



BY Pallium Canada

**Grief & Bereavement Literacy Series & All Together Series**  
**Session 8: “Exploring the Role and Impact of Advance Care Planning on Patient, Family and Caregiver Grief and Bereavement”**

Educational Presenter: Melody Jobse, Melody Jobse, Community Engagement Lead, ACP Master Trainer, BC Centre for Palliative Care

Lived Experience Presenters: Dr. Karen Cook ([kcook@athabascau.ca](mailto:kcook@athabascau.ca)) and Gayle Dunsmuir ([gayle.dunsmuir@gmail.com](mailto:gayle.dunsmuir@gmail.com))

**April 9, 2024, 12:00pm - 1:00pm**

AGENDA ITEM	DISCUSSION
<p><b>Introduction &amp; Territory Acknowledgment</b></p>	<p><b>Grief &amp; Bereavement Literacy ECHO Series and All Together Series: “Exploring the role and Impact of Advance Care Planning on Patient, Family and Caregiver Grief and Bereavement”</b></p> <p><b>Presenter: Melody Jobse</b></p> <p>Welcome to all participants, and introduction of the presenter, and presentation outline. Participants are notified that the session is being recorded.</p>
<p><b>Overview Summary Presentation &amp; Discussion</b></p>	<p><b>Presentation Summary</b></p> <p>Learning Objectives</p> <ul style="list-style-type: none"> <li>● Gain an overview of elements of Advance Care Planning</li> <li>● Be challenged to plan for their own future health and personal care wishes.</li> <li>● Be inspired to prepare to live well and die well.</li> </ul> <p><b>Introduction</b></p> <p><u>What is Advance Care Planning?</u></p> <ul style="list-style-type: none"> <li>● Advance care planning is part of life planning as we know life is complicated and full of ups and downs, but to make life easier, most people do some kind of planning for themselves. We plan financially for university or a vacation or the purchase of a new car.</li> <li>● Health care planning is planning for the changes that may occur in your health. It is all about making decisions for something even though it's not known or not anticipated so that you can speak for yourself and have a sense of advocacy and being able to share what your wishes are with others so that in the event they need to speak for you, they would also know what your wishes are.</li> <li>● Advanced care planning can simply be defined as the process of thinking about your values, beliefs, wishes for your future, health, and personal care, and sharing them with the people that you trust which can also include choosing who could make care decisions for you if you could not.</li> <li>● The elements of advance care planning are- THINK, TALK, PLAN. <ul style="list-style-type: none"> <li>○ Think about what matters most to you and who could make health care decisions for you if you could not.</li> <li>○ Talk about this with the people that you trust, your substitute decision maker or the person you choose and your healthcare providers.</li> <li>○ And then the last part is planning to record or share that plan with the people you trust in your healthcare providers.</li> </ul> </li> <li>● People often ask when to do advanced care planning and the answer is -the sooner the better. We don't know what happens, Life happens.</li> <li>● There are so many occasions of when to do and when to revisit your advanced care plan. It could be if there's an upcoming surgery or procedure, a change in</li> </ul>

your healthcare status, a change in the decision-making team, if you're retiring but most especially if a serious illness or a medical crisis happens.

#### Benefits of advanced care planning

- Advance care planning is a gift, and this is a gift that you can give your friends and loved ones as this will help them know what matters to you. When a crisis happens, it is an emotional setting of chaos with difference of opinions. ACP can help limit the disputes or confusion about what your health care wishes would be and the person that you appoint as a decision maker would be able to communicate better for your health care with the healthcare team.
- The gift of advanced care planning lets your health care providers know what kind of things are important to you. What are your cultural beliefs? What are your values and how they might affect your care decisions? What kind of life supports or interventions would you want to receive or refuse? What kind of treatments would you want to receive or refuse if you had the need for and could express capacity for those decisions?
- April 16<sup>th</sup> is the national and North American International Day of Awareness for Advanced care planning.
- For the past 9 years, the BC Centre for Palliative Care has invested in the public awareness campaign to challenge British Columbians to engage in the first steps of advance care planning- think, talk, plan. The theme for this year is If not you, who?
- Melody asked some reflective questions for participants to ponder on.
  - Have you experienced the death of a loved one who had made their values, wishes and their health care wishes known? How did living with this knowledge impact your grief, loss or bereavement journey.
- Comments and responses received during the session:
  - It was reassuring to know that we were following our loved ones' wishes, even though the decisions to be made were hard.
  - It helped a lot to feel more peace.
  - My grandmother couldn't have been more prepared or done more to help us after she passed away - financially, her representation agreement was incredibly detailed, and she talked about it regularly. It made me passionate about advocating for this advanced planning for myself and my close family, it's such a gift even though it can feel odd putting into place.
  - Gives me peace of mind. The whole family is on board because the person is in charge.
  - Having lost my husband recently - it was a relief that we had completed all of this a year ago. Made his decision to use MAID - very peaceful, but still incredibly hard to navigate this journey.
  - Have you experienced the death of a loved one without the knowledge of care or understanding of their values and beliefs? How did living without this knowledge impact your grief, loss or bereavement journey.
- Comments and responses received during the session:
  - Heaviness, no closure, guilt.
  - Caused conflict in family.
  - Without a plan, my brother's death was very difficult for us all. We had to decide. It is difficult for families when several siblings are left to negotiate the plans and can be messy.
  - I had a dear friend pass quickly and we did not get a chance to discuss ACP. She was young and felt she had time. As an EOL familiar with ACP, I felt I had failed her.
  - When we lost a loved one years ago - he had nothing in place, which caused a lot of "drama" between family members. Most felt they had a say, and arguments did occur.
- In summary, advance care planning is thinking, talking, and planning for your future health and personal care. This should be a conversation to begin with your family and your loved ones. While we are reviewing our finances and while we're doing our life planning, this is also a key time to look at your health care planning.

<p><b>Questions/discussion</b></p>	<p><b>Lived Experience Presenter: Gail</b></p> <p><b>Q: Could you share a little bit about your ACP story and the impact that it had on you?</b></p> <p><b>A:</b> Gail’s personal experience with an advanced care plan was from her mother’s decision to have an advanced care plan. Following her death, she was pleased with the way things turned out. It was exactly the way her mom would want her death to be.</p> <p><b>Q: How did the ACP conversation come about?</b></p> <p><b>A:</b> The journey with the advanced care plan started on her mom's 90<sup>th</sup> birthday where they settled down to actually make the plan because she had a lot of friends and they were all getting sick and going into homes, so she knew some things that she did not want and things that she did want. In a simple way, she put forward her values, her beliefs, and her wishes. The plan was completed and then every year on her birthday, they would review together to be assured that she had not changed her mind about anything or that this was still exactly what she wanted.</p> <p><b>Q: Through and through that process did she ever change her mind?</b></p> <p><b>A:</b> A week after her 95th birthday she was taken to the hospital with suspected pneumonia. She was only in there a couple of days and then released later. The doctor was quite concerned because she had no records whatsoever as she hadn't been to the hospital since she gave birth to Gail 71 years ago in northern British Columbia. This provided an opportunity for Gail to talk about her mom’s advance care plan and get it in her record. She had a day and a night with her before she died all very calm and very peaceful and exactly what she wanted.</p> <p><b>Q: Could you speak a little bit about your grief journey like?</b></p> <p><b>A:</b> She received support from family and friends and from a local hospice where a winter memory walk was done in the dark and the whole path is lit with candles which felt special. Rituals really helped and hearing lots of other stories of other people's journeys, some quiet time and some very busy happy times.</p> <p><b>Lived Experience Presenter: Karen</b></p> <p><b>Q: Can you share a little bit about your ACP story and then also the impact it had on your grief journey?</b></p> <p><b>A:</b> Karen’s husband; Russ, died 7 years ago at the age of 57years. He was healthy and energetic. She got a phone call one sunny afternoon in February from the constable of the Calgary airport informing her that her husband was unconscious and in the back of an ambulance and she should get to the hospital in Calgary as soon as she could. Her professional life has been around end-of-life, grief, and bereavement and then suddenly it was her personal life, and this was a totally different experience. While the whole family gathered to get more reports, within 36hours they knew that there was no more Russ to come back to. Karen had lots of conversations with her husband; Russ, on what his wishes were including Russ’s friends and he made it very clear and evident at 57 years old what it was that he wanted to be done if anything happened to him.</p> <p><b>Q: How did you get supported with your loss after Russ died?</b></p> <p><b>A:</b> Knowledge from her professional experience helped as she dealt with a sense of overwhelming feeling. Sometimes having second thoughts and knowing it was the right thing to do even as hard as that was to do. It was helpful because all the immediate family were on the same page.</p> <p><b>Q: What was the most surprising thing that you found in your grief journey?</b></p> <p><b>A:</b> It was always hard because there were so many things that compounded it just some of the ordinary nuances of life that somehow create huge complications and how the most mundane thing can set off a cataclysm of grief and sadness and feeling like it is hard to crawl out of that whole place. Also, wondering if that feeling of heaviness will ever lift. Being surprised by the things that brought joy, surprised by the kindness of strangers. We tend to want to close off and not being public about it shedding lots of tears in public and it is interesting how people come alongside and help change that moment, which makes the next moment better.</p>

<p><b>Session Materials and Additional Resources</b></p>	<p><b>Resources shared during the session:</b>  <a href="https://www.bc-cpc.ca/wp-content/uploads/2020/03/Informational-Handout-English-2020-08-06.pdf">https://www.bc-cpc.ca/wp-content/uploads/2020/03/Informational-Handout-English-2020-08-06.pdf</a></p> <p><b>Session Recording</b> is uploaded on the BCCPC’s YouTube page: <a href="#">HERE</a></p> <p><a href="#">Dr. Joshua Black’s podcast’s website</a></p> <p>Action plan link  <a href="https://www.bc-cpc.ca/about-us/activities/new-projects/bereavement-study/grief-and-bereavement-support-in-bc-a-collaborative-improvement-action-plan/">https://www.bc-cpc.ca/about-us/activities/new-projects/bereavement-study/grief-and-bereavement-support-in-bc-a-collaborative-improvement-action-plan/</a></p>
<p><b>Closing</b></p>	<p><b>Next ECHO Grief &amp; Bereavement Literacy Series:</b></p> <p>Zoom Registration for next Grief &amp; Bereavement Literacy ECHO session:  <b>“Teen Grief: Responding, Rebuilding and Relearning”</b>  <b>May 8<sup>th</sup> 12pm – 1pm</b>  <a href="#">Registration link</a></p> <p><b>Past sessions in this series can be found <a href="#">here</a>.</b></p> <p>Visit the <a href="#">BCCPC ECHO session website</a> page for upcoming sessions in this series and other series currently running open for registration.</p> <p>Subscribe: <a href="#">BC Centre for Palliative Care YouTube page</a></p> <p>Subscribe: <a href="#">BC Centre for Palliative Care Newsletter</a></p>