Navigating Palliative Care at Home Insights from a Bedside Nurse

Project ECHO
Palliative Care - Canada
BY Pallium Canada

Host: Diana Vincze

Presenters: Jill Yu Tom and Paula Habib

Date: 19 January 2024

Territorial Honouring

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: www.echopalliative.com

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Project ECHO Palliative Care - Canada BY Pallium Canada

LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by CFPC and Royal College.

Pallium Canada LEAP CORE

Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Introductions

Host

Diana Vincze, Palliative Care ECHO Project Manager

Presenters

Paula Habib, RN
Home care Nurse at Nova
Responsable des PAB

Jill Yu Tom, BsN CHPNC (C)
Nurse Clinician in Palliative home care at Mount Sinai Hospital Montreal

ECHO Support

Aliya Mamdeen, Program Delivery Officer

Conflict of Interest

Pallium Canada

- Non-profit
- Partially funded through a contribution by Health Canada
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook

Host/Presenters

- Diana Vincze: Nothing to disclose
- Paula Habib : Nothing to disclose
- Jill Yu Tom: Nothing to disclose

Welcome and Reminders

- For comments, please use the chat function
- For questions, please use the Q&A function, these questions will be addressed at the end of the session
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session.

Navigating Palliative Care at Home: Insights from a Bedside Nurse

Have you ever heard?

I am not dying, why do I need palliative?

I want to die at home!

I want to stay home as long as possible!

Can I really keep my love one at home?

Do I need to go to hospice care now?

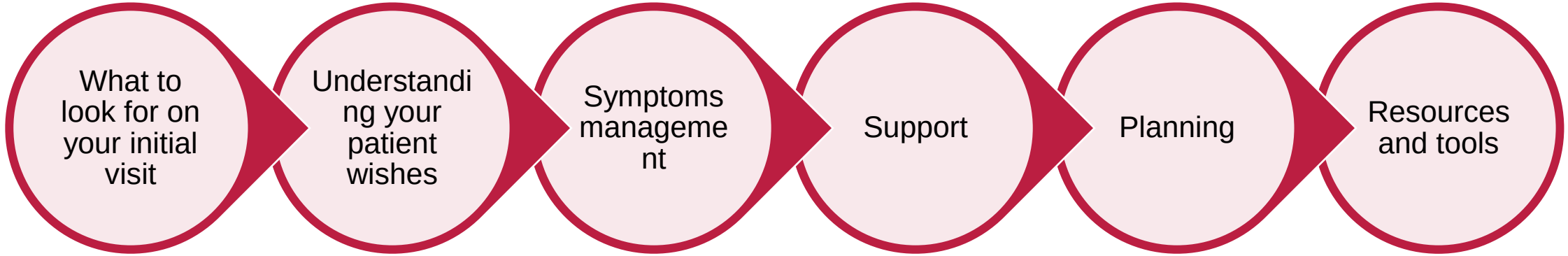
I don't want to die at home

I am not ready

I don't want my home to look like a hospital.

I don't want to be a burden on my love one

What do we need to know?



Getting to know each other

- ***<u>Who is your patient and family? (take the time to get to know the patient and environment !)</u>***
  - Take the time to get to know them! Who are they? What did they do? Religious background?
  - Who is involved?

  - Look around the house! Living environment? Pictures? Hobbies? Religious items? Books?
  - Smoker? Animal? *
  - Salable vs insoluble
  - Hazards? Carpets?
  - Stairs?

Getting to know each other

Know what they want and wishes to hear

- Explore what they know about their illness
- Ask how much information do they want to receive
- Determine what is important (wishes? Hopes?goals?)
- ** Allow time for reflection; use silence!**

- Using communication tools…

Important to know that not everyone can stay home for an end of life!

Serious Illness Conversation Guide

CONVERSATION FLOW		PATIENT-TESTED LANGUAGE
1. *Set up the conversation* Introduce the idea and benefits Ask permission	SET UP	"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay**?"
2. *Assess illness understanding and information preferences*	ASSESS	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. *Share prognosis* Tailor information to patient preference Allow silence, explore emotion	SHARE	**Prognosis:** "I'm worried that time may be short." *or* "This may be as strong as you feel."
4. *Explore key topics* Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	EXPLORE	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. *Close the conversation* Summarize what you've heard Make a recommendation Affirm your commitment to the patient	CLOSE	"**It sounds like** _____ is very important to you." "Given your goals and priorities and what we know about your illness at this stage, **I recommend**..." "**We're in this together.**"
6. *Document your conversation*		

ARIADNE LABS

https://www.ariadnelabs.org/2016/03/09/redesigned-serious-illness-conversation-guide-supports-more-better-and-earlier-conversations-about-what-matters-most/

EMPATHIC RESPONSES					
Naming	**Understanding**	**Respecting**	**Supporting**	**Exploring**	**"I Wish"**
This must be… • Frustrating • Overwhelming • Scary • Difficult • Challenging • Hard	What you just said really helps me understand the situation better.	I really admire your • Faith • Strength • Commitment to your family • Thoughtfulness • Love for your family	We will do our very best to make sure you have what you need.	Could you say more about what you mean when you say… • I don't want to give up • I'm hoping for a miracle	I wish we had a treatment that would cure you (make your illness go away).
I'm wondering if you are feeling … • Sad • Scared • Frustrated • Overwhelmed • Anxious • Angry	This really helps me better understand what you are thinking.	You (or your dad, mom, child, spouse) are/is such a strong person and have/has been through so much.	Our team is here to help you with this.	Help me understand more about…	I wish I had better news.
It sounds like you may be feeling …	I can see how dealing with this might be … • hard on you • frustrating • challenging • scary	I can really see how (strong, dedicated, loving, caring, etc.) you are.	We will work hard to get you the support that you need.	Tell me more…	I wish you weren't having to go through this.
In this situation, some people might feel …	I can see how important this is to you.	You are such a (strong, caring, dedicated) person.	We are committed to help you in any way we can.	Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you.	I wish that for you too. [In response to what a patient or family members wishes, such as a miracle]
I can't even imagine how (NAME EMOTION) this must be.	Dealing with this illness has been such a big part of your life and taken so much energy.	I'm really impressed by all that you've done to manage your illness (help your loved one deal with their illness).	We will go be here for you.	Can you say more about that?	I wish we weren't in this spot right now.

Goals of Care Conversations training materials were developed and made available for public use through U.S. Department of Veterans Affairs contracts with VitalTalk [Orders VA777-14-P-0400 and VA777-16-C-0015]. Updated June 2018.

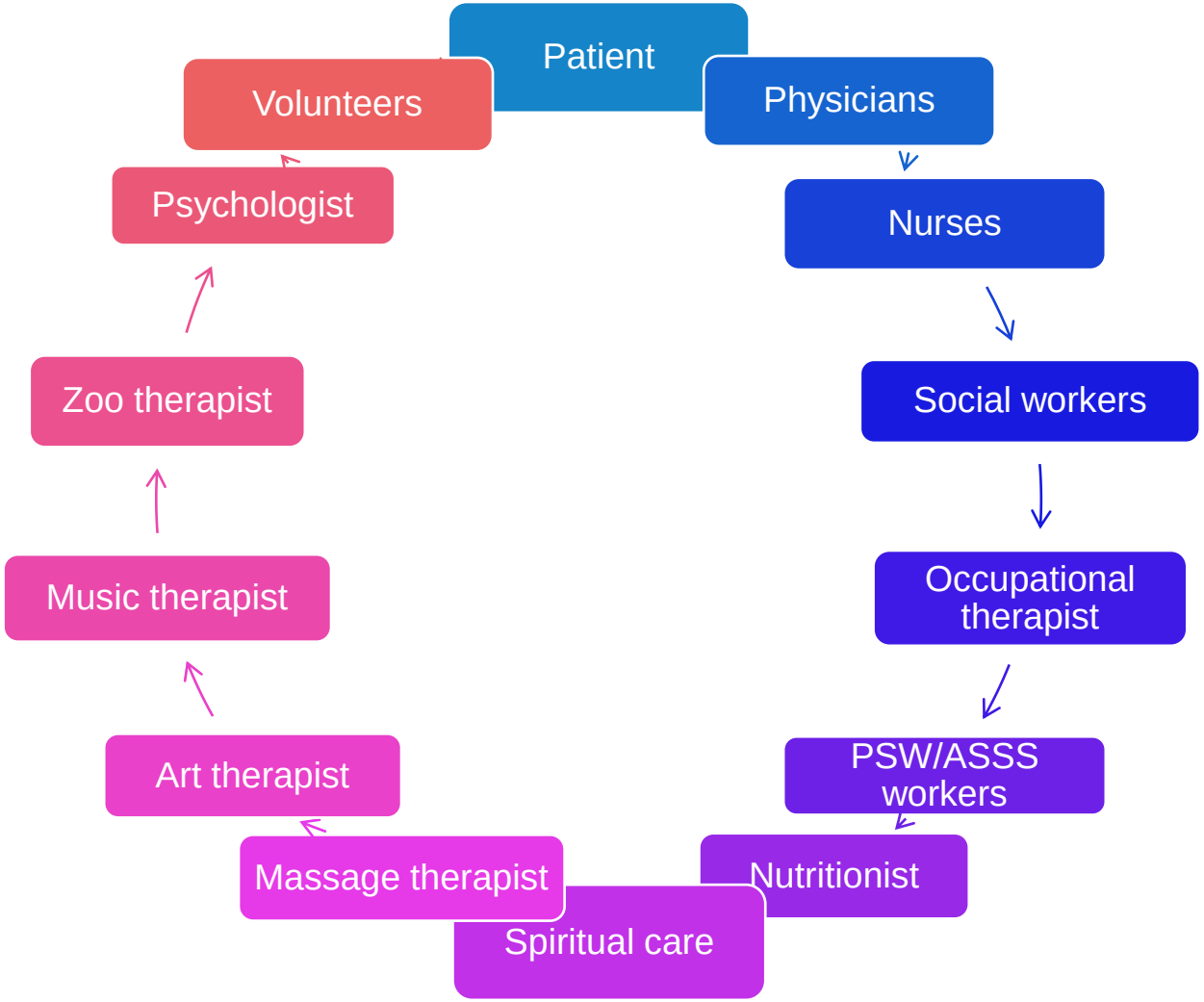
https://socca.org/newsletter/goals-of-care-conversation-in-the-intensive-care-unit-during-the-covid-19-pandemic-volume-32-issue-4/

REMAP	ADDRESSING GOALS OF CARE
REFRAME why the status quo isn't working	*(You may need to discuss serious news such as a scan first.)* *"Given this news, it seems like a good time to talk about what to do now. We're in a different place."*
EXPECT emotion - respond with empathy	*"It's hard to deal with all this."* *"I can see you are really concerned about [x]."* *"Tell me more about that—what are you worried about?"* *"Is it ok for us to talk about what this means?"*
MAP out what's important	*"Given this situation, what's most important for you?"* *"When you think about the future, are there things you want to do?"* *"As you look toward the future, what concerns you?"*
ALIGN with the patient's values	*"As I listen to you, it sounds the most important things are [x-y-z]."*
PLAN to match values	*"Here's what I can do now that will help you do those important things."* *"What do you think about it?"*

Goals of Care Conversations training was developed by VA National Center for Ethics in Health Care through contracts with VitalTalk. Updated 01/2018.
www.ethics.va.gov/goalsofcaretraining/practitioner.asp

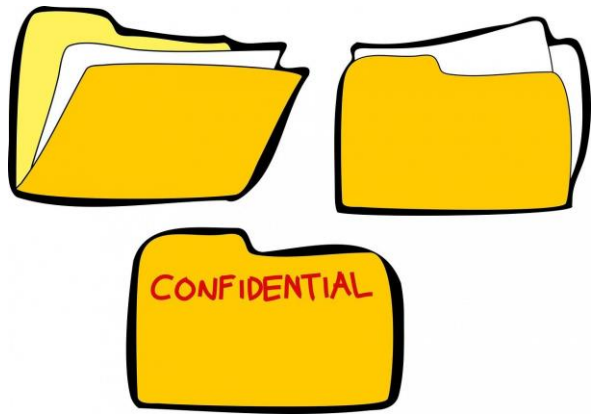
https://socca.org/newsletter/goals-of-care-conversation-in-the-intensive-care-unit-during-the-covid-19-pandemic-volume-32-issue-4/

Getting to know each other



Getting to know each other

- ***Who are you? Where can they reach you?***
  - Acknowledge that it might be overwhelming to get to know the team
  - Explain your role and prepare the patient/family about other professionals that might need to get involved.
  - If possible, do joint visits.
  - Write down all numbers in 1 area
  - Write down emergencies number in different area
  - Provide email if possible.
  - Have a patient/family folder



Providing symptoms management

- Review of symptoms
  - Many different ways! Be creative!
  - Lead the interview by doing “review of systems”
    - Advantage: more structured interview; allow you to review all systems
    - Disadvantage: may be missing some details; may sound repetitive as they might have mentioned some information when reviewing other symptoms
  - Ask patient and family to describe how a day looks like?
    - Advantage: allows you to visualize the function of your patient; sound more like a conversation and less as an interview.
    - Disadvantage: forgetting to review certain systems or information; may sound disorganized; needs to ask patient to clarify some information; takes more time.

Edmonton Symptom Assessment System: Numerical Scale

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name _____

Date _____ Time _____

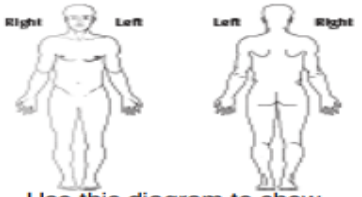
Complete by *(check one)*

- ☐ Patient
- ☐ Caregiver
- ☐ Caregiver assisted

CANADIAN Virtual Hospice

SYMPTOM DIARY

This diary can be used to record your symptoms, when they occur and what you did to treat them. It can be taken to your health care appointments to help explain the symptoms you are experiencing. If your symptoms are not relieved by your treatment, call your health care provider.



Use this diagram to show the location of your pain

Date and Time	**What is your symptom?** *Name the symptom and location. Describe the symptom and use the number scale above*	**What were you doing when the symptom started or got worse?**	**Did you take medication or try other treatments?** *If so, what, and how much?*	**How did they work?** *Rate the symptom, describe it and use the number scale above*	**Other comments, issues or side effects?**

Reviewed April 2009

Adapted from: AGS Panel on Persistent Pain in Older Person. American Geriatrics Society. J Am Geriatr Society 2002; 50: June suppl

Microsoft PowerPoint - CVH Symptom Diary [Read-Only] [Compatibility Mode] (virtualhospice.ca)

Providing symptoms management

What to consider?

- Capacity to understand information
  - Be creative in your explanations; use common language that they might understand. Use examples or comparisons. Is the patient confused?
- The finances
  - Ensuring that medications that are prescribe are within what the patient can afford.
- Support system
  - Who is the substitute decision maker? Coping? How many people are involved? Willingness to learn to administer medications?
- Environment
  - Clutter? Habits? Does the patient live alone? How do we get in the house? Children?

Providing symptoms management

- Beliefs
  - Understand the beliefs of medications; homeopathic medications? Alternative treatment?
- History
  - What happen in the past in terms of medications or other treatment? i.e. allergic to morphine.
- Community pharmacies
  - Opening hours of the pharmacies
  - Delivery time
  - Ability to prepare SC medications/pumps/magistrales (lollipops; lozanges; popcicles; suppository; elixir; etc)

Providing symptoms management

- What are the challenges that patient/family need to know?
  - Responses to symptom management strategies can vary widely among individuals. What works well for one person may not be as effective for another.
  - Awareness: Understanding that finding the most effective approach may require some trial and error, and it's essential to communicate openly with healthcare providers.
  - Effective communication about symptoms can be challenging due to the emotional nature of the situation, language barriers, or the difficulty in articulating complex symptoms.
  - Delay in diagnostic testing. STAT blood work may not be done on the same day. We may only be able to organize a blood work the following day.
  - Nurse and physicians will depend more on assessing symptoms by an interview and a physical assessments. Ultrasounds; x-rays; scans may not be available.
  - Decisions about aggressive symptom management versus focusing on comfort care can be emotionally challenging for patients and families.

Providing symptoms management at end of life

- Always be prepare for any deterioration.
  - Have SC medications for distress protocol ready (emergency toolbox: opioids; Haldol; midazolam; scopolamine/glycopyrrolate)
- Simplifications
  - Write down all the medications and it's indication
  - Color coordinate the medication with the label of the medications
  - If possible, have the cap of the medications (for prefilled syringes) color coordinated
- Repeat the information provided
  - Write down the emergency phone numbers on all documents
  - Schedule regular schedule to answer teaching
- Reassurance
  - " There is no mistakes if you give the wrong medications"

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Mount Sinai Hospital
5690 Cavendish Blvd
Côte Saint-Luc, QC H4W 1S7
514-369-2222 ext 3202

Medication if needed

☐Morphine _____ mg subcutaneously every _____ hours if NEEDED for

☐Dilaudid _____mg subcutaneously every _____ hours if NEEDED for

- Pain
- Cough
- Shortness of breath

☐Midazolam (versed) _____mg subcutaneously every_____ hours if NEEDED for

- Insomnia
- Agitation
- Anxiety
- Restlessness

☐Scopolamine 0.4mg subcutaneously every_____hours if NEEDED for

- Terminal rales
- Terminal secretions

☐Nozinan (methotrimeprazine)_____mg every _____ hours if NEEDED for

- Terminal delirium (agitation; restlessness; grimacing; sensation of pain not relief with opioids)
- Agitation

☐Haldol (Haloperidol) _____mg every _____hours if NEEDED for

- Agitation
- Delirium
- Nausea
- Vomiting

MAJOR DISTRESS PROTOCOL (PANIC MOMENTS)

1. _____. _____. mg + Midazolam _____. mg + scopolamine 0.4mg
   WAIT 20 MINUTES if still in distress, please continue to step 2

2. _____. _____. mg + Midazolam _____. mg
   WAIT 20 MINUTES if still in distress, please continue to step 3

3. _____. _____. mg + Midazolam _____. mg + scopolamine 0.4mg

IN CASE OF EMERGENCY CALL GARDE MEDICALE
514-521-2107

NB: Opioid: red; midazolam: yellow; scopolamine:orange; nozinan: blue; Haldol: green

Importance of providing support

- ***<u>Create a plan with patient and family.</u>***
  - Name what is important for the patient/family
  - “brainstorm” what would be your plan
  - Explain to patient/family that plan can change
  - What is your frequency of visit? Phone calls? Working hours?
  - Depending on the type of patient and information that they would like to obtain; prepare your patient for the future. (equipment; SC meds; respite: EOL…)
  - “Can I be honest with you?”
  - Don’t be afraid of repeating yourself.
  - ALWAYS be prepare for a plan B or C!

Caregiver support / resources

Caregivers play a crucial role in providing physical, emotional and practical support to patients receiving palliative care at home.

To ensure that your client receives optimal home care and is comfortable at home, you may need to make several referrals to different healthcare professionals and services.

Occupational Therapist (OT): To assess and address the client's ability to perform daily activities, mobility, adaptive equipment, home safety, and environmental modifications.

Social Worker: To address the client's social and emotional needs, assess support systems, and provide counseling or connect with community resources.(VON or NOVA in Quebec)

Explore respite care options to take breaks from caregiving responsibilities.

- https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/The+Video+Gallery.aspx?type=cat&cid=110f65fd-0447-4e6e-b860-7646e02b997b&page=2#VideoAnchor
- Talking about advance care planning: https://www.advancecareplanning.ca/

Resources for Healthcare Providers

- For healthcare professionals:
  - Directory Listing - Canadian Hospice Palliative Care Association (chpca.ca)
  - APES- association des pharmaciens des etablissements de sante du Quebec
  - Palli-Science : site officiel de formation en soins palliatifs et oncologie de 1ère ligne | Portail des soins palliatifs (in french only)
  - B.C. Inter-professional Palliative Symptom Management Guidelines (bc-cpc.ca) (there is a section in for patient education)
  - **Canadian Virtual Hospice:** Provides support, resources, and education for healthcare professionals and caregivers involved in palliative care in Canada.
- **Canadian Partnership Against Cancer - Palliative and End-of-Life Care Initiative:**
- Website: Cancer.ca
- Offers resources and initiatives related to palliative and end-of-life care, particularly in the context of cancer.

Case Study

- Mr. Smith; 46y.o Man lives at home with wife; 2 children (12 years old and 16years old); lives in cluttered upper duplex; has 2 cats and 1 dog.
- Spouse overwhelmed, no other relatives in Canada
- Dx with GBM in 2023
- Pmhx: alcoholism;
- Habits: drinks 1 cup of whiskey per day; smokes 1 pack/day; occasional recreational drug such as cocaine.
- Mr. Smith in complete denial about his situation and refusing nurses recommendations.
- Mr. Smith believes that his Cancer is reversable and that his treating team will find the right treatment.

Q & A

Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat

Thank You

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