## Psychosocial- Spiritual Alberta ECHO Series

#### **Session 1:**

Holiday Blues: Supporting Patients Receiving Palliative Care and Grieving Families During The Holidays





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Certified Music Therapist, Education Lead at Covenant Health Palliative Institute

Date: December 14, 2023

## Introduction

#### **Presenter:**

Sheila Killoran, MA, MTA, FAMI Certified Music Therapist Education Lead, Covenant Health Palliative Institute







## The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

Stay connected: <u>www.echopalliative.com</u>





## **Disclosures**







#### Reminders

- This session is being recorded. Your microphones are muted.
- Please do <u>not</u> disclose any personal health information during the session.
- Using the chat function:

Please introduce yourself and include where you are joining us from

If you have any comments or are experiencing technical difficulties

Please post your questions in the chat





### Learning Objectives

By the end of the session, participants will be able to:

Identify the unique needs and pressures on patients and families during holidays

Reflect on the impact and role of therapeutic presence

Learn strategies to adapt interventions and support opportunities for meaningful moments







# Holiday Blues: Supporting Patients Receiving Palliative Care and Grieving Families During The Holidays





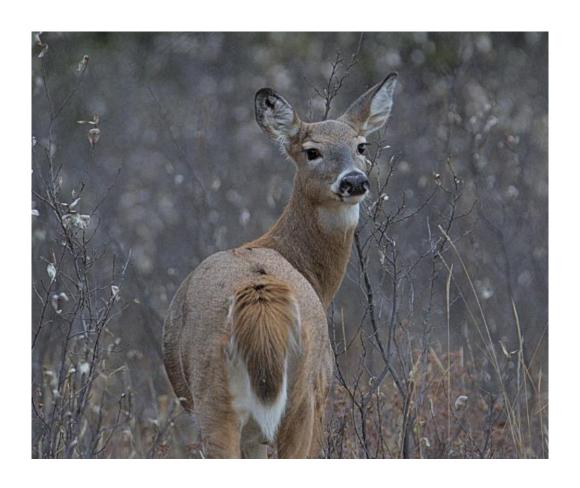
#### **Land Acknowledgement**

I am presenting to you from Treaty 6 territory and Metis homeland.





## **Gentleness**





## **Grief Experience**

Each person's grief is unique, and shaped by:

- Support network
- Past experiences
- Relationship with the person they are grieving
- Religious and spiritual beliefs/ customs
- Circumstances of death / illness
- Social and cultural background <a href="https://speakinggrief.org/get-better-at-grief/understanding-grief/grief-is">https://speakinggrief.org/get-better-at-grief/understanding-grief/grief-is</a>



### What does grief look like?

## People may experience many conflicting emotions...

- shock (numbness, disbelief)
- disorganization (confusion, yearning)
- anxiety (panic, fear)
- strong emotions (blame, anger, guilt or regret)
- sadness or depression
- relief or release

## And varying physical expressions of grief...

- low energy
- trouble sleeping
- aches and pains
- tightness in the chest
- digestive issues



## **Grief and Mourning**

"Grief is what you think and feel on the inside, and mourning is when you express that grief outside of yourself..." – Alan Wolfelt





## **Anticipatory Grief**

Is grief experienced by both the dying person and their family members before the death occurs. It may result in somatic, emotional, cognitive, or spiritual reactions and the relationship between family members may be affected.

Khanipour-Kencha, A., Jackson, A. C., & Bahramzezhad, F. (2022) Anticipatory grief during COVID – 19: a commentary. *British Journal of Community Nursing 27(3)*, 114-117.



## **Expressions**

Loss – Oriented\*: deal with aspects of the loss such as yearning, crying or dreaming of the deceased

Restoration- Oriented\*: rearranging life as a result of the loss; adjusting to one's life without the deceased, reflection on, and connection to sense of self, to others.

Grief as a spiritual and emotional experience.

<sup>\*</sup> Stroebe M. & Schut H. (1999). The dual process model of coping with bereavement: rationale and description. Death Studies 23 (3) 197-224.



## **Paradox of Holiday Blues**



Bendana, A, (2017). Coping with grief during the holidays, *Nursing* 47(11), 54-56.



## Calendar of Holidays in December

<b>4</b>		December 2023				
Sun	Mon	Tue	Wed	Thu	Fri	Sat
					<b>1</b> World AIDS Day	Int'l. Day for the Abolitio n of Slavery
3	4	5 Today	6	7	8	9
Advent Begins Int'l. Day of Persons wit	Nat'l. Cooki e Day	Int'l Volunte er Day World Soil Day	St Nicholas	Hanukkah ( Start) Int'l. Civil Av iation Day	Hanukkah ( Cont.) Immaculate Conception	Hanukkah ( Cont.) Genocide P revention D
h Disabilitie s		Juy		Tallori Day	Сопосраст	ay Int'l. Anti-Co rruption Da y
10	11	12	13	14	15	16
Hanukkah ( Cont.)	Anniv. Statut e of Westmi	TO VALUE OF THE STATE OF THE ST	Hanukkah ( Cont.)	Hanukkah ( Cont.)	Hanukkah ( End)	
Human Rig hts Day	nster Hanukkah ( Cont.) Int'l. Mounta in Day	Int'l. Day of Neutrality Int'l. Univers al Health Co verage Day				
<b>17</b> Nat'l. Maple Syrup Day	18 Arabic Lang uage Day Int'l. Migrant s Day	19	20 Int'l. Human Solidarity D ay	21 Winter Solsti ce	22	23 Festivus
24	25	26	27	28	29	30
	Christmas	Boxing Day	St John			
31						WinColondor



## A Story of Christmas In Palliative Care



## The Pressure: facing the "should's"

"This holiday should be a time of happiness and joy."

"I should make her favourite dishes."

"What will they think if we don't have the usual festivities?"

"I have to keep on a happy face for the children."

"It's his last holiday, I need to make it special!"



What holiday "shoulds" have you heard or experienced?

#### **Pressures on Clients/Patients**

- Financial pressures
- Death anxiety "I need to stay alive"
- Energy & stamina
- Pressure to be "happy" and remain "alert"
- Worry about symptoms may minimize pain and symptoms
- Try to avoid crisis

#### **Pressures on Families**

- Financial pressures
- Wish for "Extra" special, loving connection
- Pressure to be emotionally strong
- Caregiving desire to "go home / stay home"
- Hosting/ hospitality unexpected guests (helpers vs entertain)
- Energy



What meaningful or supportive aspect of the holidays have your witnessed or experienced?



## Renew resources for living

- Engage in reflection
- Meaningful spiritual or religious rituals or activities
- Time for introspection, rest, prayer, meditation
- Beloved traditions & memories
- Family & Friends

Dr. Alan Wolfelt, Helping Yourself Heal During The Holidays, Center for Grief and Loss <a href="https://www.centerforloss.com/2016/12/helping-heal-holiday-season/">https://www.centerforloss.com/2016/12/helping-heal-holiday-season/</a>



## How We Show Up: Companioning Philosophy

#### Companioning is about walking alongside...

- Listening with the heart
- Witnessing
- Being present to another's pain
- Learning from the person
- Compassionate curiosity
- Sacred silence
- Honouring the spirit
- Respectful presence
- Being still



## **How We Show Up**

Listen. Your physical presence and desire to listen without judging are critical helping tools.

Compassion. Give the person who is grieving permission to express their feelings without fear of criticism or judgment.

Be there. Your ongoing and reliable presence is the most important gift you can give.

## **Supporting Anticipatory Grief**

- Meaning-centered therapy
- Opportunities for connection
- Naming the experienced losses
- Cultural & spiritual support
- Use of non-verbal approaches for expression (Art Therapy, Music Therapy, Expressive Arts)

## **Helping Clients During The Holidays**

**Acknowledge** - that these holidays will be different from those in the past and that they will bring with them emotionally difficult experiences

**Express their feelings** – grieve, cry, be honest, and share. It goes against the expectation of the season, but making space and expressing grief and challenging feelings is very healthy

**Take time to remember** – look at photos, remember the other years, traditions, photos, mementos. What do you miss, what was special?

## **TIP: Talk about your grief**

**Be Honest** - in dealing with what to expect from the holidays. Be sensitive to the requests of loved ones as to what they do and do not want to do. Communication is key here.

If you are the patient, be upfront with well-meaning caregivers. Tell them when you need alone time and ask them to respect that, and listen to what others want, as they are also feeling grief — just in a different way

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### TIP: Do what is right for you during the holidays

**Decide on the traditions** you will keep and which ones you will put aside. You can even make new traditions this year.

Plan ahead for family gatherings, its okay no say no.

Be selective of the traditions or experiences you want to engage in.

What can you do to support special and meaningful moments?

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## Meaning - ful

#### What is meaningful?

- Of significant quality
- especially: implication of a hidden or special significance

#### Pick three things:

What three things would fill up your cup this month?

What three holiday \_\_\_\_ are most meaningful to you?

(foods, rituals, practices, traditions, songs, events, gatherings, decor.)



## TIP: Be tolerant of your physical and psychological limits

**Slow Down** - Dealing with a life-threatening illness can't be done on a full-speed-ahead schedule. Now more than ever, you have to slow down, clear your schedule of things that sap your energy, and concentrate only on the events or tasks that truly bring you happiness.

It is okay to change your mind & have a back up plan

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### **Energy Conservation Choices**

Meaning

High Meaning/ Low Energy

High Meaning / High Energy

Low Energy/ Low Meaning High Energy/
Low Meaning

Energy

#### **Examples:**

- Making homemade tortiere
- Going to temple, synagogue, service
- Listening to holiday music
- Watching lights on the tree
- Card tournament
- Lighting advent candles
- Holiday shopping at the mall
- Cleaning the house
- Buying presents



## Tips for holidays in hospice/ palliative care



- Choice (do/not)
- Adapt
- Create new







#### **Decorations**

Make the space your own!



#### Adaptations:

If desired decorations and familiar objects from home, holiday images, décor, and lights are something that can still be enjoyed and viewed with little adaptation needed.

Use electric/battery candles in facilities/hospice



#### **Rituals**

Cultural or Spiritual Rituals: connection and drawing people together in meaningful act.

Adaptation: In discussion with client/family, as appropriate and needed.

For smudging or protocol, Indigenous Cultural Advisors or cultural navigators can facilitate, and Spiritual Care practitioners can be called as needed inform staff and follow process (ie: in many Acute Care sites, call physical plant when arranging for smudging in the room





## **Lighting Candles**

Lighting the Menorah



During Hanukkah, one of the most important traditions is lighting the menorah, a nine-branched candelabra that represents the lamp (and the miracle) from the Hanukkah story... for the 8 nights of Hannukkah, families come together and light a new candle of the menorah, from left to right while saying a blessing.

Adaptations: If you will light the menorah in patient's room, consider electric candles. Light at home, and facetime with the patient, while some family is bedside with them to help them read or listen to the prayer, while it is being said at home



## **Special Food**

Eating special food can be a main feature of festivities.

Adaptations: Cook for comfort



Find out what the person's favourite dish or food of the holiday season is and prepare for them. Bring in small servings that could be eaten when they are able/alert/in the mood. You may have to adapt the tradition. Be aware that a small taste can be enough- even if they cannot stomach a large meal.



## Blessings

Blessings and prayers are part of many personal and religious holiday traditions Adaptations:



Few adaptations are needed. You may have someone come recite a blessings or prayer while patient listens, over facetime, or use an audio recording.



## **Giving Gifts**

#### Adaptations:

- Gifts of time such as having grandchildren over for a short visit to watch them open presents.
- Gifts of comfort fuzzy blanket, slippers,
- Gits of meaning Gifts of meaning- sentiment, legacy, photos
- Consumable Gifts music, movie, candy





## **Gatherings**

#### Adaptations:

Have a few people over at a time.

Reduce the amount of socializing/festivities



If at a home, have a room or place for the patient to go lie down, take a rest in a quiet room if needing a break

Be sure to be aware of pain medication and comfort medication/seating tolerance etc.

If having gatherings in the Pt. room; limit length of time; be aware of fatigue. Or patient may be happy to sleep while others are chatting and laughing in the room – brining cheer. Up to them.

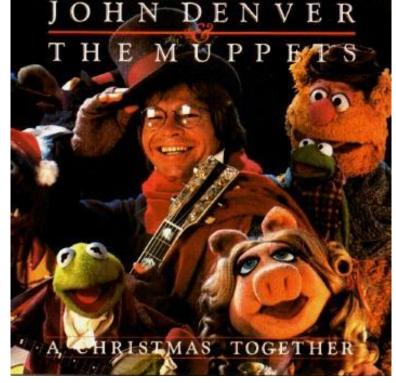


### Music

Listening to songs of the holiday.

Adaptations: not much is needed

to adapt to enjoy music.



Be aware of associated memories, if they are in the mood for listening, and the need for times of silence and quiet as well



Is Quality Time or Quantity of Time more important?



## **Quality and Quantity Time**

- Hard to determine how the person will be feeling
- May need to adjust timing of activities
- Quantity time may allow you to catch moments when person is more alert
- Energy and cost factors, self-care



## TIP: Be with supportive comforting people

Help identify them. It is not always who clients expect

- Who do you feel yourself around?
- Who can you be honest with?
- Who is giving you practical help right now? Help/respite.

Health Care Professionals, we can make an extra effort to be a supportive and comforting person to clients and families at this time of year.

#### Provide social support for someone with few visitors

### Love does not end with death

Talk about the person who died

Do things in the holiday that remind you of them – favourite song or make a special dish

Create a tradition in memory of your loved one that will keep them in your heart every year.

Light a memorial candle or ritual of remembrance

Embrace treasured memories



### **Glimmers of Gratitude**

Adjust the expectations to meaningful moments or to

Glimmers of gratitude; felt genuinely at that time.

Be prepared for grief bursts.

"Think of grief as a spiral instead of a circle: these grief bursts often feel like you are back at the beginning of your loss-like you are going in circles. But grief moves in a spiral — although it feels like you are going round and round, each time you are actually at a different level in the process". — Sandy Ayre

Yoga For Grief Support, Sandy Ayre October Newsletter 2023. www.yogaforgriefsupport.com



"As you approach the holidays, remember: grief is both a necessity and a privilege. It comes as a result of giving and receiving love. Don't let anyone take your grief away. Love yourself. Be patient with yourself. And allow yourself to be surrounded by loving, caring people."

- Alan Wolfelt



### Resources

Public Consultation | 1/11 (simplesurvey.com) — Survey on Grief — Last Day to complete is December 14, 2023 Canadian Grief Alliance

MyGrief.ca

KidsGrief.ca

www.youthgrief.ca

The Dougy Center for Grieving Children & Families | Portland, OR

HospiceCalgary.ca/ChildrensGriefCentre



### Resources

MyHealth.Alberta.ca > Palliative Care > Grief and Bereavement

Home - Center for Loss & Life Transition

<u>Learning Hub (virtualhospice.ca)</u> – training for Health Care Providers

Videos on Grief At Christmas:

Christmas and family holidays are very hard for me on Vimeo
Our first Christmas without Erica on Vimeo
My mom's Christmas legacy on Vimeo



How have families/patients you have worked with adapted their holiday traditions?



What special rituals of remembrance have you seen people engage in?











In your role, how can you support moments of meaning & connection for clients and families?

## Questions?

Do you have any questions?

Share one take home message from the presentation today.







#### Psychosocial-Spiritual Alberta ECHO Series – Session 2

# How Do I Know What I Don't Know? Exploring the Alberta Palliative Care Competency Frameworks

- Next session we will explore:
  - Application of palliative care competencies for healthcare providers
  - Reflect on how palliative care competency domains and statements apply to psychosocial spiritual care
- Join us on 18th January, 2024 at 12.00 pm
- If you haven't already, register here:
   <a href="https://albertahealthservices.zoom.us/meeting/register/u5MufuyoqDwvHNTJSNIw8UcpP7Qbm">https://albertahealthservices.zoom.us/meeting/register/u5MufuyoqDwvHNTJSNIw8UcpP7Qbm</a>
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### Thank You!

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