exciting project was initiated through a partnership between the Canadian Hospice Palliative Care Association (CHPCA) and the African Palliative Care Association (APCA). The project is entitled "Empowering Men In Five Sub-Saharan African Countries As Care Givers Through Training And Education To Enhance The Scale-Up Of Palliative Care For People Living With HIV/AIDS In The Region."

This pilot project is the first of its kind in the region. It is an effort to recognize men as key stakeholders in palliative care delivery and empower them to undertake new roles traditionally held by women and female children.

The project has three levels of partnerships, namely:

- ♦ Between the CHPCA and the Canadian International Development Agency (CIDA), the Canadian Society for International Health (CSIH) and Interagency Coalition on AIDS and Development (ICAD)
- ♦ The CHPCA and the African Palliative Care Association
- ♦ The African Palliative Care Association and five national

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**CHPCA APPROVES  
PHYSICIAN ASSISTED DYING ISSUES DOCUMENT**

The Board of Directors of the Canadian Hospice Palliative Care Association has recently approved a Physician Assisted Dying (PAD) Issues Document. This document replaces the out-dated "Euthanasia and Assisted Suicide" document of 1997. It can be found in the "Public Policy and Advocacy" Section of the CHPCA web site at [www.hospicepalliativecare.ca](http://www.hospicepalliativecare.ca).

The Board of Directors gave much thought to not only the content but also to an adequate process to bring an issue as complex as this to an organization-wide position statement. Having a membership of 3,000 brings great benefit and strength to an association but can be challenging to achieve consensus on a universally accepted Position Statement.

The CHPCA Board believes that, while it may be difficult at the moment to take an absolute position on this issue on behalf of the entire membership, there are values (as enunciated in our Canadian Model document) which we strongly and unanimously support in our quest to ensure universal and timely access to quality hospice palliative care. Further, the Board of Directors recognizes CHPCA's leadership role in providing information and guidance to the membership and general public, including resources where members and Canadians may further educate themselves about the current and ongoing aspects of the debate. The PAD Working Group thus

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*The Pallium Project works to improve and enhance Hospice Palliative Care-related access, quality and local/delivery system capacity by linking, supporting and enabling collaborators at, and across, local, provincial/territorial and national levels.*

*From 2004-September 2006, the Project worked with several hundred collaborators in Canada's 13 provinces and territories to implement Pallium Project (Phase II).*

*Phase II was supported by a \$4.3 million contribution from Health Canada's Primary Health Care Transition Fund (PHCTF) and extensive in-kind contributions at the service delivery systems' level. Local champions contributed to 72 subprojects, initiatives and strategic capacity-building activities for Hospice Palliative Care.*

*In September 2006, the CHPCA awarded The Pallium Project the Canadian Hospice Palliative Care Leadership Award.*

*In this interview with AVISO, Pallium Project co-founder and Phase II director of initiative development Michael Aherne looks back on the Phase II project and discusses the future of the Pallium Project.*

## **Q : Why was the Pallium Project created?**

**A :** Looking back, I think the Project emerged as a typically Canadian response to too few resources, too much geography and a deep passion amongst many to improve care of the dying irrespective of where they live in Canada. In the early days, we were focused on what we call the "3Cs." That is, coordinating scarce educational resources on the prairies and in northern Canada, collaborating amongst different palliative care referral programs to develop new educational responses for colleagues in primary-care settings and communicating with colleagues to reduce duplication of efforts and build on each others' strengths.

## **Q : How did the Project's focus change in Phase II?**

**A :** There was a three part emphasis on access, quality and capacity-building in Phase II, as well as a deliberate move beyond education issues to a more balanced approach to investing in service, program and systems development issues. That is, the Project focused on increasing access to Hospice Palliative Care services at the community level while also doing some tangible things to enhance quality and help build the capacity of existing local and provincial/territorial systems to improve care delivery.

## **Q : Access and quality are terms used so often in health care they've become seen as having little real meaning. What do access and quality mean for the Project's work?**

**A :** Fair point about the currency of the language. Improving access really played out four ways in Phase II. An underlying assumption in project design is that people are dying whether we are doing active palliation or not, so colleagues working within various primary-care settings such as private physician office practices, home care, hospice, long-term/continuing care and community-based small hospitals can provide much better palliation with consistent training, a robust set of tools and supports for access to consultation. This is the first face of access and is typically referred to as a "shared care" model. So the focus of this pathway has been to start building up knowledge and skills within the existing primary-care workforce as a basic strategy for improved access.

The second part focuses on improving the linkages between primary-care colleagues and palliative care specialists within larger regional and major urban centres. If primary-care providers are going to do more of this work they need to be properly supported. That's often something as simple as feeling they have permission to call a colleague who might have been a facilitator in a Regional Weekend Course the person attended. This is an area where we have much more work to do in the country to build robust linkages and sanctioned models of shared care within and across health regions.

The third part is access to "after hours" care. We have a serious challenge in Canada with those people who are trying to successfully stay in their home or elsewhere in the community as their preferred setting of care, especially when they are nearing the end of their life. For the most part we are consistently doing a poor job of having supports available to help families through the night once home care offices close for the evening. Dying and caring for the dying is hard work. It can be frightening and disconcerting if you feel or indeed are alone in the task. What I don't think many health services administrators appreciate is how quickly things can happen, particularly when someone is in the few last days or hours of life. So, we hope that the health regions and provinces and territories will take a good hard look at what they are doing to support families and patients on a 24/7 basis. I think we have a good start with the early leadership we've seen out of British Columbia in particular, in that they have helped greatly with the thought leadership/way forward in the *HPC Telenursing Protocols for Existing Health Call Centres* as an early first-step.

The fourth part of access is doing a better job with people who have been, or who are at risk of being, marginalized by health delivery systems. I for one really had my eyes opened to the local impact of how Aboriginal health services for on-reserve First Nations are organized and funded and how that often serves as a barrier to local collaboration with provincial and territorial health services. We are also challenged to be more thoughtful about our own baggage. There are many providers within Canada who continue to let their personal prejudices about Aboriginal people interfere with their duties in law and professional regulation. That has to change. I think the Project has demonstrated some useful early pathways for moving forward in building and keeping relationships with Aboriginal people to support improved access to HPC.

Working with the representative of the Canadian Association of the Deaf on the Quality End-of-Care Coalition of Canada (QELCCC) also made me aware that there is much more that we can and should do to make our resources accessible for the deaf, the hard of hearing and those who are visually-impaired. We started to experiment with ways to do this, such as in our *Dying for Care* communications video, which comes with English and French language screen captions. There is clearly more to do and with a little thought and creativity it can be done without being prohibitively expensive.

In Phase II we also supported some early exploratory work on culture and early intervention in dementia-related decline with four distinct cultural cohorts. The big learning for me, in the context of the Muslim and Chinese communities studied, is that for many, care of family members with a progressive illness or who are near death tends to be kept directly within the family. Yet so many of our current pathways for getting resources and supports to families is through some form of institutional engagement or interface with health authorities or community hospice organizations. In

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this instance, access takes the form of finding those pathways to get HPC information and resources to family caregivers, while respecting the choices of patients and families to undertake care as grounded in long-established cultural protocols.

As for the quality question, I think that well-known health system commentator Michael Rachlis has really helped greatly here if we are prepared to listen. The Project uses Rachlis' approach of quality as the over-use, under-use, mis-use of health system resources. That is, if heroic measures are being used to unduly extend life and in the process proliferate pain and suffering there is an over-use scenario. If a provider is not adequately recognizing and treating physical pain and symptoms or if they are not involving a broader range of team resources to deal with suspected existential suffering then there is likely quality issues associated with under-use of resources.

Finally, if you have a case where there has not been good training on use of medications in the home, or families or patients are not complying with a prescribed medication regime and end up with an otherwise unnecessary and lengthy hospital admission due to an opioid-induced delirium then there is clearly a mis-use issue. These are quick examples for clarity, but I think if more of our programs and services started with these three criteria to frame quality issues, structured regular review processes and built their continuous improvement processes around these simple but powerful concepts that much could be done to mitigate preventable suffering and improve resource utilization. To me that is fundamentally what a good working definition for quality in HPC is about.

**Q : Many people in Canada think the Pallium Project has been a continuing education project. You talk a lot about capacity-building. What is the difference?**

**A :** Clearly the Project started its life as an applied research project in Continuing Professional Development (CPD) for rural and remote primary-care professionals. But just as we are challenging primary-care providers to learn, grow and change, so too does the Project have to learn and change as it better understands the context in which it operates and the opportunities for contribution.

Whereas the Project did start out with an education focus it became quite clear by the end of Phase I that continuing education is only one tool in the tool box of responses we need to achieve quality end-of-life care in Canada. Developing Hospice Palliative Care in Canada is a complex equation of people, systems, policy, funding and organizational change and renewal. If the Project stuck solely with the people change focus and continued to only do more professional development, it was predictable we soon would be contributing to the frustration of primary-care providers who now knew they could and should be doing things differently, but were not able to because of systems and systemic barriers in the workplace and community.

The capacity-building concept is really one of recognizing that there are resources already existing within communities and health and social systems that can be tapped and further developed. It also considers that there are many things we need to either change or build within the systems in which people work, live and are governed so that quality end-of-life care for all people in Canada can be a sustainable proposition.

**Q : You often talk about Phase II comprising some 70 subprojects and initiatives. How was it possible to do that volume of work in 2 ½ years?**

**A :** I think three things made it possible. First was the "framework" approach we used in our Phase II project proposal as approved by Health Canada. We committed to a framework of high-level activities that would address the PHCTF Common Objectives and National Envelope Objectives. Second is a project management approach and a genuine belief by our stakeholders that "many hands can make light work." A project

approach meant people knew more or less what was expected for their contribution, when it was expected, the expected outcome and the predictable local and mutual benefits. That approach created opportunities for people to go back into their organizations and negotiate participation. The promise of investing a little now and get back a lot later appealed to many.

The Phase II project also came at a time where there was much happening locally and it presented a promise of sharing local innovation with others in the country. As a result people were prepared to spend some time and energy to move that forward for the benefit of the country if the Project was prepared to invest some resources and assistance.

Finally, there was simply a good energy about the Phase II project. Looking back, there were so many things that went right and so many things that could have gone wrong and didn't. I have come to appreciate that there is a serendipitous energy about Hospice Palliative Care and a tremendous amount of goodwill for the work. We had local collaborators, seconded staff, project staff and many external suppliers who consistently and repeatedly went beyond the call of duty because they could see that helping build HPC capacity was good, noble and necessary work. The deadlines imposed by the one-time Health Canada funding for Phase II also created a sense of urgency and focus which really moved things along at a very frenetic pace.

**Q : What difference do you think that Phase II has made?**

**A :** The evaluative process tells us that it has really raised the profile and credibility of Hospice Palliative Care at the local level, especially in western and northern Canada. The simple fact that the Government of Canada would see fit to invest \$4.3 million to help transform better care of the dying in primary-care settings has been an important symbolic contribution.

I think it's also helped address some of the isolation many feel in doing HPC work locally. It has created a sense that "I am not alone in this work" by many at the local level. More people now know each other, their capabilities, their interests, their innovations, their service and program models, including what's working and what isn't. They are learning from, and sharing with each other. There's a real sense of community that has been furthered in Phase II.

More practically, we have been able to make a series of thoughtful investments in "stuff" that people will be able to use in their education and program development work well into the foreseeable future. We have a whole range of new and renewed resources that with a little thought, planning and skill people can take "off the shelf" and incorporate right into their education and program development work.

**Q : What difference do you think that Phase II might make into the future?**

**A :** This country was built coast-to-coast-to-coast on the idea of people working together. Of that there is no question. We have endured as a country and Canada works in spite of itself and various regional differences because we have periodically had great national projects that bring us together to contribute to a common cause.

And while I am not suggesting the Pallium Project is one of those great national projects, my hope is Phase II demonstrates that there is a continued need to work together which accrues desired benefits both locally and nationally. For those involved, I think Phase II has also reinforced that we can produce much better outcomes and processes if we work together rather than trying to go it alone. That won't always be possible, but where there are opportunities to work together

constructively it encourages us to do so. Reinforcing the spirit that greater collective benefits can accrue from working together rather than alone and having the demonstrated Phase II results as something tangible is important proof-of-concept.

Phase II also reinforced and contributed to the foundation of sustainable and integrated Hospice Palliative Care within existing delivery systems. Phase II complements the work that has been done by the Canadian Strategy on Palliative & End-of-Life Care and others, but I think it has really provided a robust set of ideas and tools for people to take up locally.

**Q : You talked earlier about the local capacity-building aspect. What are some of the tangible things that people can take away to help build better local responses?**

**A :** Yes. They say in Canada that all weather and politics is local, which I take to mean that is where the action really happens and the impact is most often felt. I think the same can be said for the planning and provision of direct care. The Project has worked with a variety of partners to create a set of educational, decision support and program development resources. These range from suggested curricula and modular instructional resources in several areas through to handbooks, instructional media, reminder resources and various program development support. These are outlined in a Phase II Operations Summary Report that people can download in PDF format from the main page of the Pallium Project web at [www.pallium.ca](http://www.pallium.ca) and in our stakeholder report back video, *The Pursuit of Possibility*. Other resources are available through the CHPCA Marketplace and several are available under the PHASE II link at [pallium.ca](http://pallium.ca), but the “road map” for this is the Phase II Operations Summary Report document.

**Q : There’s a lot of talk about the Pallium Project’s being rooted in its original Health Canada innovation funding. What are some of the innovations from Phase II?**

**A :** I think there are many process and product innovations that we will be writing about for some time to come. The major process innovation in Phase II is the Community of Practice (CoP) concept. That being there are communities of people who share similar interests and goals and wish to work together to advance them. That can be and was actively nurtured and supported. In return those who collaborate expect to be able to share in the overall products of the collaboration as a reciprocal benefit from the investment of their time and resources.

Another process innovation of note is the adoption of end-user licensing models for the local uptake and use of instructional resources. That is, a “right to use” the materials flexibly under a set of terms and conditions outlined in the license agreement for each resource. We went this way to make the instructional resources available at the cost of production and distribution because Health Canada essentially paid for or “underwrote” the product development investment. This means in most instances when people are purchasing a licensed product through the CHPCA Marketplace they are paying only 10 - 15% of the actual cost of its overall development. As a result we wanted to find a way to make sure that resources developed with a public investment are used and managed to advance an important public interest as much as possible.

So, we have made the Phase II resources available at this very low cost in Canada to those who are duly qualified users working with accredited education, health care delivery/community hospice and professional associations. The licensing approach also means that we are proactive about permissions for use of copyright protected materials. That is, people have a “right to use” materials in a variety of local instructional applications without constantly having to seek permission from the Project to do so. This is an important innovation

at a time when educational and health service institutions are becoming much more concerned about proper use and management of intellectual property. We are trying to break down barriers to the proper use of intellectual property and make it easy for people to adopt the resources locally.

The Project has also been on the leading edge of developing and using new learning technologies to support workplace and just-in-time learning. There has been great interest in the use of the socio-drama based instructional videos as a teaching tool to help working professionals explore attitudinal and other complex care issues through large and small group discussion. The Project has among the first professional development audio and video “pod casts” in the country and is actively exploring ways to partner with others to ensure more local awareness and adoption of these tools. We have been told by others that we are on the cutting edge of developing and deploying new learning technologies. We hope the novelty of the innovations can help interest other clinical leaders in the content and issues and demonstrate that Hospice Palliative Care is on the leading edge, with the opportunity to use the process innovations as a way to introduce HPC content in a non-threatening and more integrated way.

**Q : What was the biggest surprise for you in Phase II?**

**A :** There were many surprises, but if forced to rank a biggest one, it would be the phenomenal uptake of the monthly Continuing Professional Development audio-conference program. There were many in the early days who told us a telephone-based, professional development event was archaic and we should be using video-conference based, tele-health. The current reality, however, is the telephone remains the most accessible and familiar learning technology for most working professionals in our country. I thought it was going to be successful, but to regularly have had several hundred people from as many as 12 provinces and territories simultaneously participate in a live telephone-based event month after month was the biggest surprise for me.

That program also had an unexpected symbolic importance which I didn’t expect. When you could hear one question originating from participants in Whitehorse and the next question coming from Halifax, it was a tangible expression that people throughout the country care deeply about and are bound together in the work. So many people have said to me that it helped reduce the sense of isolation that they felt. That is, it reinforced the sense that they aren’t alone in this work, that they have colleagues throughout Canada who are experiencing similar challenges and issues and that we are all in this together. In that sense it was energizing.

**Q : Over the last three years you have been coast-to-coast-to-coast working with stakeholders. What have you learned and do you have any major concerns?**

**A :** I am deeply impressed by the degree of compassion and concern that people have for each other wherever I go. It’s simply remarkable. When I was an air cadet, there was this saying I learned that went “we the willing, working for the ungrateful have done so much for so long, we are now qualified to do anything with nothing.” I often thought about that in my travels. There is a tremendous resourcefulness that people are demonstrating amid many management teams and governments that do not yet fully understand or appreciate the contribution that well-designed and implemented Hospice Palliative Care can have for improved quality-of-life, economic wellness and better health system utilization. This has really impressed me, but also informs many of my concerns. I actually have a list I’ve started to call my “Big 5” concerns which have emerged from my personal learning in Phase II.

Chief amongst these is continuity of care. The Quality End-of-Life Care Coalition of Canada (QELCCC) has identified five settings of HPC as home, hospice, hospital, long-term/continuing care and settings of marginalization such as the street or prison. I know of no jurisdiction or

delivery system in Canada which is currently addressing the coordination of care well across those various settings. Patients and families have issues and problems and delivery systems have at least three or four big stove pipes - home care, hospitals, hospices and long-term/continuing care. The single biggest challenge we have before us in the next decade on the systems side is seamlessly managing across settings of care in order to see that HPC issues as set out in the CHPCA Norms of Practice are addressed safely, effectively and ethically.

Compounding the continuity of care problem are health human resource (HHR) problems I think many of us know are coming, but do not fully understand. They manifest across the provider spectrum, ranging from having sufficient home care/personal care aide staff right through to sufficient people with critical clinical skill sets to do teaching, consultation and complex services. The shared care model I previously discussed can only be effective if we have the right resources with the right skills at the primary-, secondary- and tertiary- levels of delivery. I am deeply concerned that the combination of an aging population and an aging health workforce will have a “double whammy” effect on our ability to build and sustain responsive HPC at the local-level. This is why I think it’s critical that we build on the Primary Health Care model to widen the circle of those who could potentially be involved in HPC. We need to be investing in renewal of our existing health human resources, building for the future and tapping new sources of partnership and energy within our communities.

I am also concerned about the risk that the Project might unduly contribute further to medicalization of the dying if we are not very thoughtful about how we go about what we do. I think Patricia Porterfield, a Clinical Nurse Specialist from Vancouver, has addressed this very nicely in the *Dying For Care* video, when she notes that good Hospice Palliative Care requires two sets of lenses - one which recognizes that we want to do the very best health care for the person to help manage pain and symptoms and a second lens which acknowledges that dying is part of our human journey, and that we need keep that pair of glasses on and in focus in the care we offer and supports we provide.

The Project has helped develop some robust tools in Phase II to help primary-care clinicians, but there are still many other practical and life-closure supports that require attention. My concern is that the early emphasis on improved pain and symptom management doesn’t come at the expense of excluding many other capacities that have yet to be more fully developed.

In the last year, in particular, I have also become deeply concerned about the co-opting or substitution of Hospice Palliative Care language as introduced by the 2002 Norms of Practice to otherwise describe end-stage, palliative services or what most often think of as palliative care. The 2002 CHPCA *Model to Guide Hospice Palliative Care Based on National Norms and Principles* is a really robust and future focused model. It’s one which potentially puts Canada in a good leadership position to respond thoughtfully to a range of chronic progressive illness and after-death supports. It’s ideally suited for many of the emergent Population Health challenges we face.

What I see a lot of people doing, however, is “the same old stuff” and calling it Hospice Palliative Care. This has driven an evolution in my own thinking. I now describe the period of the early evolution of palliation in Canada from the 1970s to 2002 as the first generation of palliation in Canada. I think the introduction of the Norms of Practice in 2002 ushered in a second generation of potential Hospice Palliative Care responses. We need to celebrate the early pioneers and their work and contribution, but focus on building second generation solutions for our rapidly changing population.

Right now most providers are populating a relatively small part of the continuum of the role of Hospice Palliative Care in the form of end-stage, palliative services. The risk here is that many of the issues that could be addressed earlier in an illness trajectory don’t get addressed until very late

in the game, if at all. The 2002 Norms of Practice, consensus developed document opens the door to much earlier and broader involvement. In Phase II we have tried to demonstrate how this can be done with the *Driving, Decline and Dignity-maintaining Responses (3D)* subproject. This is a subproject which addresses some of the public safety issues associated with progressive dementias and the reality that we are entering an age of “retirement from driving” as one of the early and difficult life closure tasks. At the same time we have been supportive of the early leadership demonstrated in Regina, which has shown practical ways to make bereavement a more inclusive community accountability in support of improved Population Health, such as decreased distress and mental illness associated with loss.

My final concern of the “big 5” is what I have spoken about to many in the country as a “Field of Dreams” phenomena, which is somewhat analogous to the 1980s Kevin Costner baseball movie. In that movie there is a famous line which goes “if you build it, they will come.” In Hospice Palliative Care I think we need to be reframing that as a question and asking “if we build it, will they come?” This really focuses on the broader societal issue of working with our publics to help them plan for, and engage, the universality of dying and death as core to our human condition. There may be little that services and programs can do if patients and families are not prepared to engage. Increasingly we recognize the positive benefits that can come both from advanced planning and advanced care planning, but those benefits can only accrue when people are prepared to responsibly engage the issues associated with end-of-life.

**Q : There has been much talk about legacy from Phase II. What does that look like to you?**

**A :** Well I have talked about much of this already. I think there is a legacy which demonstrates there are different ways to do business which tap underused energy and enthusiasm in people to work together to get important things done. There are new educational and program development resources that we did not have three years ago and critical re-investments made to others, such as the *CHPCA Home Support Worker Training Kit* and the *99 Common Questions (and More) About Palliative Care: A Nurses Handbook*. There is also a critical mass of people, albeit mostly in western and northern Canada, who feel more confident in their ability to teach about Hospice Palliative Care and who are working to develop others. Finally, I think we have a good “road map” as to how we can build community-capacity in a variety of health services area and work together to create badly needed resources while respecting the time of busy practitioners and volunteers.

**Q : Will there be a Phase III?**

**A :** That’s a question I get asked a lot. I think the most appropriate answer is to say that it’s something which has yet to be negotiated. So stay tuned! To this end, the Phase II Project Steering Committee directed us to complete a Phase III Feasibility Study with stakeholders prior to the end of spring 2007. Clearly there is a lot of interest and energy for a Phase III. Some feel that they have not fully achieved the benefits presented by Phase II in terms of outreach education and professional development. Others feel there is important work to build up additional resources to better support psychosocial aspects of care as well as volunteer development.

I think what we have to sort out is what might a Phase III look like, who would be involved, how would it be resourced and what contributions could it make to HPC. Clearly there is a lot of work left to do and much energy to see it move ahead. I kind of see us in a similar place as to where we were between Phase I and Phase II, except that that the expectations are a lot greater this time around. People who are interested in the Phase III Feasibility Study can find out more information about it at the Pallium.ca web under the Current Events link.

