

Palliative Pain & Symptom Management



Consultation Service for Toronto

www.ppsmctoronto.com

Consultants

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Case Study

Helen is a 54 yr old female with known Hx of advancing cirrhosis secondary to HCV (Hepatitis C) and recent Dx of hepatocellular carcinoma but has refused active treatment (e.g. chemotherapy)

Helen recently has been reporting with increasing frequency, weakness, *“bad indigestion”*, pain and *“swelling”*, along with vomiting 1-2 times per day. *“I can throw up more if I eat my favorite, deep fried bannock, I used to love that stuff, but it doesn’t like me anymore”*, *“who cares ‘cause I’m not that hungry anyway.”* and *“my poop is a funny color”*.

The CCAC contracted visiting nurse on her/his initial visit with Helen where she currently resides notices weight loss > 10% of her normal weight including muscle wasting and *“my legs and belly are swelling something terrible, and the pressure Oh my goodness! It’s so uncomfortable now I can’t sleep!”* Mild jaundice is beginning to develop, increasing numbers of bruises are visible on her legs and arms, and increasing SOBOE. She reports *“I just hurt everywhere, I’m sick and tired of it all.”*

Helen, having a past history of substance use, was once street involved and homeless. She reports both her parents are deceased. She has 1 daughter, Jill (age 35 years) and 1 sister, Dianne (age 50 years, married with 2 adult children, who works as an accountant for the City of Toronto). Helen, never married, once lived with her partner Bill, who is deceased secondary to complications from substance use.

Currently she resides in a women’s shelter with a zero tolerance substance use policy. She has no long standing relationship with a primary care GP, has often been lost to follow-up. She has received most her care through presenting in emerg when in crisis.

In the last 48 hours her behaviour has become unmanageable at the shelter, due to her breaking shelter rules by returning to substance use and soliciting other residents to *“get her stuff”* and has been using in her room as she is getting weaker. Additionally Helen is having increasing incontinence and difficulty with ADLs. She notes she has begun to see some *“blood”* in her *“puke”*, but is resistant to returning to hospital.

“You matter because you are you and you matter to the last moment of your life.

We will do all we can to help you, not only to die peacefully but to live until you die”

(Saunders, 1976).

- Clients have the *right* to effective **pain** & **symptom control**.
- **Pain** & distressing **symptoms** *can* be alleviated.

Pain & Symptom Management

30 Min

Palliative Pain &
Symptom Management



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**Can you
identify
the pain
in this
Xray?**

This is key.....



***Everyone's experience
of pain is different.***

***Understand that your
frame of reference
is not
the same as
anyone else's.***

Comfort: The Absence of Pain

Pain alters the quality of life more than any other health-related problem.

PAIN Considerations

What are Helen's pain issues?

What are the potential pain issues?

What types of pain are involved?

Why?

Physical Pain

Indigestion

- Advanced liver failure brings GERD
- Malabsorption
- Pressure from ascites and hepatomegaly causing reflux

Pressure

- Abd & legs
 - Hepatomegaly due to Ca
 - Portal system engorgement
 - Ascites
 - Leg edema

Bruises

- Arms & legs
 - Altered clotting times
 - Malnourished (B vitamins; electrolyte shifts and deficiency; calcium, magnesium, zinc; etc.)
 - Edema pressure
 - » Tender?
 - » Neuropathy?

Generalized pain

- “Hurt everywhere”
 - What is she saying? Physical +/- emotional?
 - Possible causes?
 - Weight loss and muscle wasting
 - Emotional components
 - Fatigue
 - “Sick & tired of it all”

Varice risks

- dysphagia? As cause for decreased appetite?
- Catastrophic bleed risk

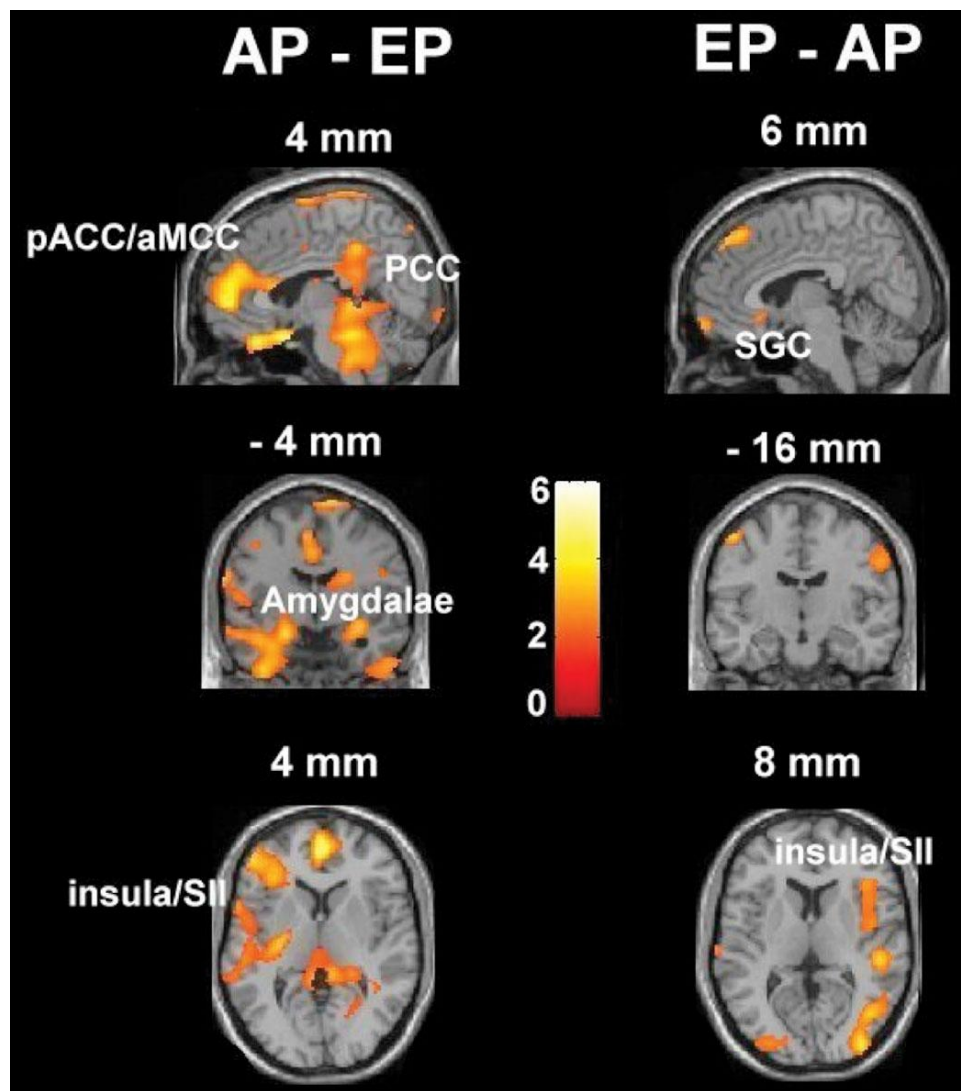
Substance Use

- Withdrawal considerations?
- Is it painful?

Emotional Pain

“Sick & tired of it all”

- Substance use relapse
- Suicidal considerations?



Social Pain

Inability to work

Financial worries

- Direct costs
- Indirect costs

Family distress

Additional **Pain** Management Considerations

Is Helen opioid naive or tolerant?

Why does this matter?

What would next steps be then?

Substance use considerations

- What is her substance of choice?
- Why is she choosing to use this, and why now?
- Why is she soliciting others to obtain it for her?
- Why does knowing her use hx help inform you?
- What is your strategy here?
- Labeling; stigma etc.

- McCaffery defined pain as

“whatever the experiencing person says it is and whenever she/ he says it does (1979).

- “The American Pain Society goes further by stating that it is

“not the responsibility of clients to prove they are in pain; it is the nurse’s responsibility to accept the clients report of pain”.

(2005)

What are your 1st priority concerns?

Followed by?

What would be your strategy to ensure Helen's pain is managed to her satisfaction?

What orders would you expect to see?

What would be your recommendations to
the Rx doctor?
med?
route?

How would you want to communicate
with the doctor and trans-disciplinary
team your findings?

Helen's Pain:

- » Transduction
- » Transmission
- » Perception
- » Modulation

**All will be skewed/ due to life style history/
survival/ coping/ substance use/ liver failure
etc.**

- Routes of choice
 - Po/sl; sc; transdermal
 - (due to malabsorption and 1st pass theory, liver damaged)
 - Harm reduction strategies
 - Selling scripts
 - Chewing patches
 - IVDU? All those issues, quick mention
 - » Safer injection or crack kits if approp depending on substance of choice
- Embolism risks and management due to increased chol? Does it matter?
- Hypercalcemia risks and management
 - Cardiac, does it matter?

Spiritual Pain

Guilt

Why me?

Regrets

Fear of dying

Life closure issues

Concept of Total Pain

- **Physical**
 - From disease
 - From tx
- **Emotional**
 - Loss of function
 - Social isolation
 - Fear
 - Depression
 - sadness
 - Coping abilities
- **Social**
 - Inability to work
 - Financial worries
 - Direct costs
 - Indirect costs
 - Family distress
- **Spiritual**
 - Guilt
 - Why me?
 - Regrets
 - Fear of dying
 - Life closure issues



Dame Cicely Saunders defined this concept as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.

***“Pain only becomes unmanageable
When the clinicians involved give up.
Although I realize that the world
in which we live
is real, and therefore imperfect,
as a physician I consciously adopt the
attitude that there is no such thing as
uncontrollable pain, only pain that has
yet to be controlled.”***

Dr. Ira Byock (*On Dying Well*)

Symptom Management

What are Helen's symptoms?

What can be done to manage them?

What meds would you expect to be ordered?

If they were not ordered what would you do?

Helen's Symptoms

- GERD
- N& V (also fat intolerance; malabsorption issues now)
- Decreased appetite
- Possible Clay stools
- Wt loss
- Muscle wasting
- Possible Apathy/ depression? Emotional exhaustion?
- Leg edema
- Ascites
- Interrupted sleep
- Jaundice
- Bruises (due to increasing INR or injections substance use?)
- SOBOE
- Re-using injection supplies (if IVDU hx)
- Fatigue & weakness
- Incontinence
- Difficulty managing self care/ decreased ability to do ADLs
- Hematemesis
 - Concerns
 - Risks
 - interventions

JAUNDICE

Concerns ?

Risks ?

Interventions

Care strategies ?

- Now?
- In the future?

• Jaundice

What degree?

- Intermittent or advancing

Risks

- Encephalopathy
- Confusion
- STML/ cognitive changes

} **Falls**

- Judgment impairment



- Safety risks for who she is asking for help off the street
- Not remembering how much of her substance of choice she has used and OD risks

Skin

- Itch
- Dryness
- Risk for breakdown

} **Transmission of HCV**

Interventions

- Bowel assessment
- Lactulose
- Safe environment with 24/7 care

Community Care Tip

Being unprepared
Can exacerbate suffering &
lead to emerg visit
for timely pain and symptom
management.

Goal: *to avoid this*

How?

By being prepared to manage pain
& symptoms well, wherever
Helen is.

- When individual wishes to die at home
 - **forecast needs and have meds in home before symptoms develop**

(so can admin as symptoms appear and not have to wait for doctor to order; then get Rx to pharmacy; then get the Rx pickup and delivered)
- Use knowledge of disease trajectory and assessments to forecast care needs
 - **To bring in other members of trans-disciplinary team in timely manner**

Assessment & Implementation

30 min

Comprehensive Assessment

“Get to know Helen”

Assessment tools to assist you:

- ESAS
- PPS
- PPI
- Physical Assessment (all systems)
- Pain & Symptoms
- Braden
- Functional (FAST)
- Intimacy
- Spiritual
- Cultural
- Social
- Aspects of total pain

Benefits of tools

- Help communicate declining trajectory
- Individual’s right to know
- Identify priorities
- Helps to inform:
 - when to bring in additional providers
 - care provisions/ supplies
 - Interventions/ referrals in a timely manner

- ESAS

PPS Level	Ambulation	Activity & Evidence of Disease	Self-care	Intake	Conscious Level
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 <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/housework 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
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	-	-	-	-

PPI

Palliative Prognosis Index PPI Survival Prediction: PPI Score & Classification of Patients Into Three Risk Groups		
Palliative Performance Scale (PPS)	Partial Score	Explanation
10-20	4	<ul style="list-style-type: none"> ▪Determine the client's PPS ▪Determine the PPI Partial Score
30-50	2.5	
60-100	0	
Clinical Symptom	Partial Score	Explanation
Oral Intake: Normal	0	<ul style="list-style-type: none"> ▪Assess the client's oral intake ▪Determine the PPI Partial Score
Moderately Reduced	1	
Severely Reduced	2.5	
Edema	1	<ul style="list-style-type: none"> ▪Assess client for Edema, Dyspnea or Delirium Please Note: →Edema refers to peripheral bilateral edema due to low albumin – not from a DVT →Rule out reversible causes of Delirium (see Delirium/Confusion Protocol)
Dyspnea at Rest	3.5	
Delirium	4	
Risk Group Mean Survival +/- Standard Error	Total Score	Add the Total Partial Score.
A. 155 Days +/- 20 Days	≤ 2	Expected length of life based on the total Partial Score.
B. 89 Days +/- 7.7 Days	> 2-4	
C. 18 Days +/- 2.9 Days	> 4	
SCORE: _____ DATE: _____		

Untreated Pain Risks

- Additional analgesic requirements
- Immune system suppression
- Cardiac complications
- Withdrawal
 - ❑ Social
 - ❑ Pharmaco-considerations
- Anxiety
- Depression
- Insomnia
- Exhaustion
- Decreased coping
- Decreased quality of life
- Shortened Life

Pain Assessment

Comprehensive pain assessment must include:

- Location
 - Including radiation
- Intensity
 - Worst, least, average, etc.
- Quality
 - Burning, aching, dull, stabbing, tingling, etc
- Pattern
 - Onset and duration, constant, or intermittent etc.
- Aggravating factors
 - Posture, movement, activities, etc.
- Relieving factors
 - Posture, rest, alternative therapies
- Effect on quality of life
 - Sleep, activities, intimacy, etc.
- Medication history
 - Efficacy, adverse effects, etc.

Prognostic Indicators

Where does Helen score on all the indicators?

- Life limiting condition?
- What Dying Trajectory?
- PPS score less than 50?
- Documented progression of disease(s)?
- Need for frequent hospitalizations, ER visits, physician visits?
- Lab studies and radiologic or other studies?
- Dependence in most ADL's?

Forecasting Prognosis End Stage Liver Disease

Signs & Symptoms progression from palliative to EOL (< 3 months)

Palliative

- Progressive
 - Malnutrition
 - Wt loss > 10% in 6 months
 - Muscle wasting with
 - reduced strength
 - Endurance
- Low grade fevers
- Depression
- Sleep disturbance
- Emotional lability
- Obtundation (decreased mental capacity)
- Flapping tremor (tremor of the wrist when hand extended)
- Cirrhosis
- ↑ creatinine and BUN
- Oliguria 400ml/day
- Urine sodium concentration <10 mEq/l

EOL

- Jaundice
- Ascites
 - refractory to sodium restriction and diuretics
- Hepatic encephalopathy
- INR > 5 seconds
- Serum albumin < 25
- Recurrent variceal bleed despite
 - Oral beta blockers
 - Injection sclerotherapy or band ligation
 - Transjugular Intrahepatic Porto systemic Shunt (TIPS)
- Decreased awareness of environment
- Somnolence
- Slurred speech
- Stupor (late-stage)
- Coma (late-stage)
- Hepatorenal syndrome or Spontaneous bacterial peritonitis (survival generally days-weeks)

Overview Liver ca symptoms

- often vague
- weight loss,
- poor appetite
- right upper abdominal pain or discomfort
- jaundice ↘
- Fatigue
- Bleeding may occur
 - into the abdomen or bile duct, (unusual)
 - Ca may invade and block
 - the portal vein causing esophageal varices.
 - risk for hemorrhage
 - Rarely, the cancer itself can rupture and bleed into the abdominal cavity, resulting in bloody ascites.

(physical assessment)

The cancer/ tumor can:

spread locally to neighboring tissues or invade the veins that drain the liver (hepatic veins & inferior vena cava).

Blockage can occur in these veins
congestion of the liver (hepatomegaly)
ascites

Metastases

- liver cancer frequently spreads to the lungs
- Rarely, in very advanced cases, liver cancer can spread to the bone or brain.
 - These are an infrequent
 - many do not live long enough to develop these complications

Liver cancer cells may take on the characteristics of other types of cells

E.g. the liver ca cell can produce hormones that are ordinarily produced in other body systems resulting in

- high red blood count (erythrocytosis),
- low blood sugar ([hypoglycemia](#))
- high blood calcium ([hypercalcemia](#)).

- Hypercholesterolemia
 - (liver cancer cells are not able to turn off (inhibit) their production of cholesterol)

Engaging Families

- Preparation:
 - Who are the family members?
 - Who are the family members as identified by individual?
 - What is their understanding (or what have they been told) of the illness, what to expect and prognosis
 - Who will be the contact person for the family?

Engaging Families

- Preparation cont'd:
 - How did the family relate to each other before the illness experience?
 - How is the family relating to each other/coping as the illness progresses?
 - How are the family members coping regarding the impending loss of their loved one?
 - » Anticipatory Grief Assessment
(Re-assess Regularly)

Topics to address with individual/families

Meeting them where they are at on their grief journey...

- Goals of Care
- Advanced Care Planning/POA
- DNRc form
- Practical Issues/Care team planning
- Funeral planning
- Dying process: what to expect
- Planned death at home process
- Unique need of family situation

Review

Regulary

Benefits of Family Conferencing

- Family members gathering together to focus energies toward common concerns
- Everyone hears the same words
- Each participant has the opportunity to share their own perspective
- Facilitation promotes:
 - Listening , valuing each person's contribution
 - Agreed upon steps forward in care planning

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Questions

