Personal Support Worker Community of Practice Series

The Personal Support Worker's Role in the Last Days and Hours

Project ECHO
Palliative Care - Canada
BY Pallium Canada

Presenters: Tracey Human and Diane Roscoe

Date: March 8th, 2022

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

Thank you!

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.

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Project ECHO Palliative Care - Canada BY Pallium Canada

Welcome and Reminders

- Please introduce yourselves in the chat!
- Your microphones are muted for background noise, but we do want dynamic sharing, so please raise your hand to unmute to talk. Sharing or asking questions in the chat is also welcome.
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session
- Terminology (Personal Support Worker)

Series Objectives

Our PSW Palliative Care Community of Practice

- **PSWs with a passion to become PSW experts in palliative care**
- A place for Peer-to-Peer practice support
- Facilitated and coached by palliative care experts
- Shared skill building in the Palliative Approach to Care
  - We engage in topic-based discussions, share knowledge and experiences to learn from each other, used cases to practice applying our skill caring for individuals/ families living with life-limiting illness
  - We share resources, tools, best-practice approaches
- Build on foundational knowledge acquired through LEAP PSW

Overview of Topics

Session #	Session Title	Date/ Time
Session 1	Introductory Session	Nov 16th, 2021 from 5-6pm
Session 2	Essential Communication Skills Part 1	Nov. 30th, 2021 from 5-6pm ET
Session 3	Essential Communication Skills Part 2	Dec. 14th, 2021 from 5-6pm ET
Session 4	Tools Practicum Part 1	Jan. 11th, 2022 from 5-6pm
Session 5	Tools Practicum Part 2	Jan. 25th, 2022 from 5-6pm ET
Session 6	Pain and Shortness of Breath Management	Feb. 8th, 2022 from 5-6pm ET
Session 7	The PSWs Role in the Last Days and Hours	Mar. 8th, 2022 from 5-6pm ET
Session 8	End of Life Medications and Side Effects	Mar. 22nd, 2022 from 5-6pm ET
Session 9	End of Life Delirium	Apr. 5th, 2022 from 5-6pm ET
Session 10	Post-mortem Care: Cultural Considerations and what happens at the funeral Home	Apr. 19th, 2022 from 5-6pm ET
Session 11	Culturally Relevant Care	May 3rd, 2022 from 5-6pm ET
Session 12	Trauma Informed Care and Cultural Safety	May 17th, 2022 from 5-6pm ET
Session 13	Indigenous End of Life Care	May 31st, 2022 from 5-6pm ET
Session 14	Understanding Tubes, Pumps, Bags and Lines	Jun. 14th, 2022 from 5-6pm ET

TOPIC:

PSW Role
Last Days and Hours

Tools: PPS

Palliative Performance Scale (PPSv2)
version 2

	PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
STABLE	100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
	90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
	80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
	70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
TRANSITIONING	60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
	50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
	40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
END OF LIFE	30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
	20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
	10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
	0%	Death	-	-	-	-

Signs Death is Approaching

What are some common signs death is approaching?

- Profound (intense) weakness and fatigue; Bed bound
- Total care is needed
- No appetite; Minimal intake
- Difficulty swallowing
- Decreased urine output and incontinence of both bladder and bowel
- Drowsy or reduced alertness/cognition and difficulty concentrating
- Dozes off easily and spends more time sleeping
- Restlessness, agitation, confusion or Delirium (we will focus on the April 5th session)
- PPS 20 - 10% and declining

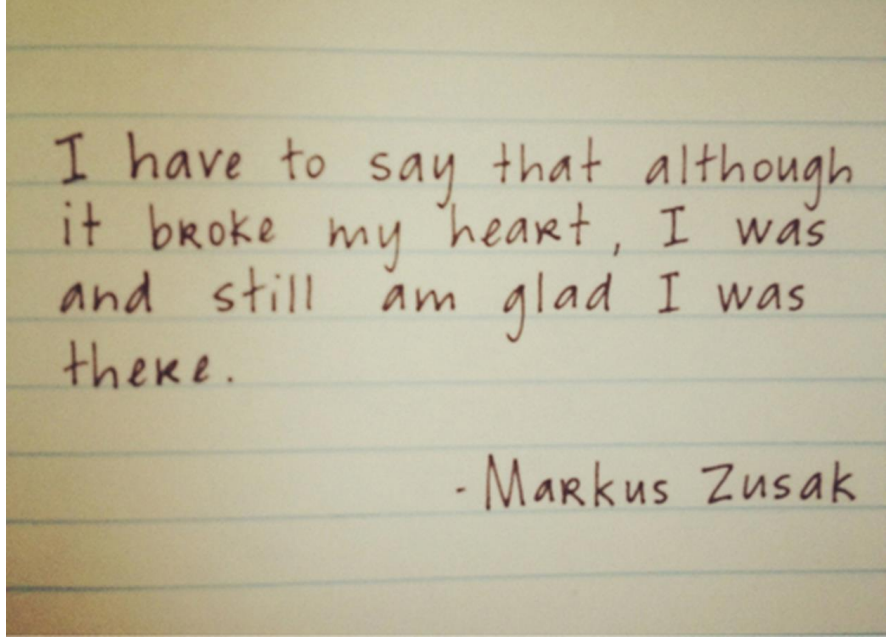
Signs Death is Imminent

What are common signs seen in the last hours before death occurs?

- **Breathing Changes**
  - apnea; Cheyne Stoke Breathing
- **Decreasing Level of Consciousness**
  - semi-responsive to non-responsive/comatose
  - eyes “half mast”; no longer blinking
- **Skin changes**
  - Mottling progressing to cyanosis of hands, feet, legs
  - Extremities cold to the touch
  - core of body and head may feel warm to touch (no fever)
- **Saliva & Secretions collect at back of throat**
  - family often refer to it as the “Death Rattle”
- **Terminal Delirium**

Understanding What We See
&
PSW Care Approaches


I'd be
lying if I
told you
losing you was
something I
could handle.


I have to say that although
it broke my heart, I was
and still am glad I was
there.
- Markus Zusak


© Fox News

Weakness & Fatigue / Drowsiness & Comatose

WHY

- body is succumbing to the damage from the illness and is shutting down
  - Usually happens over a few days, but sometimes very quickly over a few hours

WHAT YOU SEE

- Fatigue easily
- No energy or strength so need total care
- May now be spending all of their time in bed
- Incontinence; bladder progressing to include bowel
  - urinary retention so catheter may be inserted
- May appear to be in a light sleep all the time, and may be more awake at night
- Progresses to a coma
- Person may be too weak to respond or may not be able to speak, but they will still be able to hear

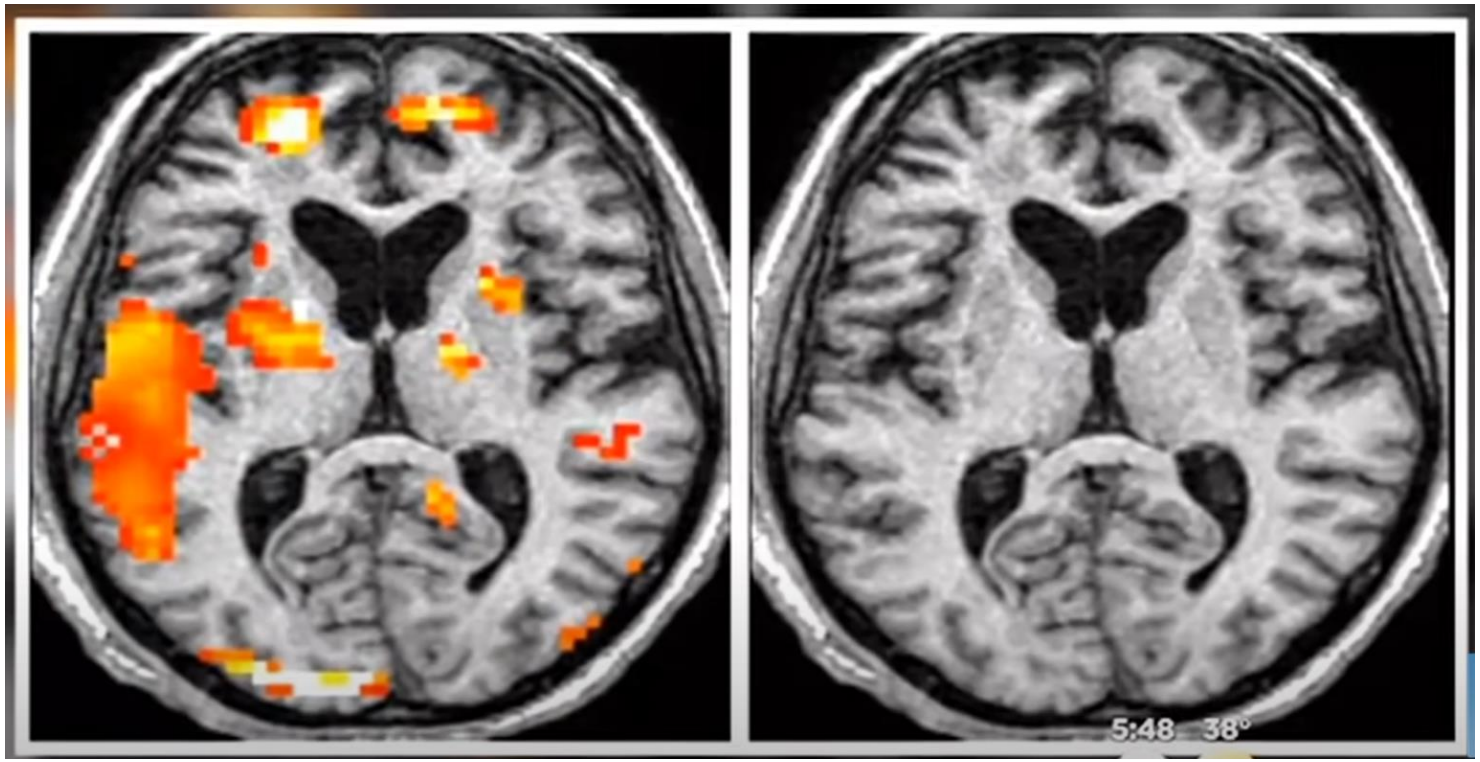
WHAT IS YOUR ROLE & APPROACH TO CARE?

- Preserve Dignity
- Energy conserving care
- Safety in assisting with eating/drinking
- Positioning; turning; impeccable skin care
- Reporting urine and bowel output
- Continued pain and symptom observations (ESAS); PAINAD
- Always talk to the person/they still hear everything
- Use Touch & Listen “Soul Care”

Observe and care for family

- Exhaustion; coping; anticipatory grief
- Guide to connect even when loved one is comatose
- Invite them to participate in care as wish, be mindful they also need relief and to be able to just focus on quality time and not be the caregiver

Can A Person in a Coma Hear? YES



Hearing loved one call their name Hearing a stranger call their name

https://www.research.va.gov/pubs/varqu/summer2015/summer15-14.cfm

Eating & Drinking

WHY

- When the body is shutting down, it is no longer in need of or asks for food
- It is not trying to make new or healthy cells
- Appetite and desire to eat and drink decline or stop
- **This is NOT starvation**

WHAT YOU SEE

- No interest in food; Eating exhausts them
- Start taking only sips; can't coordinate mouth to straws to drink
- Swallowing muscles get weak; slow swallowing; pocketing food in cheeks or spitting food out
- May have a choking episode
- Tongue & Lips get dry
- If on G-tube feeding - may aspirate or get diarrhea
- Eating or drinking seems to make their pain or symptoms worse

WHAT IS YOUR ROLE & APPROACH TO CARE?

- Eating if for pleasure
- We listen to the person and their desire to eat and drink, we do not push if they are not interested
- Assist with eating/drinking slowly; position on back, head raised, chin slightly tucked
- Use cup with spout, spoon or syringe
- Do lots of mouth, eye, and skin care
- Watch for signs of aspiration or choking risk
- Use favorite tasting foods/fluids for pleasure

Mouth, Eye, Skin Dryness

WHY

- Dying process metabolism revs high, so uses up body mass and also dehydrates
- Medications
- Mouth breathing
- Eyes get dry as lose blink reflex

WHAT YOU SEE

- Lips, tongue, eyes, skin get dry
- Dry crusts around eyes; flaking of lips
- Eye lose shiny appearance, become cloudy looking
- Slow blinking; eyes stay partially open during sleep
- Skin become thin and fragile, tears easily
- Boney prominence redden easily and can break down fast
- Artificial lubricating products are used to moisten
- Immobility is uncomfortable, we reposition frequently, use special mattresses
- Skin care for comfort and to avoid skin breakdown

WHAT IS YOUR ROLE & APPROACH TO CARE?

Frequent Mouth, Eye, Skin care

- warm water wash eyes and lips
- oral care not with water alone; moisten and follow with water soluble lubricating products e.g. KY jelly; or artificial saliva products e.g. Biotene
- eye care with artificial tears or eye ointment
- Vaseline to lips, avoid wax based products, they cause lip cracking

May bite down on the toothette sponge when you first put it in their mouth

- This is a normal reflex reaction
- If this happens, continue to hold onto the stick - after a few moments, the person will relax the bite and release it

Example of dry lips and mouth

dying person dry mouth photo credit

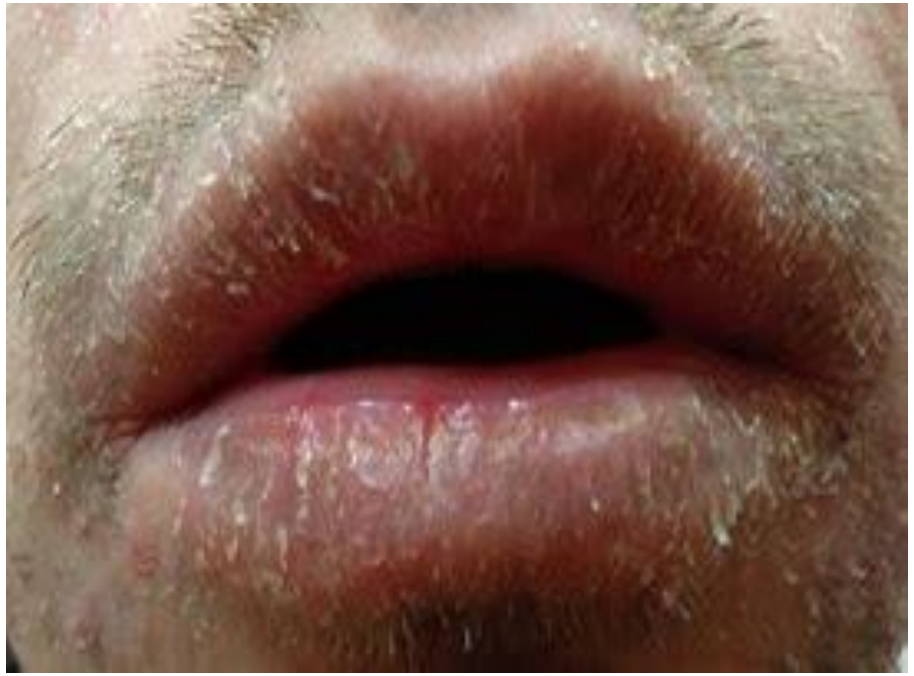
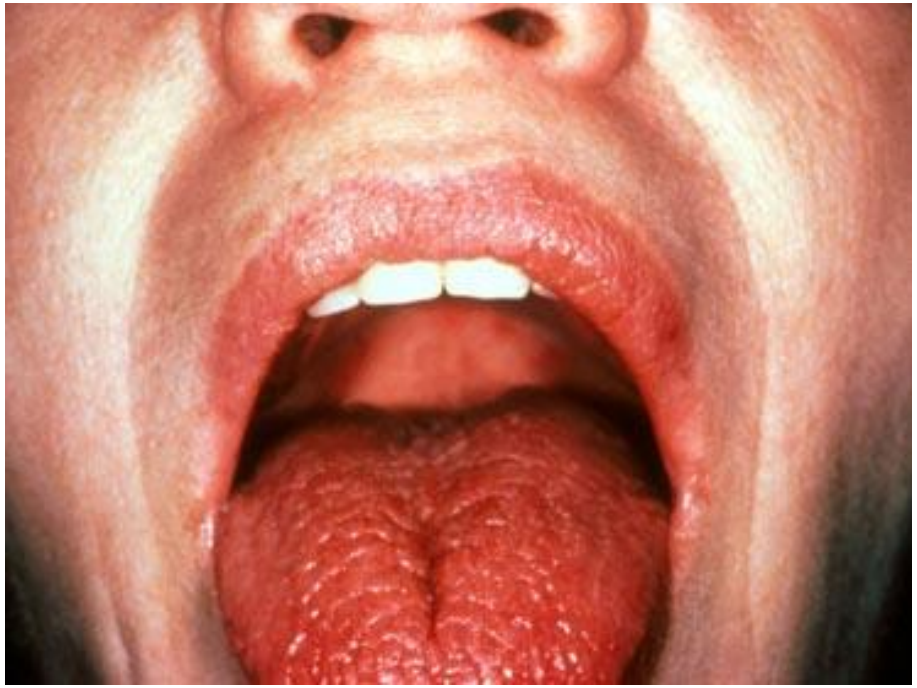


Photo Credit Dry mouth



Victoria Hospice - Mouth Care Training Video

The Video Gallery :: Personal hygiene - Helping with mouth care

Time to watch 4 minutes

Breathing Changes

WHY

- heart and brain is shutting down, CO2 drops, O2 level high and breathing is not triggered

WHAT YOU WILL SEE

- Breathing becomes shallow and frequent
- **Apnea**
  - short periods when the person stops breathing temporarily (apnea), period between breaths gets longer and more shallow closer to death
- **Cheyne Stoke Breathing**
- alternating crescendo-decrescendo pattern with apnea in between
- accessory respiratory muscle becomes prominent
- Breaths eventually get further and further apart until breathing stops
- Last reflex breaths signal death

WHAT IS YOUR ROLE & APPROACH TO CARE?

- The person is not breathing this way because of lack of oxygen, but often oxygen is used as family find it comforting
- Help reassure the family; have nurse/doctor explain
- Stay with or check in frequently
- Family find very distressing and need lots of reassurance and comfort their loved one is NOT suffocating
- ***It is not distressing to the individual nor are they aware of it at this point***
- ***Focus family on goodbyes; permission to go; loving words; cuddling togetherr***

apnea

https://youtu.be/soay0K891EQ

cheyne stoking

https://youtu.be/VkuxP7iChYY (elderly lady, partially responsive)

https://youtu.be/VShpIJdTHIc (young lady, comatose, eyes open)

https://youtu.be/Rw0g6j3kQSM (man with snoring sound with cheyne stoking)

last moments reflex breathing

https://youtu.be/sbFS7z-S95Q

End-of-Life Throat Secretions

WHY

- small amounts of saliva and mucus collecting at back of throat because in no longer swallowing to clear them
- the jaw dropping back or the tongue moving back due to the relaxation of jaw and throat muscles amplify the sound through the open mouth

WHAT YOU WILL HEAR/ SEE

- gurgle sound from back of throat
- may hear snoring-like sound
- may hear a soft short moan as breathes out sound with each breath out

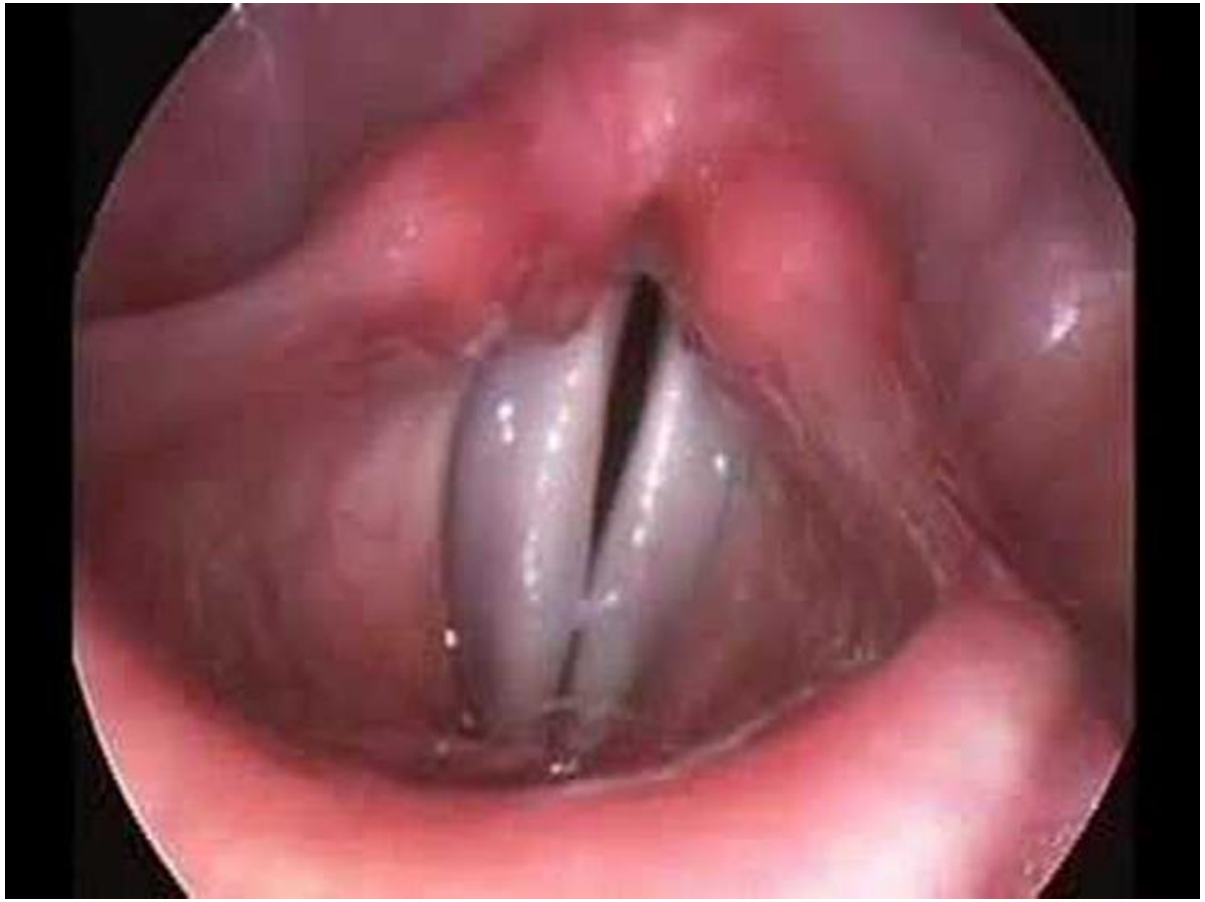
WHAT IS YOUR ROLE & APPROACH TO CARE?

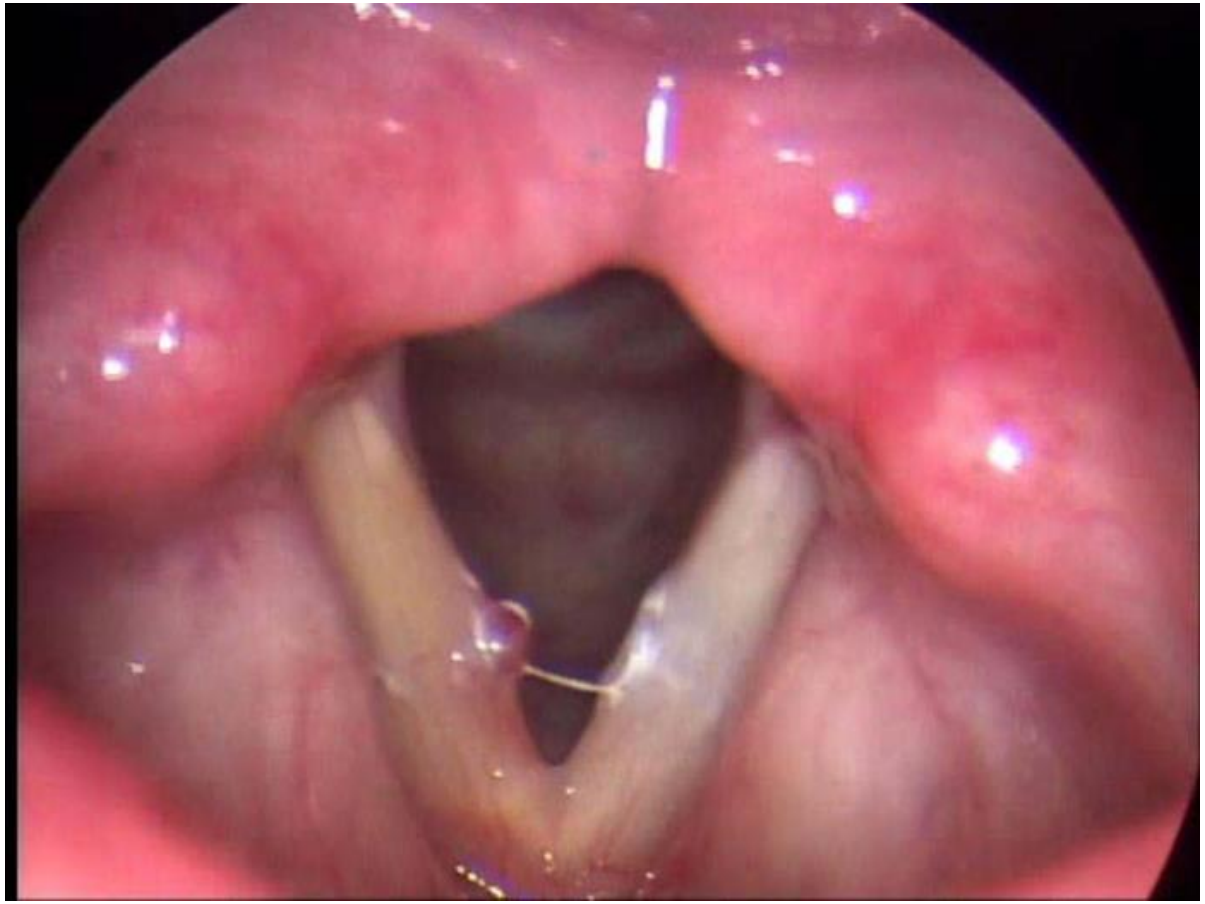
- Turn person on their side
- Do mouth care to clear any secretions from the mouth
- Make sure the person's head and neck is well supported by pillows
- Report up for nurse/doctor to explain
- Reassure family

Suctioning is not recommended

Terminal Secretions Sound - “Death Rattle”

https://youtu.be/ysSIjklb6D4





Restlessness; Agitation; Delirium

WHY

- lots of causes, we will cover in Session 9
- brain shutting down; medications; toxins building up from kidney or liver failure; low oxygen; untreated pain

WHAT YOU WILL SEE

- disoriented or confusion in fluctuating pattern through the day
- restlessness or agitation worse at night
- report visions or hallucination
- pulling at bed linens, clothing, trying to get out of bed or very quiet staring off into space

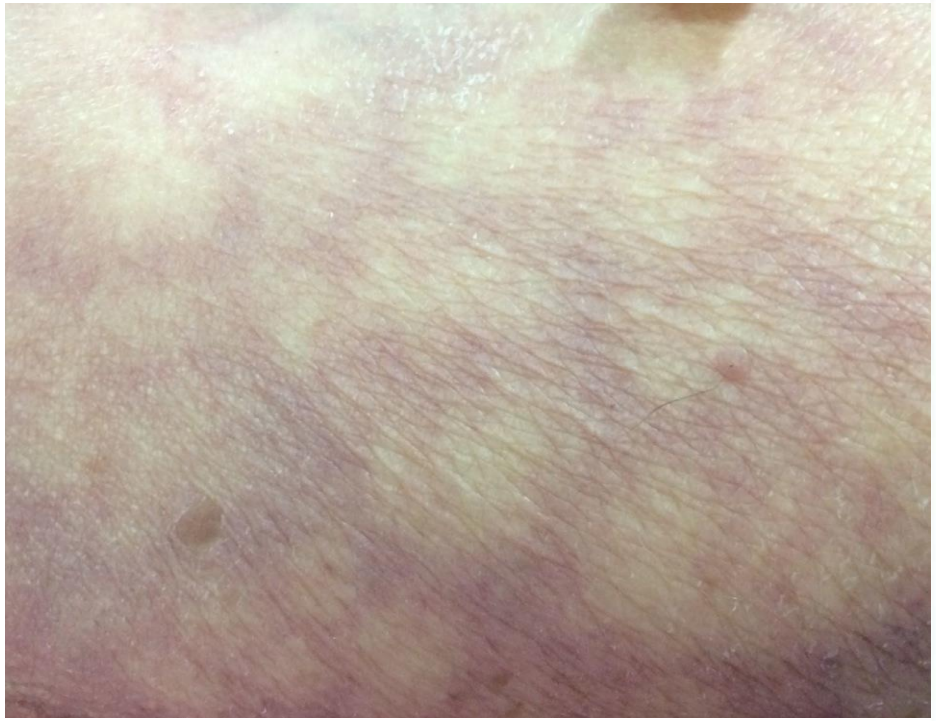
WHAT IS YOUR ROLE & APPROACH TO CARE?

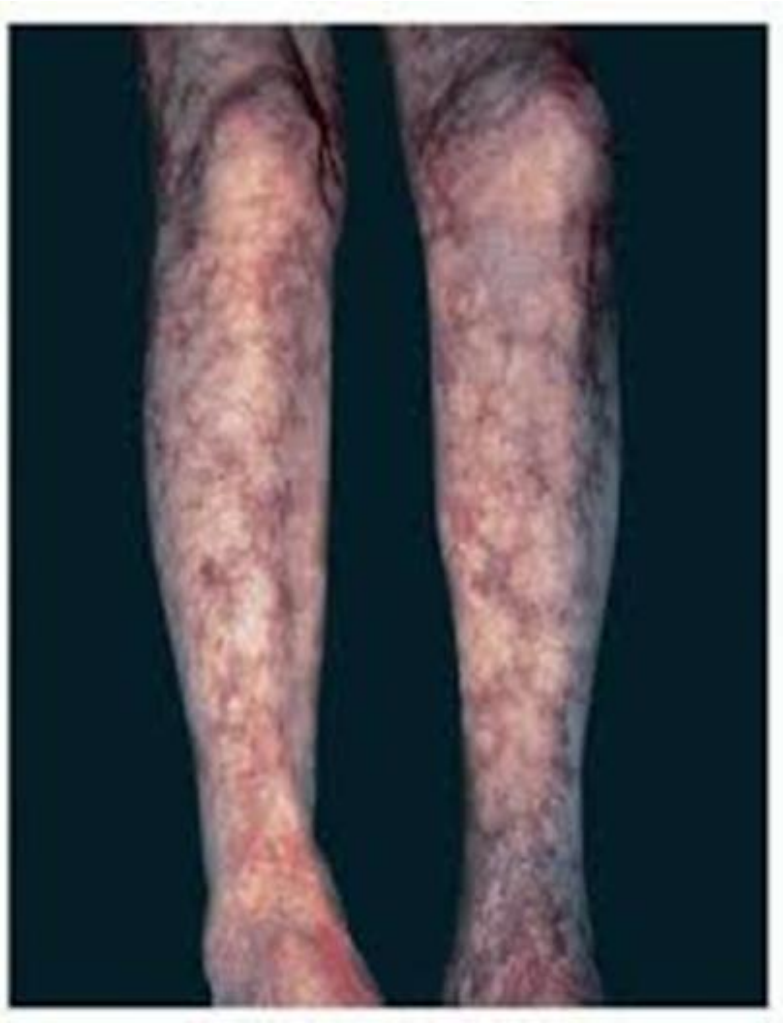
- Gently remind they are safe
- Gently tell them the time of day, where they are and people who are with them
- Observe and ask if in pain or short of breath
- Check for urine retention and last BM
- Do not restrain, keep safe
- Be calm and reassuring
- **Report up - Let nurse know**
- **When medication is given; observe and report back affect**

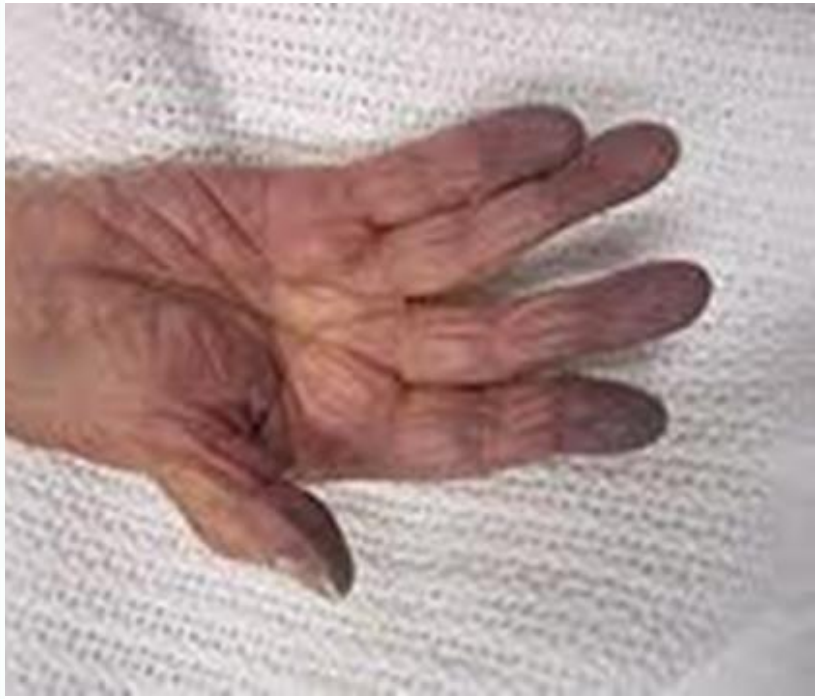
Very Near Death

- Cool to touch arms and legs
- Arms and Legs mottling (pale & reddish blotchiness) progresses to cyanosis (blue color)
- Torso and Head may feel quite warm to touch, this is not a fever unless have a known infection
- Urine output decreases or stops
  - dark color, cloudy or thick looking
- The person's eyes will often be partially open and not blinking
- Occasionally, someone who is unresponsive may suddenly become more alert as death approaches

- Blood pressure and pulse are not reliable signs of impending death
- Hot torso or head is not treated with Tylenol, it is not a true fever
- May need Foley catheter for urine retention
  - urine retention is painful and can a person restless
- We ensure BMs every 3 days by PR route even when no intake (enema or suppository)







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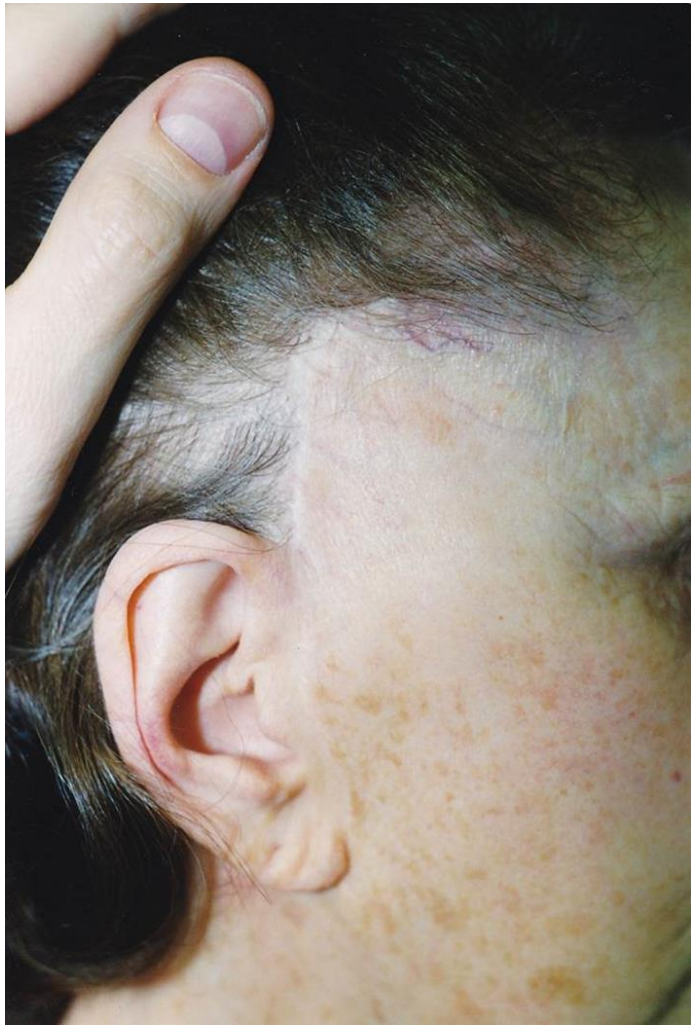


Signs Death Has Occurred

- No breathing or pulse
- Eyes do not move or blink and look cloudy (not normal shiny appearance)
- Pupils are fixed and dilated (enlarged)
- Eyelids are slightly open
- Jaw is relaxed and the mouth may be slightly open
- No response

What do you do?

Case-Based

Applying Learning to Practice

Case Study - Edina

Edina is 55 years old and had been diagnosed with Stage 4 small cell lung cancer just 3 months ago. The cancer has progressed rapidly. She has been admitted to the local palliative care unit (PCU) at hospital for management of pain and dyspnea.

Monday, in hospital, Edina's status declined significantly. She is "sleeping" most of the day, no longer has an appetite, is taking only sips of fluids and a few bites of soft food, she needs assistance with intake and she is now total care.

Edina is supported by her husband, 5 adult children, 1 living locally and 4 in various provinces. Family have been notified and those outside the province are flying in to be with Edina and to have their final goodbyes.

When they arrive they are distressed by how much their mother, Edina, has changed, that she is "sleeping" most of the time and is "so thin"! Edna is briefly rousable, responds to her children's presence with a smile and holds their hands, but exhausts quickly and resettles to "sleep".

Knowledge Check

1. ***What is the life-limiting illness in this case?***

1. ***What PPS score would you give Edina?***

1. ***Are there signs death is approaching? What are they?***

1. ***Who should you report your observations to? What tool is good for you to organize your report?***

Knowledge Check
PSW Role in caring for Edina

1. *What PSW care approaches would you apply in caring for Edina?*
2. *What would you be observing Edina for?*

1. *How can you support the family?*
2. *What would you be observing the family for?*
3. *How can you help the family to connect with Edina in her semi-responsive level of consciousness?*

1. *How should you in your PSW role respond when one of the daughters asks you why Edina is sleeping so much?*

SBOR Example

Situation: Edina is sleeping a lot the family is concerned

Background: PPS is 20% condition changed quickly over the last 2 days. Family has arrived from out of town/province

Observation: Drowsy, rouses briefly to voice and touch with care. Oral intake is only sips with assistance.

Request: Can you come explain to the family what is happening and what to expect

PSW – SBORS REPORTING TOOL

1. Know the observation that concerns you, the Client/Family
2. Know the client's diagnosis
4. Read the most recent Progress Notes from the last PSW & NURSE visit
5. Have the contact number(s) to be reached at ready (You; Nurse; Supervisor; Doctor; SDM/POA; Family contact)

S

SITUATION
- ✓ Client/ Resident you are calling/ reporting about
- ✓ Change/ issue you are concerned about
- ✓ Your Name, Designation (PSW), and Agency you work for
- ✓ Number to call you back at if leave a voicemail

B

BACKGROUND
- ✓ Briefly explain what has been going on recently
- ✓ Recent discharge from hospital/ Emergency/ Change in condition
- ✓ Include any incidents e.g. Fall
- ✓ Individual's diagnosis

O

OBSERVATION
- ✓ **Changes in client's self-report of a symptom**
- ✓ **Changes in your observations**
- ✓ **Change in behavior**
- ✓ **An incident e.g. Fall**

"The client & family is reporting..." or "I have observed..."

☐ Pain ☐ Shortness of Breath ☐ Tiredness ☐ Drowsiness	☐ Anxiety ☐ Restless/ Agitation ☐ Confusion ☐ Behavior Change	☐ Appetite Change ☐ Nausea/ Vomiting ☐ Difficulty Swallowing ☐ Constipation	☐ Fever ☐ Increased edema ☐ Semi - responsive ☐ Bleeding Other: _____

Any Change or Decline	*Describe*
Physical Issues	*Describe*
Psychological Issues	*Describe*
Social Issues	*Describe*
Spiritual Issues	*Describe*
Practical Issues	*Describe*
End-of-Life Care Issues	*Describe*
Grief/Loss Issues	*Describe*

R

RESPONSE/ REQUEST

Do you think ... ☐ Nurse needs to come ☐ the Doctor needs to come ☐ Other _____

If this does not improve, when should I call again? _____

Anything else I should watch for? _____

Case Study - Edina Continued

Edina is now unresponsive. You observe a change in her breathing pattern from shallow breathing to Cheyne Stoking pattern. Her arms and legs are cool to touch and appear mottled, her torso and head are warm to touch. You can hear a rattling sound coming from her throat.

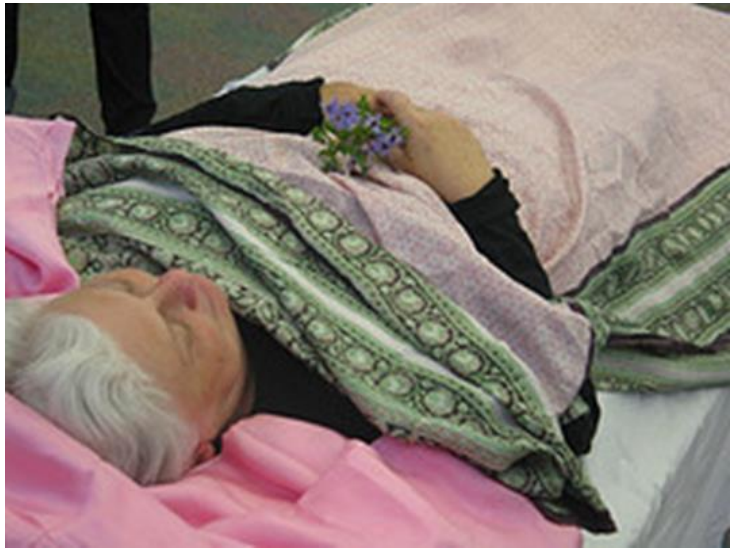
What do these observations mean?

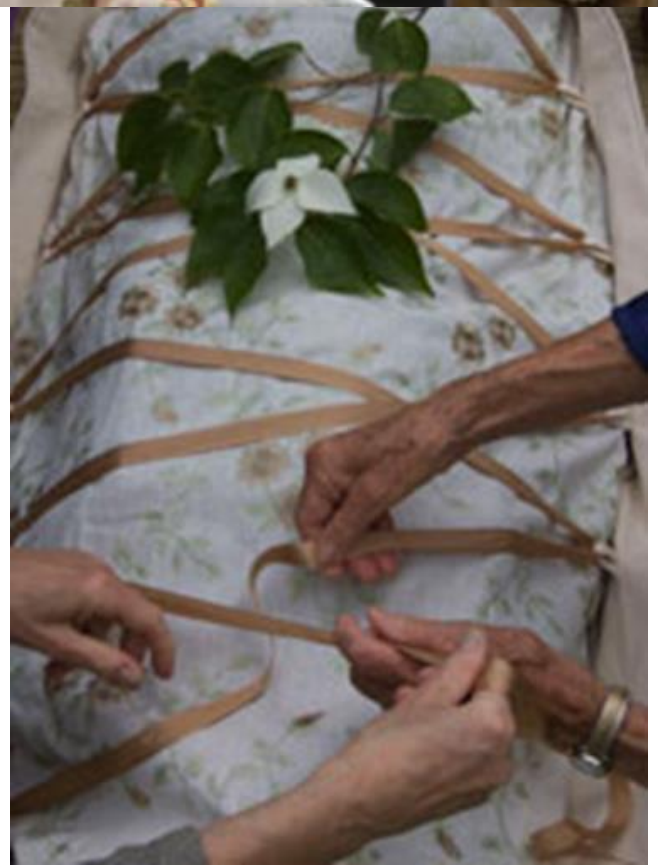
a. **death is approaching**
b. **death is imminent**

Who do report these changes to?

How can you and the team support the family at this stage?

AFTER DEATH CARE





After Death Care

- **What can you do?**
- **What is important to know?**
- **Who do you notify?**
- **How can you support the family?**

After Death Care

- The way the team members interact with the person after death will be observed closely by family members; Touching the person after the death gives the family permission to do so as well

- Remember, people live and die in families that have histories and cultures. Generally they approach death in the same way that they approach life but death is often a new experience that is comforted by the team's guidance

After Death Care

- When the time seems right, ask permission from family present and begin caring for the person's body with dignity and respect
- Follow the wishes of the family and invited to participate as they wish
- Pay particular attention to cultural customs
- There is generally no need to rush

After Death Care

Tubes and masks can be gently removed by the nurse

Dressings may be left intact on draining wounds

The removal of these things is a concrete act that makes real the fact that the person is truly dead

It can be shocking to the family so determining readiness to move forward with care of the body is important.

The body can be washed/shaved/dressed and the environment tidied to receive visitors

Cultural traditions, rights, rituals are done

Practice universal precautions related to blood and body fluids

The dentures can be inserted if appropriate

The body is positioned lying on the back with the head slightly elevated on a pillow

Close the eyes (if possible). Some families like to have a small rolled up towel under the chin if necessary to keep the jaw closed

- Private alone time should be provided as desired
- The funeral home is called when the family is ready
- Family is empowered to assist with transfer of the body if wish

- Be sure to protect the person's head when lifted to the Funeral Home Stretcher
- Avoid totally closing/zipping the body shroud over the face, this is undignified and very distressing to family

- Honor guard as the team transfers care into the care of the funeral home
- Information on the memorial service is requested to be shared for team to attend
- Arrangements are made for the belongings
  - **it is far more dignified to ask family for suitcases or boxes for belonging. Avoid packing belongings in garbage bags!! It sends a terribly insensitive message the family's loved one's belongings are garbage.**

Wrap Up

Wrap Up

- Please fill out our feedback survey! A link has been shared in the chat
- A recording of this session will be emailed to you within the next week
- Make sure you have the next session marked in your calendar!
  - End of Life Medications and Side Effects
  - March 22nd, 2022 from 5-6pm ET

LEAP Personal Support Worker

- LEAP Personal Support Worker is an online, self-learning course that provides personal support workers and care aides with the essential competencies to provide a palliative care approach
- Register at: https://www.pallium.ca/course/leap-personal-support-worker/?enroll=enroll

"I feel this course was great, and straight forward. It was easy to navigate, and had very good information, and knowledge"

"A great course, lots of information just for the PSW role. Information very informative and easily learned."

"This course is really amazing, well made and really helped me understand palliative care"

"I feel this course was absolutely fantastic! I enjoyed it very much."

"Wonderful journey, thank you"

Thank You

See you on March 22nd

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