



FAMILY CAREGIVER: HOW TO PROVIDE SUPPORT?

Priscilla Koop, RN, PhD
Faculty of Nursing, University of Alberta
Edmonton, Canada

Companion written transcript for a post-event MP3 Podcast (Individual Web License)

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Pallium Project Development Office
Box 60639, University of Alberta RPO
Edmonton, Alberta T6G-2S8
or via fax to 780 413-8196

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

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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.

- I. 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:

- Key risk factors to the family caregiver's own personal health status.
- Three typical end-of-life care scenarios and how those influence engaging with family caregivers.
- The evidence-informed needs of family caregivers within palliative/end-of-life care situations.
- The importance for a broad, flexible approach to respite services in end-stage, palliation/end-of-life care.
- The importance of tailoring the information sharing and communication process to one which is characterized as anticipatory, flexible, well-paced and sensible to the patient and family caregivers' reality.
- The importance of addressing common myths about pain and symptoms with family caregivers.
- The importance of re-inforcing the important contribution of family caregivers in direct care/case management.
- Strategies for self-care – of self as professional caregiver and in working with family caregivers.
- Strategies for effectively engaging and navigating dysfunctional family relationships.
- Strategies for helping family caregivers manage stress and feelings of being overwhelmed.

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Guest Resource

**Priscilla Koop, RN, PhD
Faculty of Nursing, University of Alberta**

Moderator

Jacque Peden, RN, MN

Original Air Date – February 24, 2005

DR. PRISCILLA KOOP

Typically family caregivers are women in their sixties (although many of them are much older than that) and there are also significant numbers of male caregivers. Typically caregivers are first order relatives; they may be spouses or partners. They are often wives and daughters, husbands and sons. Often, daughters-in-law get involved in this and sometimes siblings.

It should also be said that although the typical primary family caregiver is a woman, when you look at care networks, male and female caregivers are approximately equal in numbers, but the females tend to give more hours of care and broader ranges of care.

About half of family caregivers in palliative care have chronic illnesses of their own and so health concerns are very important especially given the intensiveness of end of life care giving. When you look at care tasks on their own and the increase in household tasks that come with end of life care, people give in the order of 7-8 hours of care, but if you take monitoring and emotional support into account, the hours then move up to 13-20 hours of care per day.

Sleep is often disrupted and exercise and meal patterns get disrupted as well, so health concerns are really a big issue. Remember that family caregivers at end of life don't get weekends off, they don't get holidays and often they don't even get good sleep. So, we need to really take care of support for the caregivers.

It's important to recognize that as a society, we owe a huge debt to family caregivers. They are doing the care that I gave when I was a young staff nurse and they are doing that care without the education that I had, without the training that I had and without the time off. Although, primarily it seems that caregivers are happy to provide care, given enough information and support, there are some caregivers who really feel coerced into giving care and don't feel they ever get a chance to extricate themselves once they are in it. We need to be careful about that.

JACQUIE PEDEN

Can you tell me the difference between Alzheimer's and end of life care? Can you tell me a little bit of the differences between family caregivers for those groups of people?

DR. PRISCILLA KOOP

Well, I am not sure if this is what you are asking Jacque, but there was an author who wrote about the three typical end of life scenarios. One of these is what we typically associate with advanced cancer and that is where the person is relatively well until close to the end of life and then there is very rapid and significant deterioration and that is where the caregiving becomes so intensive.

Alzheimer's disease and simple frailty have another trajectory and that one is more where there is decline over years prior to the death. Caregiving can become intensive or can be intensive for years. Very often institutionalization occurs and also in Alzheimer's disease the person's mind disappears while their body is still quite strong, so there are different care needs.

The third trajectory is the one you see with organ failure and there you typically have highs and lows and this is also typical of the hematological cancers so the person may be pretty ok and then say the person with advanced heart disease or pulmonary disease catches a cold or the flu and that is life threatening for them and so they may be admitted to an intensive care unit or to a hospital unit. They may die from that event or they may recover and be relatively well for awhile. Those are the three scenarios. Is that what you wanted to know or is there something else I can add?

JACQUIE PEDEN

No, that is what I wanted to know. You mentioned family caregiver needs. What are the needs of family caregivers?

DR. PRISCILLA KOOP

The needs that both you and Joanne Pollard listed in your Master's research on the needs of family caregivers are good and it seems to me that the needs are quite simple and straight forward but we need to remember what they are.

First and foremost, I would say that family caregivers don't want their needs to be the focus of nurses, social workers and others who help them in the home. They want the patient's needs to be paramount. They do appreciate getting support and help but they don't want that to happen at the expense of the patient. Now, having said that, their needs are for the information, the skills, the equipment and supplies that will help them do a good job of providing care. Information is something that comes up again and again in our interviews with caregivers.

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They want information on the disease process and they want information about symptoms. They really appreciate it when they are told what to expect down the road. Caregivers have told us over and over again that they really appreciate it when the home care nurse, for instance, would say over the next few weeks you can expect this to start happening, this is what that means and this is what you can do about it. They want to know what to expect and how to handle the symptoms.

When you are talking about end of life care there are symptoms that would otherwise need urgent treatment but which in palliative care may be something which they just need to put up with or to watch and wait. There are other things that they need to get help with really fast and so caregivers want to know the symptoms that are going to occur and they want to know what they should do about them and the timeframe.

The last thing that I think is important to mention is that caregivers want respite. We are going to talk later, I think, or maybe we should do it now about what respite means. A lot of our notions of respite come from the Alzheimer's literature and the Alzheimer's caregiving system - and for people in advanced cancer those needs for respite are often different. In health professional terms, respite typically means a service and that often it is a service that demands that the caregivers and care recipients are physically separated from each other.

Now, the caregivers in palliative care have told us (I am talking about family caregivers) that they find those respite services to, in fact, increase their stress and anxiety, not to help relieve them. We found out in the research (and you were involved in this research, Jacquie) that to caregivers in palliative care respite often means relief from being the caregiver and the freedom to be who you are in relation to the dying family member. It is relief from being the caregiver role, while being allowed to be the wife, daughter, son, or husband. That means that respite is a strategy actually for caregivers to get a mental break without necessarily the physical break. A mental break from caregiving and the freedom to be who they really are.

Caregiving can interfere with being a wife or a daughter so our caregivers, when they achieved respite, did very simple things. They did them often while they were in the same room with the care recipient. They would do crossword puzzles, they would read together, watch TV, did yoga, meditated – things like that. Sometimes they wanted to go for a walk or there was one woman who talked about being with her horses in the barn. But always these activities seemed to be nearby so that they could come and check in on the person when they needed to.

JACQUIE PEDEN

You said that the typical services for respite often cause more stress to the family caregivers or increase stress. Why is that?

DR. PRISCILLA KOOP

It seems to be because the respite services often separate the dying family member from the caregiver. It is the separation that causes this and they want respite in the vicinity of the dying family member. The dying family member is going to be gone in the very near future and they want to maximize their time with that person.

JACQUIE PEDEN

Providing respite to someone who is closer to death – is that different than providing respite to a family caregiver who is looking after someone who has a disease such as Alzheimer's which has a longer trajectory of illness?

DR. PRISCILLA KOOP

Well, it seems that it is, but I think that that is always the question to ask the caregiver what would work for you, but I think it is really important for the professional caregivers to realize that the separation we often insist on with perfectly good intentions, we insist that they take that respite because we want them to be able to take care of themselves and hang in there for the long haul, but in fact, we may not be doing them that much good. I think that the important thing is to ask them what would work for them and try to work around that. It is also important for us to realize that respite can be achieved while they are right there in the same room.

JACQUIE PEDEN

So are you suggesting that for home care services, for instance, that you could put in respite services for someone who could actually be there to provide care for a certain length of time but not actually expect the family caregiver leave the home?

DR. PRISCILLA KOOP

Absolutely! And while that person is in there giving care, sit down and have a cup of coffee or a cup of tea at the kitchen table and just...

JACQUIE PEDEN

Could you tell us how else we could provide support to family caregivers?

DR. PRISCILLA KOOP

Absolutely. I think that, in general, if you can think of yourself as a colleague with family caregivers in the care of the dying patient then probably what you will do is just fine. If you keep that role in mind, the chances are that you will do what is needed, but here are some other ideas. As I said earlier - offer information. Try to think about what the family caregivers may need to know down the line and offer that information rather than waiting for caregivers to raise the question themselves.

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Many of us have had that experience of being too overwhelmed to know the questions to ask. It takes a lot of energy to think about the questions one should ask, to formulate the questions, to figure out who is the best person to ask will be and to keep those questions in mind until that person comes around.

I would suggest to try to anticipate what the family members and patients will encounter down the road and try to give them that information. Having said that and having said that family caregivers want a lot of information, I also think it is important to pace that information a little. People can absorb only so much information at a time.

Also, be prepared to repeat information, two or three times. Anxiety interferes with learning. We do know this and when you see that caregivers are anxious tell them, let them know that they may need to ask that question of you a few more times and you understand that and you will be happy to go over that information with them again if they need to ask it a second or third time.

I think that it is also important to normalize the information that is given about caregiver's needs. Let them know that what you are telling them are very normal questions and normal concerns. I think you can say something like "many caregivers wonder about something like this or that" and ask if it something that has occurred to you and would you like information about this. For so many of us in the kind of work we do, we deal with a lot of information that is quite intimate and sometimes quite embarrassing and it is routine for us - but we need to remember that it is not routine to family caregivers. To them, the information is new and simply not part of their everyday life.

I think also that it is important to interpret to family caregivers what is happening and why. Keep in mind that family caregivers typically have limited anatomy and physiology knowledge. It is important to listen to what they know and what they need to find out.

I remember a man who had coronary artery bypass surgery a couple of months prior to this visit that we made and he had blood in his urine. It really scared him and there was a reason for the blood in his urine. I don't recall what it was but it was a test or something that he had had and the blood in his urine was quite normal. He was very worried about it and a few questions lead us to realize that he thought that one of the stitches had come loose after his coronary artery bypass surgery and that the blood in his urine meant that he was bleeding from his heart. Now if you know simple anatomy and physiology, you know that is not possible, but he didn't know that. We did a very simple anatomy and physiology lesson and he was so relieved that he then could hear our explanation for why he had blood in his urine. Until that point he had told doctors and others about the blood and his concern, but they just told him not to worry about it. But he did worry. Once he understood the anatomy and

physiology, he realized that there was a good reason not to worry and he stopped.

I think it is also really important in palliative care to deal with common myths in pain management. Pain is not a problem for everybody in end of life care, but when it is I think it deserves extra attention. When caregivers give inadequate analgesics, it is often because they have these commonly held myths about the dangers when giving regular narcotics. They worry about addiction. They worry about tolerance and that when death is near and when pain medication is really needed, that it is not going to work and they'll be having family members screaming in agony. They also worry that, inadvertently, they will kill the family member by giving them narcotics. I think it is worth it to go over those common myths and misconceptions as well as to be open and gentle, but to raise those issues right from the start and to teach them.

I think, also, that it is important to try to establish the kind of relationship with patient and family caregivers that makes it clear to them that they are free to ask anything at all. There are no stupid questions and the easy questions are sometimes our favorite! Go ahead and ask them and we will answer them. I think that the concerns that the family caregivers are embarrassed to ask us are the concerns then that we cannot deal with. We need to hear about those.

Early in the illness trajectory, try to encourage family members to think about and write down the friends, neighbors, family members who might be able to contribute something along the line when things get tougher. There may be people in their social system who can shovel the driveway, sit with the patient when the caregiver goes for a walk, cook a meal, whatever is needed. It is really hard to think about these things when the caregiver is overwhelmed. There are people out there who want to help but do not want to intrude and the people who need that help are often too overwhelmed to ask or they don't want to put anybody on the spot. I think it is up to the professionals to do whatever we can to connect those two groups of people.

Also, early in the illness process, encourage photographs and discussions about family history. These things can be very helpful later on when things start to seem somewhat bleak and, in bereavement, these are things that bereaved family caregivers really appreciate.

Finally at some point, I think that it is important to let family caregivers know that what they are doing is really important. And valuable to the care recipient, to their family as a unit because they are training the young ones about how to provide care to someone who needs it, but also their caregiving is important to society as a whole. Also, warn them that there may come at time when they simply cannot continue to offer care. They may need to get a family member admitted or ask for additional support. If you can, tell them to keep you in touch with how they are doing about

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this and to give you a bit of warning so you can arrange for further support or an earlier admission to hospice or to the hospital. For many caregivers this final admission can feel like abandonment or giving up and that can cause tremendous guilt. I think it is important to tell caregivers that every day they have been able to keep their family member at home is a gift. What they have done is important.

JACQUIE PEDEN

Providing care at home can be very stressful. Can you give us some tips on how to help the family caregivers cope?

DR. PRISCILLA KOOP

Yes, absolutely. Luckily enough it is probably for the most part what all of us can do to cope, so it is not all that different. When I was a staff nurse at the St. Boniface Palliative Care Unit, we had a motto that said something like our job was to help our patients to live until they died. In fact, CBC did a video of our unit and it was called "Living While Dying". I think that we do whatever we can to help our patients and their family caregivers to really live everyday that they have.

The key factor is to manage symptoms while keeping the patient alert. Severe symptoms or drowsiness can really interfere with really living everyday. Then the focus must be on using each day well. Use the day to talk about what is important. Have a little fun and be a little silly and have a satisfying day. In many ways this isn't all that different from dying patients and the family caregivers as it is for everyone else. At the end of each day we should be able to say that we used this day well and it is during bereavement that it is the memory of those days that used well that sustains survivors.

JACQUIE PEDEN

How do you provide support in a dysfunctional family caregiver situation?

DR. PRISCILLA KOOP

Dealing with dysfunctional families sure can be difficult. It is so easy to get caught up in their dysfunction or to want to side with one family member over another who you think is the victim and to try and solve the dysfunction. If the patient and caregiver dyad or the dysfunctional family units want to get therapy, then by all means see what you can do to get them the help they need. However unless you are trained in providing clinical/family therapy, I urge you not to try to fix the relationship on your own. It is so easy to violate the boundaries between the client, the family unit and yourself and it can really cause further problems. There are several strategies that you can use in your work with these families and these strategies are simple, but difficult and very important.

One is, and it is very important that you make it clear, that you are on each person's side - so you are for everybody. You are for each of them and this is hard to do. You need to

make that clear and that will help you stay out of the middle of problems.

Second, I think it is important to offer understanding that it is very difficult to give or receive care from someone you don't get along with. It would really be ideal if the caregiver and care recipient could achieve unity and by all means encourage them to work towards that if they are interested. The reality is that impending death does not turn any of us necessarily into easy to get along with people. So, we sometimes give or get care under these less than ideal circumstances.

Now here is one exception. If the dysfunction at any time jeopardizes the safety of the patient or the caregiver then you have to deal with it and maybe seek early admission to a hospital or long term care institution may be required.

JACQUIE PEDEN

The next question is what can the caregivers do to help themselves when they are struggling or feeling exhausted?

DR. PRISCILLA KOOP

We had some discussion here at the Pallium offices about whether this question referred to professional caregivers or informal caregivers. I initially thought that this was for professional caregivers and many of the strategies can be used for both. I will try to be clear about what I am talking about.

Here is one strategy that I highly recommend and that is to keep a simple journal. Now, I know that for professionals this can seem very daunting. There are some days you can barely crawl home from work. I am going to stress that the word is simple. At the end of the clinical day, write down and only answer one question and that question is, "What did I do well today?". The answer may be really simple. It may be that you persuaded Mrs. S to give her husband his analgesics regularly instead of PRN or just as needed. It could be that you handled a bad situation better than you ever did in the past. It may be something very profound and those I don't need to tell you about because you will remember them. The important thing is to write down a little something everyday that you did well and then to read over your entries over time. I think that is a terrific pick-me-up.

I think that informal caregivers or family caregivers can be encouraged to keep a journal as well. At the end of the day write what went well in the day or what was a good thing that happened today. Again, keep it simple, therefore it is more likely to be done.

The second strategy that I recommend, and I know I am going to start sounding like a Pollyanna, but just bear with me for a while. I think that I have friends who do this routinely and it really works and I try to remember to do this myself and that is to give thanks for the good things in your life. You can do this as well as the family caregivers. A supportive will have something in our lives and it is good to give thanks for that.

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It can be a supportive partner, a child who is delighted to see us at the end of a busy day, our health, a joke you read in the paper or somebody tells you or you hear over the radio, the sight of sun glinting of hoar frost on the trees, the sight of the northern lights, a car with a really good heater on a cold day, good music to listen to – all of those things are reasons for gratitude.

A third one is exercise! I am so glad that you all have your mute buttons on so I cannot hear you moaning and telling me to mind my own business and I have been there and as I said some days you can barely crawl home. This strategy can be useful for you as well as the family caregivers. Think about the shortest walk that you can do even on those horrible days or the short exercise video you are willing to watch or the two or three yoga stretches you are willing to do everyday. Just do them. While you do them, try to put away the stress of your work life and for family caregivers try to put away the stresses of caregiving. For those moments, just be who you are and be good to yourself and love yourself. Then prepare to deal with your personal and family life and get right back into it.

Another strategy is very similar to one that I said before in relation to family caregivers and that is to find out what your friends and neighbors and family members are willing to do for you on your really bad days and then ask for what you need. Even young children can bring you a glass of juice and give you a hug and say, “I love you Mom” or “I love you Dad”. Accept those efforts and say thanks for them. Those strategies are what I would call really positive ones and we aren’t always in the space for them, so you are also going to have to develop some strategies for really, really bad days. Here is one idea.

I have a colleague who writes down all the horrible things that someone says or does and she has a special file and it has a really fowl name which I won’t tell you now. So you may want to keep one of those files, but I suggest that you not do that. I suggest that after you write down the horrible thing that someone says or does that you stop and think if there is something you need to do about that. Maybe you need to go to the union or to the police or someone’s boss and deal with it. Plan to do so. If you cannot do this, then have a ceremony in which you tear that paper into little, tiny pieces and burn it. While you do that, say to yourself that I am not going to allow this person or this event to darken my life any further and do your very best to forget about it. I know that’s hard.

Another thing, when you’re body leaves work, try to take your mind with you. This isn’t always possible and sometimes we even resolve important issues after work hours, however, really try to tell the difference between ruminating and problem solving and try to avoid ruminating. It just destroys your psyche and it takes energy away. Many, many years ago Elizabeth Kubler Ross said that when you leave work, go home and soak up some sunshine. That way, when you go

back you will have the sunshine to carry with you and to your patients. I think there is wisdom in that. The last strategy I want to talk about is one we often use and we call it letting off steam or bitching and I think it is important to pay attention to how we feel after we do that sort of thing. We can call it seeking support from others by discussing our stressful events and the question always is to ask oneself, do I feel relieved and understood after I have a session like that or do I feel worse? Letting off steam can be helpful but it can also simply allow the stress to intrude upon our free time. So try to tell the difference and ask questions accordingly.

JACQUIE PEDEN

The last question is what do you do when the family caregiver becomes overwhelmed and panic-stricken? You go to make a home care visit and there a family caregiver is in distress.

DR. PRISCILLA KOOP

I think that is a tough situation and I think that what we need to remember is to keep our stress levels down when that happens. The first thing you do is breath. Panic and extreme fear launched at somebody else panicking can interfere with brain functioning and so take a few deep breaths and get some oxygen up to the brain and think through what needs to be done.

I think it is important to try to figure out the kinds of situations that cause caregivers to panic. Often there are patterns for each individual. It is important to identify what those patterns are. Is it seeing pain and anxiety in your family member? Is it fear of death and concern that you didn’t do enough and that you should do more? It is important to remember that few lay people have been present with someone at the point of death and TV portrays death in a way that it is very anxiety provoking.

So once you figure out what that trigger situation is, walk them through it and say that I am here to help you and I am going to help you figure out what to do when this situation happens again. You may need to write out simple instructions that they can use because of course the worst situations, the situations you don’t know how to handle, typically happen when there is nobody around to help you or three o’clock in the morning. It is important that caregivers have a few resources to walk them through those stressful situations.

I also think that for many people if they have taken care of themselves then they may have fewer of those anxiety provoking situations. It seems that many problems occur when they seem insurmountable and we feel overwhelmed. It is really important that we take care of ourselves so that fewer situations seem that way.

JACQUIE PEDEN

We now have time to open up for questions from the audience.

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TAMMY McCLUSKEY – TRAIL, BRITISH COLUMBIA

Hi, it is Tammy McCluskey from the West Kootenays. I was just reflecting on, as I was taught in working in home care nursing, that you let the patients and the families lead and not necessarily putting your agenda onto them. In looking at anticipating some of those questions, what would you suggest then to balance those two things?

DR. PRISCILLA KOOP

Thanks, Tammy, for your question. Absolutely, I think you were taught well that the patients and family open their home and you are a guest when you are giving care in their homes. What I suggest you do is offer the information. I think this point also raises the issue that not all of everybody wants information. There are many people who do. So, I think it is important to say, "Here is something I think that is going to be happening in the next few weeks and is this something you would like to know more about?". Then follow their lead from there. What I am suggesting is to simply raise the questions so they don't have to go through that process of thinking them up themselves and keeping them for you.

LEA KRAMER – BASSANO, ALBERTA

I just need a little clarification of a couple of the things that you refer to in the early part Priscilla. You referred to a study that Jacquie and someone else had done and I was wondering if you could either now or later email me the citation for that study?

DR. PRISCILLA KOOP

I will tell you very quickly and simply – Jacquie Peden and Jo-Anne Pollard were my Masters students at the University of Alberta and both of them looked at family caregiver needs. If you look up their names in any library database, you will find the titles for their theses at the University of Alberta and through interlibrary loan you can get them. **Editorial Note:** Peden MN thesis is entitled *Family caregiver needs just prior to the cancer patient's hospice admission to die* and Pollard MN thesis is entitled *Family caregivers of home-based clients with advanced cancer : needs and preferences*. Interlibrary loan available via www.library.ualberta.ca

BARB BIGGS – CALGARY, ALBERTA

I just wanted to acknowledge what you said again, specifically in regards to dementia care and individuals with Alzheimer's disease. There certainly is a difference in the trajectory and the needs of caregivers. There is a lot of concern and lack of understanding as families and providers enter into the end of life care and that people have not been informed, I guess, or supported as to what the death for that person will look like and be like. We, at the society (i.e., Alzheimer Society), are trying to work with other colleagues to better support families around end of life care because individuals with Alzheimer's Disease and other dementias certainly have the need also for quality end of life care and that quite often kind of gets misplaced with the disease process (particularly Alzheimer's can seem so very long).

DR. PRISCILLA KOOP

Absolutely! I think that you are absolutely right. I think it is important, too, to remember that family caregiving continues even if the person with Alzheimer's is admitted to a long-term care facility.

BARB BIGGS – CALGARY, ALBERTA

It is a different kind of role, but there still continues to be a misunderstanding around that area as well. When people see that transition of care, we used to think that people would be so very relieved and, in fact, they weren't because there were still all these other expectations and many of them weren't clarified and worked through so there were misunderstandings on both sides. The professional and the provider and then from the family caregiver end and I guess again with our learning we're getting a better handle at where people are at and what they need and that is very much continues to be team care and a team approach.

DR. PRISCILLA KOOP

I agree. I am involved in some research dealing with Alzheimer's caregivers after they have made the decision to institutionalize their person with Alzheimer's disease. We know that it is a very huge, stressful decision to make and yet once they have made that very stressful decision, they have to continue to give care for often up to years after before the person is admitted. We wanted to know what that was like so we're just analyzing that data now.

DR. PRISCILLA KOOP

I am just going to repeat your question. If I heard you right, you said that humor is really important and that it is important to bring laughter into end of life care. Is that correct? I think you're right. Who was it who said that everyday you should read a good book, listen to some fine music and tell a good joke or something like that? I think that is part of everyday life and we need that.

CHERYL McMILLAN – CRESTON, BRITISH COLUMBIA

Even in the Alzheimer's I see with clients yesterday and just going over some of the things and he was mentioning it like he shouldn't be saying anything related to humor and then I just started to laugh. Can you imagine that and he laughed out loud. I think that we have to give them permission to laugh at themselves or laugh at some of the things that are going on. It doesn't have to be walking into a home because it is end stage and having it be very sedate.

DR. PRISCILLA KOOP

It can get very grim, can't it? I think we need to be very sensitive in our humor. Some of us can have a very black sense of humor sometimes that can be seen as inappropriate. I really have to be careful about that, but I think that humor is very important. I would agree with you. It lightens our loads.

FAMILY CAREGIVER: HOW TO PROVIDE SUPPORT?

TAMMY McCLUSKEY – TRAIL, BRITISH COLUMBIA

It is Tammy McCluskey again from the Kootenays. I am reflecting on the system pressures that are on us at end of life and looking at respite and the sort of prescribed criteria and how to work within those because those can be huge challenges as well, particularly with the information you gave on causing caregiver anxiety that they have to leave and go somewhere else so that they can actually get some respite.

DR. PRISCILLA KOOP

I think the information I gave you adds a level of complexity to respite care but also I would think that at the same time it can be a relief because what we need to do is find out what respite means to any given individual. I am a crossword puzzler. I am still learning how to meditate. I don't do that well. I love to read. Those are things I need to be encouraged to take time out to do on a regular basis so that I can get respite for myself. It is not going to cost the healthcare system a dime. I think that other people like to

watch TV or do other things so I think it is a simple matter of finding out what it is that feeds people's souls (to use a certain phrase), or what helps people rejuvenate themselves. What have people done in the past to cope with stressful situations to make their life worth living and we need to figure out what those are and offer them.

In a sense it is a bit of a relief to the healthcare system that the respite services only work for certain people. For many they interfere with achieving respite. I guess it just means that we have to be a little more creative. We, in palliative care, tend to be very creative, resourceful and good problem solvers and we need to put those skills to work in a really down to earth kind of way.

JACQUIE PEDEN

It was a very informative session on family caregivers and hopefully answered your needs in the various areas that you are coming from.