



# USING “A CAREGIVER’S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE”

## Invited Panel Discussion

**Robert Clarke, Order of St. Lazarus**

**Carleen Brenneis, Capital Health**

**Jacquie Peden, Nurse-in-Independent Practice**

**Edmonton, Canada**

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<sup>1</sup> A companion kit entitled *Conversations on Caring – Volume 1* is available through the CHPCA Marketplace ([www.chpca.net](http://www.chpca.net)) for use in Canada in staff development, continuing professional development (CPD) and health sciences education.

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

**INTRODUCTION AND SUGGESTED LEARNING OBJECTIVES**

**INTRODUCTION**

This transcript is a web-based version for use with a companion MP3 professional development podcast. This MP3 session is also part of a larger set of digital audio recordings forming a resource entitled *Conversations on Caring, Volume 1* (CoC). CoC 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 of the original CPD sessions and as learning resources to help support improved access and enhanced quality for provision of Hospice Palliative Care in Canada.

The MP3 audio files and this PDF of the written transcript have been post-produced from the original event in order to provide essential information and enable use, generally within 1 hour time blocks. 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 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 rationale and role of *A Caregiver’s Guide* as a tool in helping co-manage care with families.
- Common general uses of *A Caregiver’s Guide*.
- Common specific uses of *A Caregiver’s Guide* in working with individual families.
- The importance of actively, thoughtfully and deliberately using *A Caregiver’s Guide* guide in co-managing care with families.
- Strategies for introducing and using *A Caregiver’s Guide* with families as Goals of Care are re-framed.
- Effective uses for *A Caregiver’s Guide* across settings of care (i.e., home, hospital, hospice, LTC/continuing care).

**USING “A CAREGIVER’S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE”  
INVITED PANEL DISCUSSION**

**Robert Clarke, Publisher (Panelist)  
The Military and Hospitaller Order of St. Lazarus of Jerusalem (Order of St. Lazarus)**

**Carleen Brenneis, RN, MHSA (Panelist)  
Concept co-founder for *A Caregiver’s Guide*;  
Program Director, Regional Palliative Care Program (RPCP)  
Capital Health, Edmonton, Alberta, Canada**

**Jacquie Peden, RN, MN (Panelist and Moderator)  
Co-author, *A Caregiver’s Guide***

**Original Air Date – April 28, 2005**

**Editorial Note** – This panel discussion was conducted to support the release of the national edition of *A Caregiver’s Guide: A Handbook About End-of-Life Care*. At the time of release of this transcript the book is distributed in English, French and for Inuit by the Canadian Hospice Palliative Care Association (CHPCA) via <http://www.chpca.net/marketplace/index.htm>

**JACQUIE PEDEN**

The first group of questions I have are for Carleen Brenneis which pertain to the development of the original “Caregiver’s Guide” which was distributed in Alberta. Carleen can you share with us why the guide was developed?

**CARLEEN BRENNEIS**

Jacquie, we have a physician handbook in Capital Health Region. We also have a nurses’ handbook. We found that that was a very good way to keep the information together and a really well-received teaching tool. Homecare had excellent fact sheets and information, but we thought it would be helpful if it all came together in a handbook. At the same time that we were thinking about doing this the Palliative Care Association of Alberta and the Order of Lazarus began talking about it. It sort of became a joint project for us. We knew there were other books out there for caregivers. What we were looking for was something that dealt with not only the psychosocial issues, which are very important, but also the physical issues (how to turn someone, how to you might start a hypodermoclysis if you are doing that). So, we wanted to cover both the physical and the psychosocial components and we didn’t see something out there that quite met our needs. So, that is essentially why it developed.

**JACQUIE PEDEN**

Ok, thanks. Who was involved in the original development of the project?

**CARLEEN BRENNEIS**

The Palliative Care Association of Alberta, the Order of Lazarus and our region – we were the group who sort of instigated it, however in the involvement was with every region in Alberta. We went out to every region and we asked them to talk to their home care staff and find out any common questions/information that they think the caregivers needed. Those three groups instigated it, but it involved home care from right across the province.

**JACQUIE PEDEN**

What was the process for actually developing the guide?

**CARLEEN BRENNEIS**

It was very grassroots. We asked the homecare staff to identify what they would like covered in the book. We presented the outline of the book and asked what was missing and what would you like to see. It was back and forth with homecare until we got a product that we thought was ok and then we sent it out to patients and families in different parts of the province and got their input. We were very interested that it worked not only in urban centers but also rural centers. The book had to meet the basic needs of the patient no matter where they were.

**JACQUIE PEDEN**

How was the guide distributed originally?

**CARLEEN BRENNEIS**

We felt very strongly that the book needed to be – the Order of Lazarus donated the books to our Palliative Care Association of Alberta and we distributed them to all the home care regions (we meaning the Palliative Care Association) and we all agreed across the province that they would be distributed by homecare because what you want is a homecare case manager to provide this to the families. The families can then see them as a major resource. They would talk to them about the book and they would be the first contact for all the questions that they may have. Of course the family physician would be involved, but it is really palliative homecare that we wanted to be the main distributors and discussing the guides with patients and families.

**JACQUIE PEDEN**

Thank you very much. Now, Bob, can you give me some information pertaining more to the development of the national guide because it has gone national?

**BOB CLARKE**

Yes. I think that the strength of the process that Carleen identified has been very much proven by the national book. Senator Carstairs came across the book a few years back and at the Order of St. Lazarus Conference in Montreal three years ago and she said, “You know, this is so good you should make it national.” I approached the CHPCA and, much as we did with the Palliative Care Association of Alberta originally,

## USING “A CAREGIVER’S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE”

we put together a very small team of knowledgeable palliative care workers. We also included a couple of people associated with the original book and we sent it out to various parts of the country. We had reviewers in BC, Ontario, Quebec and the Maritimes that were picked by the CHPCA. They reviewed the book and all felt it was quite appropriate. The number of changes that we had to make to the basic information were very minimal. Certainly we added provincial contact information, financial and legal information for the other nine provinces and especially the province of Quebec where it is very different. The actual homecare nursing information we developed in Alberta five years ago was only marginally changed and therefore the reprinted national version looks very much like the original book itself.

### JACQUIE PEDEN

I actually just gave a tele-health conference at the Cancer Board here in Edmonton because Marie-Josée Paquin who works with the Palliative Care Initiative (*Alberta Cancer Board, Hospice Palliative Care Network*) wanted to distribute the caregivers guides throughout the Cancer Board in Alberta and one of her comments was that when the Cancer Board was actually approached for funding for the publication of the national guide that what they had wanted was to change the decision that it was only distributed into homecare. They had thought there were times through the Cancer Board, pain and symptom clinics and outreach chemo sites that the guide could actually be distributed there as well. I think that you were involved in that conversation with her.

### BOB CLARKE

Yes, I was. Actually what we did discover (our primary focus was through homecare) was that what was happening both in Alberta and nationally was that the market just broadened significantly and more copies were picked up by volunteers and other professionals in a broader area than we had originally envisioned. We did the first 10,000 in Alberta in 2000 exactly as Carleen had mentioned and indeed in Alberta we printed another 5000 a couple of years ago. Now the national book, if you will, has been distributed (7500) in Alberta in a similar fashion. For the rest of the country what we did was the CHPCA actively promoted the book and they have about 400 programs coast to coast that are registered with them. A case of 50 books was sent to each of the programs and then anyone who wishes more copies to use in an appropriate fashion was to order them free of charge (just paying the shipping and handling fee through the CHPCA offices and they can be ordered through the CHPCA website). I think the distribution is a little broader than we had originally foreseen, but that is good and certainly the Alberta Cancer Board was one of the organizations that helped us finance both the original edition and the secondary one. The cancer clinics throughout Alberta all have copies now.

### JACQUIE PEDEN

Can you tell me how the Order of St. Lazarus was involved?

### BOB CLARKE

Well, our original involvement was that we try to facilitate and support a variety of palliative care programs in the various regional commanderies where the Order operates. We have 11 units across Canada. The need in each is different. We support a variety of programs, hospices and services. We had looked nationally at doing a book of this nature and it just wasn't working. It is tough sometimes to do things on a national basis. During the development of the national one I had spoken to Carleen and intriguingly I have an interest in health education (certainly through *Family Health Magazine* that I publish) and I could see the potential need here in Alberta, so I talked to Dennie Hycha and other Albertans about the PCAA and intriguingly just about the time we were to have our first meeting, Carleen called and said, “Bob, have you gotten any further?” I said that we are having a meeting and let's get together and that is what happened. We put the committee together which is in the book. St. Lazarus again, it was a combination of us having a desire to work with a local program. Our Calgary people were involved in the fundraising and we looked after that. Certainly through my experience in publishing I was able to coordinate that other side. Again, the Order feels that the book worked very well in Alberta. It was about a \$120,000 project to do it nationally. We raised about \$70,000 from outside sources and invested the other \$50,000 or so ourselves, so we could print the 50,000 English language and there were 15,000 copies of the *Guide des aidants naturel* (15,000 French language copies).

### JACQUIE PEDEN

I am impressed with your French language! Thank you very much! I think what I will do now is briefly go through what is in the book because I know that some of you have just recently received a copy. If you have noticed, there is a brief description of the development of the guide. It talks about the publication committee. There are also acknowledgements of who actually provided funding for the book.

If you look in the table of contents, what we talk about in the introduction is “what is hospice palliative care”. We also go onto talking about when the illness is first diagnosed, that is a big section, so we determine what is happening, caring for yourself the caregiver. We provide the caregiver with information on how to develop a support network, how to effectively communicate with others. We talk about spiritual needs and also adapting their homes. There is also a huge section on giving physical care, so information like how to position someone in a bed or making a bed. Then there is a section on care of physical problems and complications that might occur. We have included the complications that might occur although there was some discussion on that, just because people need to have that information just in case. I know as a home care nurse I would often provide this type of information to family caregivers if I thought there was a risk of spinal cord compression or superior vena cava syndrome.

## USING “A CAREGIVER’S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE”

We also have a section on when life ends which we talk about dying at home and the last days of life. We have provided books and other resources that might be helpful and then there is a section in there that helps provide information on books that would help grieving children. In the appendices we have information about the financial aide, legal affairs and there’s a home medication schedule and a symptom assessment scale. There is a chart that the family caregiver can copy for keeping track of break through medications. We provide information about inserting and removing subcutaneous sites.

There is information on the back about Canadian Virtual Hospice ([www.virtualhospice.ca](http://www.virtualhospice.ca)) which I will mention later and the Order of St. Lazarus and the Canadian Hospice Palliative Care Association. What I wanted to do next is just share with you some comments from family caregivers about the “Caregiver’s Guide”. Since the guide has been available for family caregivers in Alberta since 2000, I asked health care providers in this province to share comments they had heard from family caregivers. We thought that you may be interested in what family caregivers thought of this guide. So what comments that were sent to me include:

- It gave family caregivers control over their loved one.
- It provides common sense and easy to understand information.
- It provides information about preparing for death and what to do following.
- They wish they had the guide in a previous situation.
- Family caregivers from a peer support group voiced how helpful the guide would have been if available when they provided care for their loved ones.
- This is the greatest book. I had no idea about all these things happening with my husband. It helped me understand what he was going through.
- I read it after my father died. It helped me to appreciate why he was short with me sometimes.
- This is my bible. I have read it from cover to cover and I have highlighted some parts and scribbled notes all over the book.
- According to caregivers, it is a valuable tool. It is built in a straight-forward way and presented in a useful and realistic way.
- The new book is colorful and appealing.
- Bob Clarke shared with me a letter from the director of the palliative care division of McGill University that said, “Thank you for translating it into French. It is the best guide of this kind that I have seen.”

What I wanted to do now is to talk about how the resource can be used effectively by the family caregivers. I think there are two parts to this question. First of all, there is a general use of the book and then there is a use with an individual caregiver. First, let’s focus on the general use of this guide. Some health care professionals that I have talked to about this guide have shared with me the following uses of how

they have actually used the book or plan to use the book in the future. So for general use:

- Using it in a family caregiver workshop.
- Using it with a family caregiver support group.
- Using it with family caregivers attending counseling or bereavement groups.
- Someone actually thought that there should be some more funding put into the book so that we could make more copies and make them available in libraries and palliative care rooms in acute care.

I would like to open up for participants to discuss the question, do you have any other ideas for general use of the book or comments about the suggestions I made or any comments about the book itself.

### **ELAINE MARRINGTON – KAMLOOPS, BC**

From what I understand you are describing the “Caregiver’s Guide”. From how I see it, our program goes right across residential, acute and communities. I also see in residential that it would be helpful for caregivers or family sitting by the bedside to get a good understanding of what is really happening through end-stage, so I would like to suggest that also.

### **JACQUIE PEDEN**

So, putting it within a residential facility?

### **ELAINE MARRINGTON – KAMLOOPS, BC**

Yes, they set up packages for when a person is going through the end stage of life. They are going to have the resource material there. That is where the booklet would be.

### **JACQUIE PEDEN**

Are you talking about continuing care centers or I am not sure what a residential place is?

### **ELAINE MARRINGTON – KAMLOOPS, BC**

It is a place where elderly live. They can also die there.

### **JACQUIE PEDEN**

Ok, thank you for clarifying that. That is a good idea.

### **BOB CLARKE**

Actually, Jacquie, we found that numerous copies are going to hospices across the country and also those in more long term care. It is not that location (where the family and individual are located) as much as it is the relationship it is between the family and that patient. The location isn’t all that important.

### **CARLEEN BRENNEIS**

I agree Bob. One of the reasons we emphasize home care is that because people move through different areas from acute care to perhaps residential hospice or homecare that was sort of where we centered it. It would be useful in any setting.

## USING “A CAREGIVER’S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE”

### **MAUREEN TURNER – WHITEHORSE, YUKON**

Hi, it is actually a comment rather than a question. In our continuing care facilities in Whitehorse we are actually using your guide book for our meetings for completing advance directives with residents and families so your section on hypodermoclysis has been very helpful. Also we are using it in individual family situations where they have questions about the care for their family member. We use it in that regard as well.

### **JACQUIE PEDEN**

Thank you. I think the next section I wanted to talk about was how to use the guide effectively with individual family caregivers. I think that there was a discussion that some of the individuals on the publication committee can go into and maybe with Michael Aherne who is the Director of Pallium about the concern that the book might be just given to a family caregiver without any introductions in how to use it effectively. I know that often people can become overwhelmed with being handed a one-page sheet, so to be given a whole book as a resource may be a little overwhelming. What I did was I actually looked through the literature so I could have a basis or a few guidelines that we could start from. What I am hoping is that we can add to these guidelines for effective use. This handout was sent out to you by the Pallium office. So, the guidelines I have come up with are:

- Determine whether or not the family caregiver can read.
- Assess the family caregiver’s emotional readiness to read and review the information in the book.
- Assess the family caregiver’s willingness and ability to review the information in the guide.
- Determine what information the family caregiver wants.
- Identify what information you want the family caregiver to know.

So, examples under possible complications that could occur are often is if you have someone in the home who you know is at risk for a spinal cord compression, you might direct them to that section in the book so that they can review some of the symptoms you have identified that might occur if this complication happens.

Also, help the family caregiver determine their priority. Offer information for their priority and learning. Because the book is so big, it might be important for the family caregiver to know what exactly at this point in time? Identify parts of the book that are pertinent to the family caregiver at certain times. So instead of the whole book, you might tab certain sections of the book. Refer to the information in the book during a teachable moment. So when the family caregiver asks you a question about physical care, it could be that you provide that explanation but also refer them to the section in the book for review when you are not there.

Help the family caregiver understand what he/she has read in the handbook. Although the book is written very well and the readability is at a very low grade and for most people it is

understandable, I think that there still might be some questions that a family caregiver might have.

Actually the session I had today at the Cross Cancer Institute with the Cancer Board, one of the comments was that if the person at the Cancer Board gives out the book, then she also gives her number so that the family caregiver can call back to her if she has questions about the book. Specifically, especially if she has not gotten connected with home care at that time.

Also, HealthLink (*Editorial Note: HealthLink is the provincial primary-care call centre in Northern Alberta; similar primary-care call centres services exist in British Columbia, Southern Alberta, Saskatchewan and Manitoba*) can give new information from the handbook to previous experiences and provides them with positive feedback when a family caregiver demonstrates learning of new knowledge and skills. I don’t think that this is complete and I certainly would like your comments/ideas on how we could actually use this guide effectively. So the question is, do you have any other ideas for effective use of this guide or comments about the guidelines mentioned? So, it is open for discussion.

### **BOB CLARKE**

While you are waiting for call-ins Jacquie, I should just point out that it was uniquely designed to complement the role of home care/ palliative care worker and just as every case is different, the usage of the book will vary. I think that you have covered most of the areas that could be used, but it’s the intuitive understanding of patients based on the experience of the home care professional that can make the book be most valuable and exactly as you say by interpreting it for the caregiver.

### **ANDREA HOYE – VERNON, BRITISH COLUMBIA**

Hello. I just wanted to make a comment about the timing of giving the booklet. In our area, we have developed a binder similar to this and we have had several years of working with it and getting feedback from patients and families. I think that it is important to not think that we as health care professionals know the exact timing to give a booklet like this. I think that giving it early with explanation is good. Some people like to read a lot. Anything they can get their hands on is good. Some people don’t like to read things at all. Some people like to read things as they come up.

With the explanation that this is a book that has got a lot of information that you may or may not need or you may need some in time and make a point of going over what is in it. If you feel that some people don’t even want to look at that, you can say that you can read as much or as little as you want in this book as you want. And then it may be 4 o’clock in the morning that they finally decide that they may want to read something in there. If we think we can decide when they are ready or not, we are wrong. I think that if the book is there, then they can do it in their own time.

## USING “A CAREGIVER’S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE”

### **JACQUIE PEDEN**

Thank you. I think that is a good suggestion.

### **BOB CLARKE**

On page 95, under the beginning of what the complications that might happen section, that may be sort of a warning to the reader that it may or may not be appropriate at this time. You may wish to have a look at that.

### **JACQUIE PEDEN**

Does anyone have any questions or comments about the guide? Any comments on how they have used the guide or anything that they want to share with the group?

### **CARLEEN BRENNEIS**

Jacque, it's Carleen. One other way that we have utilized this book is, what we have found is that we have provided this book to families but the support care workers that were going into the home didn't necessarily have this information. So, we actually use this book in supporting in-services and so forth with personal care aides as well. I think we need to be careful if we are providing patients and families with information. All the people in and out of the room need the information as well.

### **MEG MILNER – CASTLEGAR, BRITISH COLUMBIA**

Hi there. This book is a fabulous book from my perspective. It is very easy to read. The pictures make it warmer and friendlier as well as helpful with what you are describing. The idea of having recipes in the book is a great idea. It is a book that could be used all across sectors right into kids when we are presenting palliative care or the fact of death to young people or situations coming up. It could be used as an educational tool. The more we talk about the process of dying, it takes the unknown out of it, so the more acceptable it will be and the more we will focus on the positives of it (which is where we would all like to be). I do like the complications that there is a warning that this might be disturbing because, again, this is not a horror novel. It is about your loved one. I am really impressed with the process you have gone through to develop the book. One other comment is that I have heard that some people that have this book have put a label on it saying that it is, “For your use until you no longer require it and please return to whoever it was that gave it to you so it can be passed onto someone else” because we will never be able to produce enough of these books.

### **JACQUIE PEDEN**

Thank you for your comment.

### **CARLEEN BRENNEIS**

Jacque, it's Carleen. The quality and the outlay as well as the really professional look is accredited to Bob Clarke and his experience in publishing. It is really a much nicer book than we would have been able to do without his expertise. So, thanks very much to Bob. You are a champion!

### **BOB CLARKE**

Well, there are a lot of knowledgeable people who did it. Thank you!

### **TAMMY M'CLUSKY – TRAIL, BRITISH COLUMBIA**

Hi Jacque, it's Tammy and a group of hospice volunteers and this is our first time we have gotten together as a group to look about the book. I am thinking as well as using the book to do something in-service with the volunteers so that they can be aware and that it can be a resource to family caregivers and the volunteer can direct them to the book as well if they know it exists. We can use the volunteers as another point of entry of information that is in the book.

### **JACQUIE PEDEN**

Yes, I think that's a good idea. It also provides the volunteers with information about communication that I think would be pertinent when talking to someone who has been diagnosed with a terminal illness. Some of the information is valuable to them as well.

### **BOB CLARKE**

Actually, Jacque, the experience we have had over 5 years is that the volunteers use it just as a textbook and virtually everything is valuable to them because their role is not dissimilar to that of the family caregiver in so many ways. That was a market that we didn't really identify when we developed the book originally but it is probably the second largest market area for it.

### **DEB GITZEL – STETTLER, ALBERTA**

Hello. Just as a group, we are wondering a little bit about the title page or the cover where it says, “A Handbook About End-of-Life Care.” Some folks are just a little reluctant to hand that over to folks. Any comment about that?

### **JACQUIE PEDEN**

I know that we had a big discussion about that when we were actually developing the book. I had other comments from health care professionals in different regions who actually put a piece of tape over that so the person doesn't see that part. I think that it is a book about end-of-life care. I think that we need to be able to talk about end of life care in a normal way and normalize it because life is terminal and it is something that is going to happen. Certainly when you are giving it to a family caregiver, you would provide some explanation about the book.

I know at the Cancer Board session this morning, they said that they would say to the family caregiver that, “You know you are coming for treatment, but there is valuable information in this book. Just because we are giving you this book, it doesn't mean that we are saying there is no hope and the treatment is not going to be effective.” I think it really depends on the health care provider or whoever is using the book how they actually present the book to the family caregiver. Are there any more comments about that issue?

## USING “A CAREGIVER’S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE”

### **BOB CLARKE**

I think that Carleen could comment effectively but you are so right Jacquie. When we developed the book, it was very specifically designed for the palliative care community and, therefore, the entry was for people who had accepted a diagnosis of such. The family and the patients needed that type of care, therefore, it is focused there. Carleen, your comment?

### **CARLEEN BRENNEIS**

I think that you both said it very well in that we did have a big discussion and we did choose to use end of life care. I know that Pallium is just looking at the feasibility. A lot of this information is very useful for people who have long-term chronic illnesses as well and Pallium is just beginning to look at the feasibility with their partners of is there a need for a book that deals with chronic care. Now, having said that, it is very early and I am not sure where that will be and it is true that there are lots of people out there that are receiving long-term home care that could also benefit greatly from this book.

### **JACQUIE PEDEN**

The other thing that was mentioned at the Cancer Board was they asked me if they could photocopy parts of the book. I said that would be fine because they may have someone undergoing chemotherapy who is having some symptom issues and who isn't really palliative but they would like to take that part of the book that pertains to that symptom and give that part of the book to the family caregiver at that time. I see no problem with doing that (picking out what is best for the person who is in that situation).

### **BOB CLARKE**

From a copyright point of view, I have no problems with any homecare worker or any palliative home care program in doing exactly that. If the circumstances warrant, there is no copyright issue. Just don't sell it! (Ha,ha!)

### **JACQUIE PEDEN**

I had a question that was actually sent in on the registration form. The question was and I wanted to put it out to the group and then maybe you can answer it. When is it culturally not acceptable to speak about the end or death? What is the best approach? When is it culturally not approachable? Does anyone have any ideas on how to answer that question?

### **ARLENE JENNINGS – EDMONTON, ALBERTA**

Hello, this is Arlene. Generally speaking in palliative home care we rely on whoever has made a referral or if they have a family member to tell us the culture. We don't know automatically where it would be inappropriate to discuss those things or not. We are usually given a heads up on the referral or from a family member what areas that we do not discuss with a client.

### **JACQUIE PEDEN**

Right. That was actually was one of the ideas – to assess or to talk to the family caregiver to find out if there were any cultural issues or any taboos about speaking of death or end of life. Any other comments about this question?

### **CARLEEN BRENNEIS**

Yes, it is Carleen. I think respect is the key term. Being respectful and asking the family and using cultural brokers if you are lucky enough to have them. Showing the family respect is the key.

### **SANDY NEWANS – RED DEER, ALBERTA**

In relation to what was just discussed about when it is appropriate to talk to families about death or not, we have a really good resource book here. It is called, “Customs and Traditions in Times of Death and Bereavement” by Kathy Cloutier. It is published by Park Memorial Ltd. And it is a very comprehensive book discussing many different cultures and what is appropriate or not. Have you heard of this book?

### **JACQUIE PEDEN**

Actually, I did have a copy of that when I was practicing in home care, but I looked for it the other day and I couldn't find it and I couldn't remember who it was who put the book out, but it was a good book. Is there any information in that book, like a phone number you could provide, so people could access it?

### **SANDY NEWANS – RED DEER, ALBERTA**

Well, I am just looking here. I have an Edmonton number here, but I am not sure if these numbers are current, but the Edmonton number would be 780-426-0050.

### **JACQUIE PEDEN**

Thank you. I have seen that book and I know that it is very good. It actually reviews a number of cultures some of the practices for funerals, taboos - that type of thing. It is a good resource if you can get it (maybe a copy of it from that funeral home).

### **BOB CLARKE**

Yes, that number is still good and they also have a website ([www.parkmemorial.com](http://www.parkmemorial.com)).

### **JACQUIE PEDEN**

The other thing that I wanted to talk about as another resource was the Canadian Virtual Hospice. This provides high quality health information about death and dying as well as a forum for Canadians to share their experiences about illness and grief. This resource is targeted for families, friends, health care professionals and volunteers. The address for the website is [www.virtualhospice.ca](http://www.virtualhospice.ca). This can also be found at the end of the Caregiver's Guide on page 159. This is another really good resource, not only for you but for family caregivers and volunteers.