



HOUSE OF COMMONS
CHAMBRE DES COMMUNES

Ottawa

Room 578
Confederation Building
Ottawa, Ontario
K1A 0A6
Tel: (613) 995-3611
Fax: (613) 995-3612
Uppal.T@parl.gc.ca

Constituency

141 Seneca Road
Sherwood Park, Alberta
T8A 4G6
Tel: (780) 467-4944
Fax: (780) 449-1471



Tim Uppal

Member of Parliament for
Edmonton—Sherwood Park
Député de Edmonton—
Sherwood Park

Ottawa

Pièce 578
Édifice de la Confédération
Ottawa (Ontario)
K1A 0A6
Tél.: (613) 995-3611
Télééc.: (613) 995-3612
Uppal.T@parl.gc.ca

Circonscription

141 Seneca Road
Sherwood Park (Alberta)
T8A 4G6
Tél.: (780) 467-4944
Télééc.: (780) 449-1471

October 4, 2010

M.J. (Mike) Aherne, Med, CMC
Pallium Project
Box 60638, U Alberta RPO
Edmonton, AB T6G 2S8

Dear Mike,

I am writing to invite you or someone from your organization to participate in a national dialogue regarding Canada's palliative and compassionate care systems.

The non partisan Parliamentary Committee on Palliative and Compassionate Care (PCPCC) has been conducting local hearings as part of broad national consultations. On the committee's behalf, I will be hosting a round table at 9:30 a.m. on Saturday, October 23rd, 2010 at Sherwood Park Alliance Church, 1011 Clover Bar Road, Sherwood Park, AB.

For your benefit and information, I have enclosed a copy of the PCPCC Declaration Statement, the PCPCC Public Hearing Framework, and a proposed agenda for the round table.

You would be speaking to one of the four "pillars" under PCPCC's umbrella: palliative & long term chronic care, elder abuse, suicide prevention, and the rights of persons with disabilities. **Please try to focus primarily on recommendations that will lead to improved care in the pillar you are addressing.** Please be aware that you may need to share your time with another person speaking to the same pillar. I would also ask that you submit a written brief which I will forward to the committee along with notes recorded from your presentation.

Whether or not you are able to attend, I would appreciate hearing from you in writing on these issues. Your thoughts, expressed in a letter, email, or brief will be invaluable as we move forward. Your submission can be any length, however longer documents should be accompanied by an Executive Summary of no more than 2 or 3 pages.

Please contact Cathay, my constituent assistant with any questions and to let me know if you will be able to attend. Her email address is uppalT1A@parl.gc.ca or she can be reached at 780-467-4944. Please RSVP your intent to participate and the pillar you wish to address no later than October 18, 2010.

Sincerely,

Tim Uppal, MP
Edmonton - Sherwood Park



HOUSE OF COMMONS
CHAMBRE DES COMMUNES

Ottawa
Room 578
Confederation Building
Ottawa, Ontario
K1A 0A6
Tel: (613) 995-3611
Fax: (613) 995-3612
Uppal.T@parl.gc.ca

Constituency
141 Seneca Road
Sherwood Park, Alberta
T8A 4G6
Tel: (780) 467-4944
Fax: (780) 449-1471



Tim Uppal

Member of Parliament for
Edmonton—Sherwood Park
Député de Edmonton—
Sherwood Park

Ottawa
Pièce 578
Édifice de la Confédération
Ottawa (Ontario)
K1A 0A6
Tél.: (613) 995-3611
Télé.: (613) 995-3612
Uppal.T@parl.gc.ca

Circumscription
141 Seneca Road
Sherwood Park (Alberta)
T8A 4G6
Tél.: (780) 467-4944
Télé.: (780) 449-1471

BACKGROUND NOTE TO THIS PACKAGE

October 4, 2010

M.J. (Mike) Aherne, Med, CMC
Pallium Project
Edmonton, AB

① MR. AHERNE SUGGESTED TO MR. UPPAL'S OFFICE THAT AN ARTICULATE, REFLECTIVE PERSON FROM A RURAL LOCALE WITHIN OR NEAR EDMONTON-SHERWOOD PARK AND LIVING WITH A NON-CANCER SERIOUS ILLNESS FILL THE PALLIUM/MR. AHERNE SLOT ON THE OCT 23/2010 P.C.P.C.C. PANEL.

Dear Mike,

I am writing to invite you or someone from your organization to participate in a national dialogue regarding Canada's palliative and compassionate care systems. **ENVIRONMENTAL INSTITUTIONAL IN EDMONTON.**

The non partisan Parliamentary Committee on Palliative and Compassionate Care (PCPCC) has been conducting local hearings as part of broad national consultations. On the committee's behalf, I will be hosting a round table at 9:30 a.m. on Saturday, October 23rd, 2010 at Sherwood Park Alliance Church, 1011 Clover Bar Road, Sherwood Park, AB. **③ MS. BROOK'S WRITTEN NOTES FOR THE PANEL ARE APPENDED**

For your benefit and information, I have enclosed a copy of the PCPCC Declaration Statement, the PCPCC Public Hearing Framework, and a proposed agenda for the round table. **ALONG WITH THE T.O.P. FOR THE P.C.P.C.C. AND LOCAL PANELS.**

You would be speaking to one of the four "pillars" under PCPCC's umbrella: palliative & long term chronic care, elder abuse, suicide prevention, and the rights of persons with disabilities. Please try to focus primarily on recommendations that will lead to improved care in the pillar you are addressing. Please be aware that you may need to share your time with another person speaking to the same pillar. I would also ask that you submit a written brief which I will forward to the committee along with notes recorded from your presentation.

Whether or not you are able to attend, I would appreciate hearing from you in writing on these issues. Your thoughts, expressed in a letter, email, or brief will be invaluable as we move forward. Your submission can be any length, however longer documents should be accompanied by an Executive Summary of no more than 2 or 3 pages.

Please contact Cathay, my constituent assistant with any questions and to let me know if you will be able to attend. Her email address is uppalT1A@parl.gc.ca or she can be reached at 780-467-4944. Please RSVP your intent to participate and the pillar you wish to address no later than October 18, 2010.

Sincerely,

Tim Uppal, MP
Edmonton - Sherwood Park

UPLOADED TO
Pallium.ca WEB
BY MICHAEL AHERNE

PH-780-413-8195

FEBRUARY 2011

Parliamentary Committee on Palliative and Compassionate Care

Round Table – DRAFT Agenda

OCT 23, 2010

Tim Uppal, MP Edmonton – Sherwood Park

			Time Frame (minutes)
Introduction	Hosting MP, Tim Uppal	MP	3
Introduction	Review of Agenda	MP	3
Introduction of participants	All members in room	1 minute each contributing party	10
Overview of Round Table	<ul style="list-style-type: none"> - Goals of discussion - Review theme of PCPCC - Emphasis focus on recommendations 	MP	7
Discussion - Pillar 1	Palliative Care <ul style="list-style-type: none"> - Presenter (s) - Tabling of Briefs 		20
Discussion - Pillar 2	Elder Abuse <ul style="list-style-type: none"> - Presenter (s) - Tabling of Briefs 		20
Break			5
Discussion - Pillar 3	Suicide Prevention <ul style="list-style-type: none"> - Presenter (s) - Tabling of Briefs 		20
Discussion - Pillar 4	Disability Issues <ul style="list-style-type: none"> - Presenter (s) - Tabling of Briefs 		20
Wrap up	<ul style="list-style-type: none"> - Commonalities - Review of all notes - Describe follow-up - Thank participants 		15
Q & A			
Photo Opp			
Total			2h15m

Ms. Brook's WRITTEN
NOTES OF OCT 23/2010,
USED TO SUPPORT HER
PANEL STATEMENT.

**October 23, 2010 Presentation for Palliative and Compassionate Care Round
Table Panel Discussion with Tim Uppal, MP in Sherwood Park, Alberta**

Presented by

Nancy Brook, Ryley, Alberta

Citizen; Public Member for Health and Wellness Disciplinary Hearings

As you read my personal story, please remember that this is only one of many personal stories that could be told by any number thousands of citizens in Alberta or across Canada. At the time of writing and presenting my story there were 765 acute care beds in hospitals occupied by people waiting for long term care, and behind them is a list of 1,400 more people on waiting lists for long term care in Alberta.

October 23, 2010 Presentation for Palliative and Compassionate Care Round Table Discussion in Sherwood Park, Alberta

Presented by Nancy Brook

Thank you for inviting me to speak with all of you about Palliative and Compassionate Care today.

I'm Nancy Brook and my husband is Arnold [REDACTED]. He was diagnosed four years ago with Severe Mixed Dementia. He was in a Secure Designated Assisted Living facility until Monday of this week.

We have no children, and he has only one sibling, a sister who is retired and has been exceptionally generous in her support with all aspects of his care.

Four years ago, when my husband was diagnosed, I entered the gateway to caregiver Hades, and about four months ago I entered the ninth and, I hoped, the final level of caregiver Hades. It's called "The Hunt for Long Term Care".

I almost didn't make it to this discussion today, because on Monday, while I was researching and preparing my presentation, the phone rang. It was The Designated Assisted Living Facility calling to tell me that they had sent Arnold to the Royal Alex hospital. I dropped everything, including this presentation, so I could make the one and half hour trip into town to attend to the emergency. It was one of the many emergency trips I'd had to make over the last four months.

This time, Arnold's behaviours and needs had finally become too much for the facility and its staff to handle. We had spent four months trying to find a facility that could and would take him... we failed... there was no room anywhere, or at least there was no facility that would take someone in Arnold's present stage of Alzheimer's. In the meantime, we tried to find short term placement with facilities and accommodations better equipped to care for him until we could find long term placement for him. We tried rural facilities like Rose Haven in Camrose, this facility was closer to me and would have been able to accommodate his needs, but they wouldn't take him. Then we explored facilities in Edmonton, but we were turned down... no one wanted him. The excuses I heard ranged from not enough room for him to not enough personnel to care for someone in Arnold's condition.

During this process, the facility that Arnold was in, headed up the search and they were as frustrated as we were with the process and the lack of facilities. They worked very hard to help and promised his sister and me that they wouldn't evict him, and they would do their best to get him placed. But on Monday, after four months of endless interviews with numerous facilities and being repeatedly turned down, they didn't evict

him... they just called 911 and had him taken to hospital. They would later advise us that he wouldn't be allowed to come back.

When I arrived at the hospital on Monday evening, Arnold was on a stretcher in the hallway and attended by two paramedics.

I stayed with Arnold for a while, but he was getting restless and wanted to get up. The paramedics let him walk around with me for a few minutes. But Arnold was being kept in the hallway leading into emergency, and we were in the way. Finally, he had to be put him back on the stretcher.

Arnold was anxious and confused. He didn't understand what was going on. I helped the paramedics and we finally coaxed him back onto the stretcher. But Arnold refused to settle down. The paramedics decided to strap him in. It was clear in a matter of moments that this was going to go badly... very quickly.

I couldn't help. I couldn't watch. I left.

As I left, I knew that I had just been securely locked into the tenth level of caregiver Hades, and I thought about this presentation for today... the Non Partisan Parliamentary Committee on Palliative and Compassionate Care Round Table Discussion... and wondered how this horrifically broken system could be fixed. What was there that I could possibly tell you that you didn't already know and, for that matter, what could I suggestion to fix it. Then I wondered where I'd even find the time to write this presentation. I knew this week would be filled with many hours of travelling from my home to the hospital.

On Tuesday, I went to see Arnold. He had been admitted at two-thirty that afternoon. He had spent twenty-two hours in the emergency hallway. I wondered if the paramedics had stayed with him all that time. They had told me that he had to be supervised until he was admitted. They wouldn't leave him alone. I wondered if those two paramedics and an ambulance had been tied up looking after my husband for twenty-two hours...I don't know.

I walked through the ward, found his room, and entered. I almost fainted when I saw him writhing, groaning, and taking gurgling breathes as he aspirated his own saliva. His hands and feet were blue and swollen from being strapped to the railings of his bed. Since then I've tried very hard to erase the picture from my mind... but I couldn't. It will stay with me forever!

This was his palliative and compassionate care!? I suddenly discovered there's still another level of caregiver's Hades, and I'd just entered it.

From the beginning four years ago to today, this is just one story among many that I have to tell.

I could talk to you today about things like caregiver burnout. I could talk to you about providing a better and enhanced Home Care system.

I could tell you that we need more help rurally, and the Alberta Government will tell you that they have spent over 140 million dollars since 2005 doing just that. But in the end when I needed a place for my husband in the earlier stages of his Alzheimer's, it was two hours away from me. I'm in Ryley, Alberta, and my husband was in Warburg, Alberta. And then, when he needed more care, he was moved to a secure Designated Assisted Living facility in Edmonton, but at least that was closer, only an hour and a half away.

I could talk to you today about a number of different issues and solutions, but at this point I'd like to focus on the following.

There are many people who can't keep their loved ones at home even if they desperately wanted to... even with extremely good community support programs (which as of yet, we don't have) keeping a loved one at home is a wonderful idealistic idea, but in most cases it's not practical or possible.

"Aging in Place" programs and community based help programs are good ideas and needed, and will help to provide services, but we need more!

For those who can't be cared for at home, we need affordable care facilities and accommodations, and in particular, we need long term care facilities, AND we didn't need them yesterday... we needed them years ago.

I know that you are looking for and wanting suggestions on how to make the system better. And frankly, I wish I had more time to research suggestions and put it all in elegant prose, but time and energy are at a premium these days. So here's what I can offer at this time.

- 1) We need the creation of more long term care accommodations and we need them now. We might be able to accomplish this quickly and affordably by repurposing facilities that already exist. We are closing down schools in Alberta; maybe we should consider repurposing these facilities for palliative and compassionate care. The bonus here would be that schools are in communities already and they are close to home for many people, this means loved ones and friends are close at hand.

- 2) We need to staff our “care” facilities with well trained people. I’ve noticed that in many of the facilities I’ve looked at for Arnold’s care, there seemed to be issues on two levels regarding staffing. On one level there isn’t enough money to hire the amount of help that is required. On the next level, there seems to be a shortage of trained people to staff the facilities. We need to take measures to make sure there is enough funding to run care facilities properly, and we need to find a way to address the training issues. Finally, we need to find ways of attracting people into this field of palliative care at a grass-roots-hands-on level.
- 3) We need to provide caregivers with the financial means to stay at home with loved ones who need care. We need to investigate and implement caregiver financial support systems that would provide for people who want to and/or need to stay at home and look after their loved ones. Implementing a system that would provide financial support might help lessen some of the load on the health care system by adding more options other than using intermediate and long term care facilities.
- 4) And finally, for whatever systems that are initiated or set into place, please, please, reduce the paperwork – simplify it, streamline it, eliminate duplication, and provide ease of access to help. Simply put, remove all the garbage between caregivers and accessing the system. **Make it easier to get help!**

There is much more that I could say, and would like to say, but as you understand from my opening in this presentation, I’ve spent this week making day trips to the hospital to see my husband, while I’m still trying to earn a living. I’ve barely had the time and energy to write this and present it to you today.

I’d like to close now by sharing some goodbyes with you. I used to give Arnold a hug and a kiss. He’d look at me with his pale grey-blue eyes that still had a small spark of mischief in them. He’d give me his innocent rosy Santa-Claus- cheeked-smile, and after hours of not being able to put two words together that made sense, he’d say, “Can I go home with you.” After many of these goodbyes, I finally just decided to sneak off, and I knew that he’d forget my visit in a matter of minutes. And then yesterday, he lay heavily sedated to the point of unconsciousness, strapped securely to his hospital bed. He didn’t smile. He didn’t even know that I was there. I kissed his forehead, rubbed his arm, and prayed that God would take him home with him.

Thank you



Parliamentary Committee on Palliative and Compassionate Care Declaration Statement

The *Parliamentary Committee on Palliative and Compassionate Care* (PCPCC) is an ad-hoc multi-party group of MPs dedicated to the concerns of a growing number of Canadians for the quality and accessibility of care available to our aging population, the dying and persons with disabilities. Faced with deficiencies in Canada's palliative and compassionate care framework, PCPCC seeks to foster dialogue and substantive research on an array of related subjects; undertaking broad consultations with organizations and individuals from all parts of Canada.

Areas of concern to be addressed:

i) Palliative and long-term chronic care:

Canada faces a nationwide shortage of expertise and material resources in the fields of palliative, hospice, and home care. A recent study from the Canadian Cancer Society states, "Formal palliative care in Canada is a patchwork of services that varies significantly both within and between provinces."

Long-term chronic care is equally affected, with our health care system stressed by increased usage and limited resources. Family/home centered care giving, with adequate respite and support services, may be one direction to investigate as a means to both improving care relationships, and utilizing health care resources wisely.

Pain control also needs consideration, whether at end-of-life or for chronic conditions. Adequate pain control is a human right, and remedial efforts are essential if the health system is to deliver satisfactory pain control to the suffering.

ii) Elder Abuse:

The Government of Canada has recognized Elder Abuse as a serious concern. This hidden crime often goes undetected, with up to 10% of seniors experiencing various forms of abuse. Whether physical, emotional, financial or abandonment by families or institutions: elder abuse is a serious societal problem.

Also to be considered are the pressures on caregivers, and how they can be lessened through various forms of support; strengthening the caring relationship and the well being of our seniors.

iii) **Suicide Prevention:**

Suicide is a major problem in Canada, being responsible for 1.6 % of deaths nationally (3,743 deaths in 2005). The percentage is higher among certain groups and in certain regions of the country.

We intend to identify the issues and seek a framework for a national strategy for suicide prevention. There are no current federal standards.

Also required is study of our nation's mental health crisis, care for vulnerable populations, and improvements in the diagnosis and treatment of depression in the elderly and other vulnerable groups.

iv) **Disability Issues:**

Canada is proud to be considered an inclusive society: respectful of every individual. As a signatory to the 2006 U.N. convention on the rights of persons with disabilities we recognize that disability issues are a question of fundamental human rights. Despite positive public statements, questions remain about implementation. Concerns have been expressed about the devaluation of persons with disabilities. Questions have been asked about health care delivery to people with disabilities.

We intend to explore the real life situations of persons with disabilities and seek information concerning their full inclusion and equality in relation to the needs that exist in health care.

United in the belief that Canada's elected representatives should confront such contentious issues boldly and without recourse to partisanship, the MPs of the PCPCC look forward to receiving the input of their fellow Canadians; working together to develop realistic solutions to very real and systemic problems.

Hearings will be held in mid June, and again in the fall session of Parliament. Local and Regional meetings will be held throughout the summer. Public hearings will conclude by mid October, with a report and list of recommendations completed by early December.

For further information, contact:

Office of Joe Comartin, MP: (613) 947-3445

Office of Michelle Simson, MP: (613) 995-0284

Office of Frank Valeriote, MP: (613) 996-4758

Office of Harold Albrecht, MP: (613) 992-4633

Office of Kelly Block, MP: (613) 995-1551

George Dienesch, research secretary: albreH8@parl.gc.ca, phone: (613) 992-4633



Public Hearing Framework for the Parliamentary Committee on Palliative and Compassionate Care

Welcome to the public hearings of the Parliamentary Committee on Palliative and Compassionate Care. The Committee is a multi-party group of MPs who are concerned with the quality and accessibility of care available to our aging population, the dying, and persons with disabilities.

There are serious concerns with the state of health care in Canada. Through these public consultations and through the submissions of organizations and individuals from all parts of Canada; we hope to capture the ideals, ideas, complaints, and recommendations of Canadians, as a first step in the process of correcting the deficiencies in Canada's palliative and compassionate care framework.

The Committee will address four primary areas of concern:

- i) Palliative and long-term chronic care, respite, and family centered care giving, along with the fundamental human right to adequate pain control at every stage of life.
- ii) Elder Abuse in its various forms including physical, emotional, financial, and the abandonment of the vulnerable by families or institutions. Also to be considered are the pressures on caregivers, and how they can be lessened through various forms of support, thus strengthening the caring relationship and the well being of our seniors.
- iii) Development of a National Strategy for Suicide Prevention, improved diagnosis and treatment of depression in the elderly and other vulnerable groups, and the implications of Canada's mental health crisis and how we care for vulnerable populations.
- iv) The rights of persons with disabilities especially regarding health care accessibility. Canada is proud to be an inclusive society: respectful of every individual. As a signatory to the 2006 U.N. convention on the rights of persons with disabilities we recognize that disability issues are a question of fundamental human rights. We seek to apply this disability perspective to questions of health care delivery.

In order to facilitate discussion we welcome feedback in any or all of the following areas of study:

Palliative Care:

- 1) On the positive side what are our strengths and areas of excellence in the domain of palliative and chronic care, respite and family- centered care- giving, home-care, and delivery of pain control?
- 2) What are our problems and short falls in the areas of palliative and chronic care, respite and family centered care giving, home care and delivery of pain control?
- 3) Identify the barriers to remedying the problems. For example: Provincial /Federal Jurisdictional problems, funding deficiencies, lack of awareness and training on the part of health care professionals, attitudinal and cultural shifts, etc.
- 4) Please make recommendations as to how to achieve our ultimate goal of effective palliative and compassionate care for all Canadians based on short term (2 year) medium term (5 year) and long term (10 year) goals.

Elder Abuse:

- 5) In the area of elder abuse, what are the positive approaches and successes that we have achieved to this point in our society?
- 6) What are the problems and short falls as regards combating elder abuse at both the private and institutional levels? How can we provide support to our caregivers so as to strengthen the caring bond with our seniors?
- 7) Identify barriers to remedying problems of elder abuse in our nation.
- 8) Please make recommendations as to remedying problems of elder abuse based on short term (2 year) medium term (5 year) and long term (10 year) goals.

Suicide Prevention Strategy:

- 9) In the area of suicide prevention, diagnosis and treatment of depression, and mental health care, particularly the mental health care of vulnerable groups, what are the positive approaches and successes we have achieved to this point?
- 10) What are the problems and short falls in Canada's response to Suicide, depression and mental health care of vulnerable groups?

- 11) Identify barriers to remedying these problems and short falls.
- 12) Please make recommendations as to improving suicide prevention initiatives, diagnosis and treatment of depression, and mental health care particularly of vulnerable populations based on short term (2 year) medium term (5 year) and long term (10 year) goals.

Disability Issues:

- 13) In the area of disability issues and rights, what are the positive achievements, approaches and successes that we have achieved to this point?
- 14) What are the problems and short falls as regards disability rights, inclusion, and access to care in Canada?
- 15) Identify barriers to remedying these problems and short falls.
- 16) Please make recommendations as to disability rights, lack of inclusion and access, particularly in relation to health care, based on short term (2 year) medium term (5 year) and long term (10 year) goals.

The Parliamentary committee thanks you for your input. We invite written submissions and anecdotal material to be sent to the:

**Parliamentary Committee on
Palliative and Compassionate care**

Mr. Joe Comartin MP
Justice Building Rm. 713
House of Commons
Ottawa, ON K1A 0A6
Phone: (613) 947-3445

George Dienesch, research secretary: albreH8@parl.gc.ca, phone: (613) 992-4633