Dying Homeless

UBC Division of Palliative Care

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Disclosures

No conflicts of interest

What we want to share today

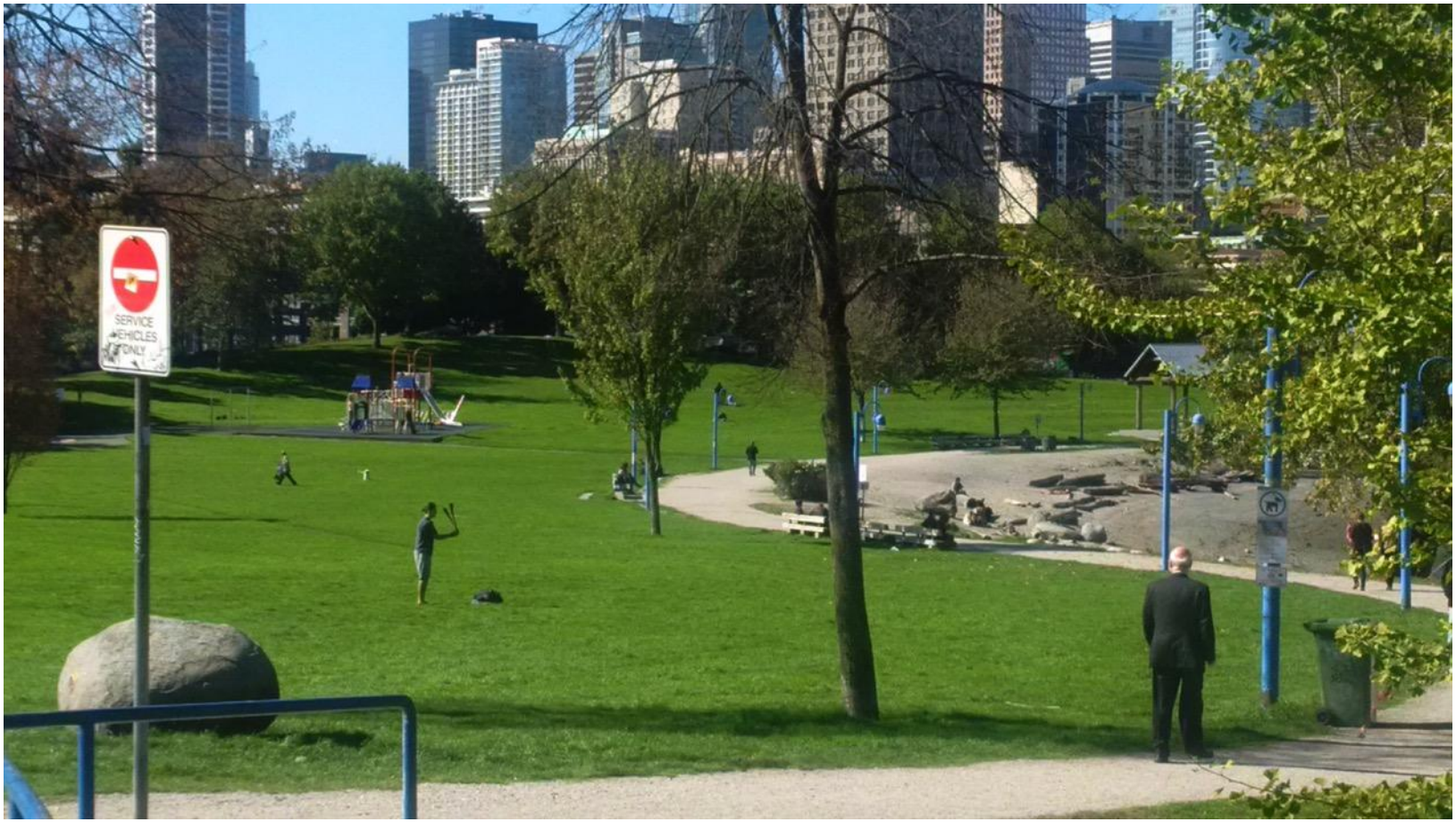
1. "Dying with Your Boots On”

2. Approaches to symptom management while caring for a "homeless" population

3. Uniqueness in the spiritual journey of those living "homeless" at the end of their lives


REGENT
HOTEL
HOTEL

Crab Park, Vancouver



Pain & Suffering

What is the DTES?

- Geographically small
- High rates of HIV/HCV
- Poorly controlled chronic diseases
- Mental illness
- Substance abuse
- Cognitive impairment
- Poverty
- Marginal housing
- Multiple social problems
- Racism
- Loneliness
- Injuries from accidents and violence
- 30% Aboriginal
- **Life expectancy 50-60**

British Columbia

Aboriginal people:

- 4% of the general population
- 13% of new HIV infections
- less likely to engage in effective care
- twice as likely to die without ever receiving anti-retroviral treatment (ART) compared to non-Aboriginals

What is "Homelessness?"

- Poor social determinants of health
- Sleeping on the streets
- Couch surfing
- Sleeping in shelters (out 0630-2030)
- SRO with no heat, window coverings, bed

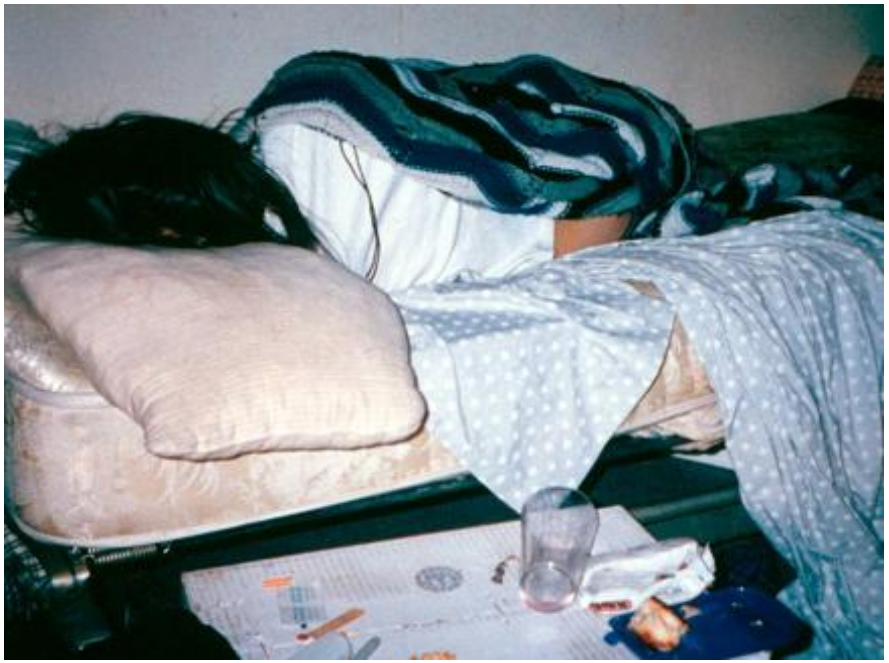
and shared bathroom floors away

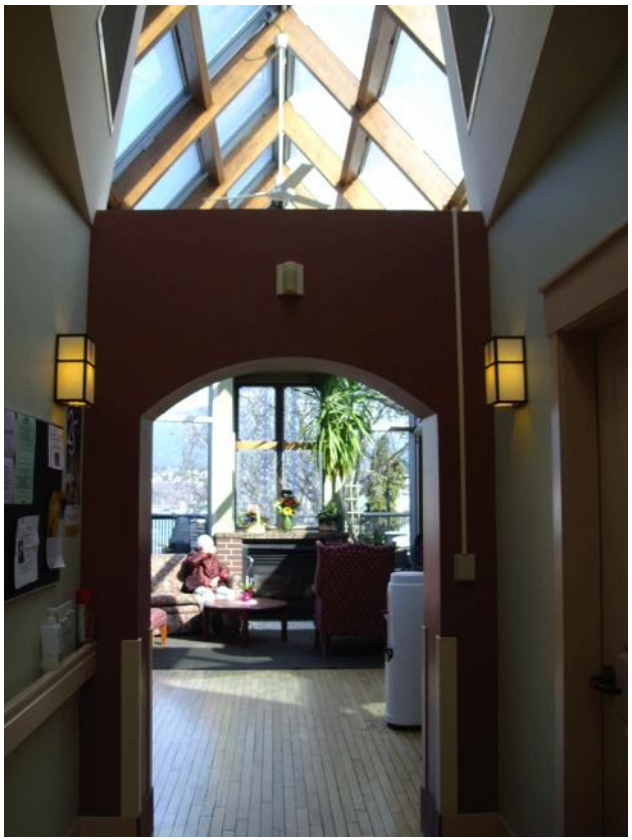
It's a difficult life….

Typical Day…

- Consists of looking for shelter
- Standing hours in a food line up, or not eating
- Standing in pharmacy line ups for medications
- Looking for warmth in the winter, clean water and shelter
- Considering a shower (or not), laundry (or not)
- If addictions – withdrawing, looking for a fix or hiding so won't use
- Possibly engaging in street work or crime to pay for drugs
- Managing personal safety – from drug dealers, stimulant induced violence
- Looking for companionship

What does palliative care look like in DTES?





Middle class concept needs adaptation

Home Death?

What is unique about palliative care in a homeless population?

- Marginalized persons don't "fit" the regular system
- We often need to go out and find our patients
- Where we provide care- clinics, SROs, shelters, alleys, doorways, in a food lineup, walking alongside in the street
- How we give care daytime only and in pairs for safety
- Harm reduction NOT abstinence approach
- Assessments are sensitive to impact of trauma
- May be a small window of opportunity to provide care
- Crisis management is common, unfortunately

Barriers to Palliative/EOL Care

- Lack of telephone access and after hours service access
- Lack of access to housing with 24 hour access to nursing/medical care for advanced health conditions, not yet ready for hospice
- Lack of clinicians comfortable with harm reduction approach in pain & symptom management, with withdrawal management & discrimination
- Expectations re: abstinence

Case Example

- Mr T: 56 year old man
  - Advanced COPD, ? Lung cancer, a-fib, chronic pain
  - Anxiety/panic, alcohol abuse, PD, on parole
  - Significant number of hospital days and ER visits
  - Couldn't connect – out of shelter at 630 am, in at 2000
  - Goals of care unclear
  - Took me 3 months to catch up with him, involving ER SW, outreach team
  - Hospital agreed to update his imaging while in ER knowing outpatient arrangement would be difficult

- Where are DTES residents when sick or dying?
- What are our ‘ethics of access” with respect to this population?

Palliative

- ***"Pallium"*** – to cloak or cover

- How to spread "a cloak of care"?

Dying With Your Boots On

Better Put Your Own Boots On!

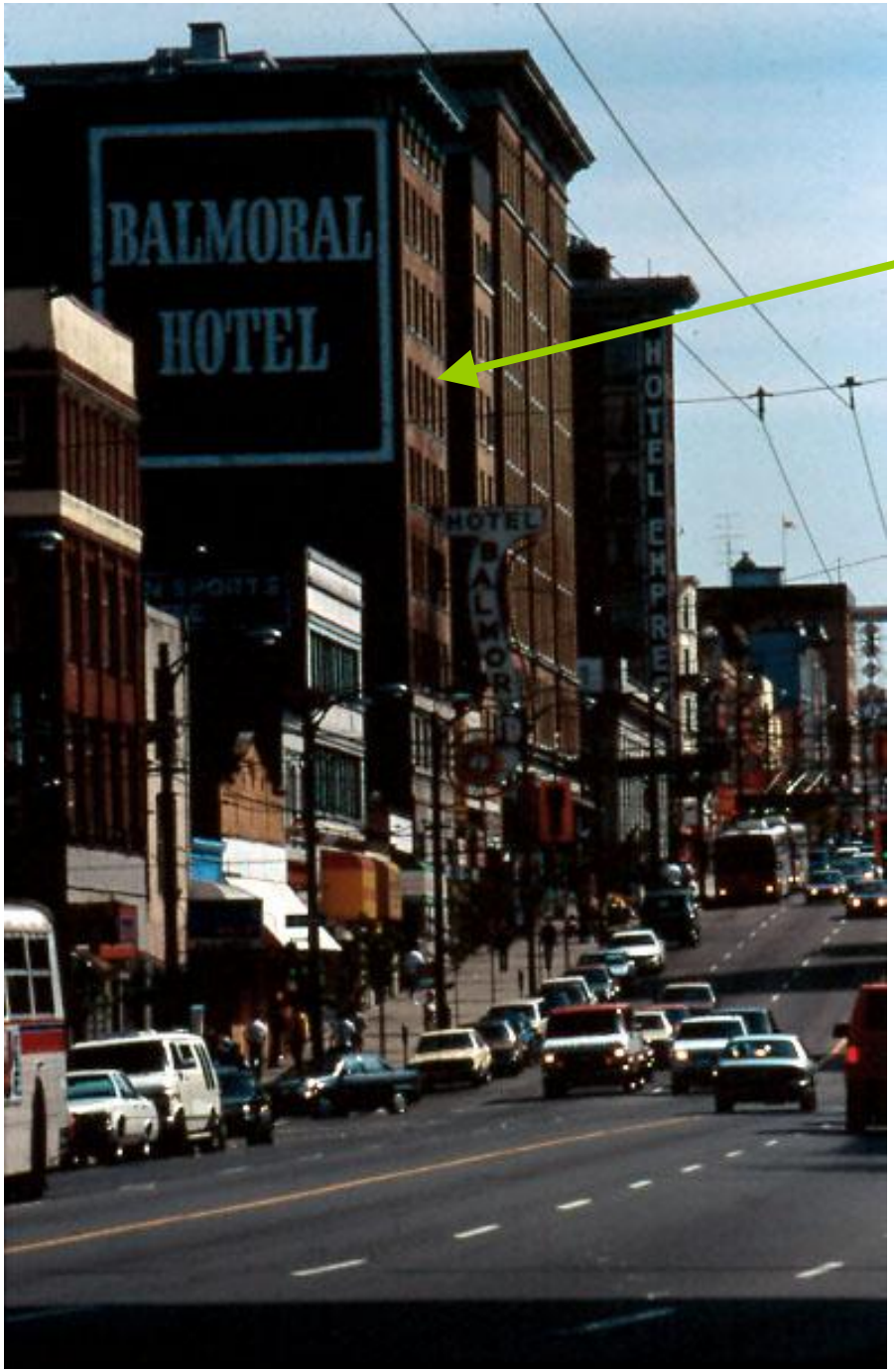
Imagine other care options

- Follow in footsteps of patient
- Know that that person exists
- Will tell us what is possible

“Laura”

"Laura"

- 20 year old Aboriginal woman
- FAS – Hep C+
- HIV/AIDS, CD4:20, CD4%:4, MAC
- Living in SRO hotel
- Mom also FAS living in same hotel
- History IVDU heroin, cocaine
- Began drug use age 9; drug counseling age 13; sex trade worker; street involved



AT NINE YEARS OLD, YOU ARE HERE

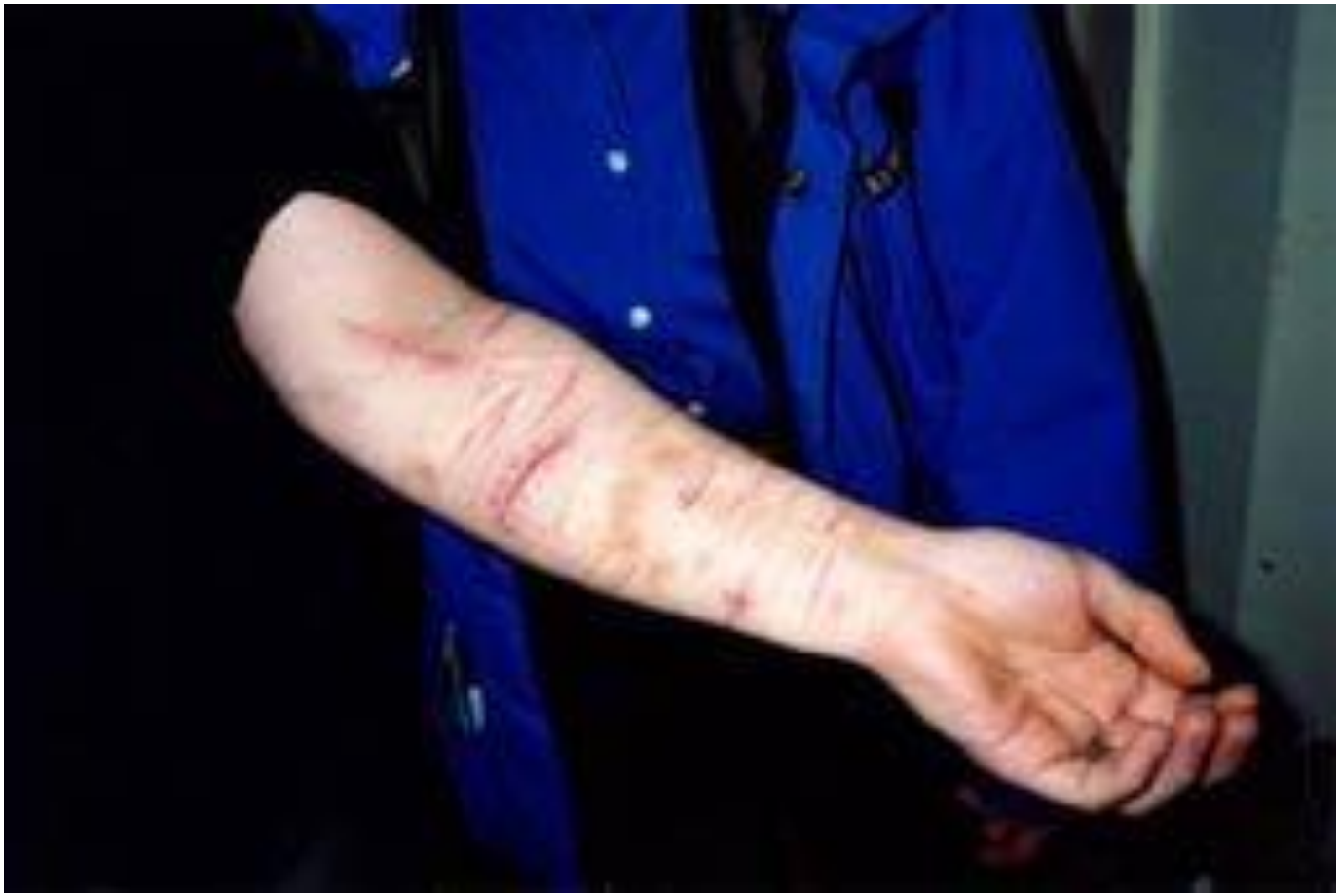
Classic		DTES
• Home	→	• SRO hotel
• In bed	→	• On the street
• Rx analgesic	→	• Self medicate
• Family	→	• Drug buddy
• Home cooking	→	• Food line
• 24 hour nursing	→	• Crisis care

What can we offer Laura?

Home Hospice in a Hallway

But there are issues that get under everybody's skin

The patient as irritant



The culture as irritant

Age as an irritant

Associated diseases as irritants

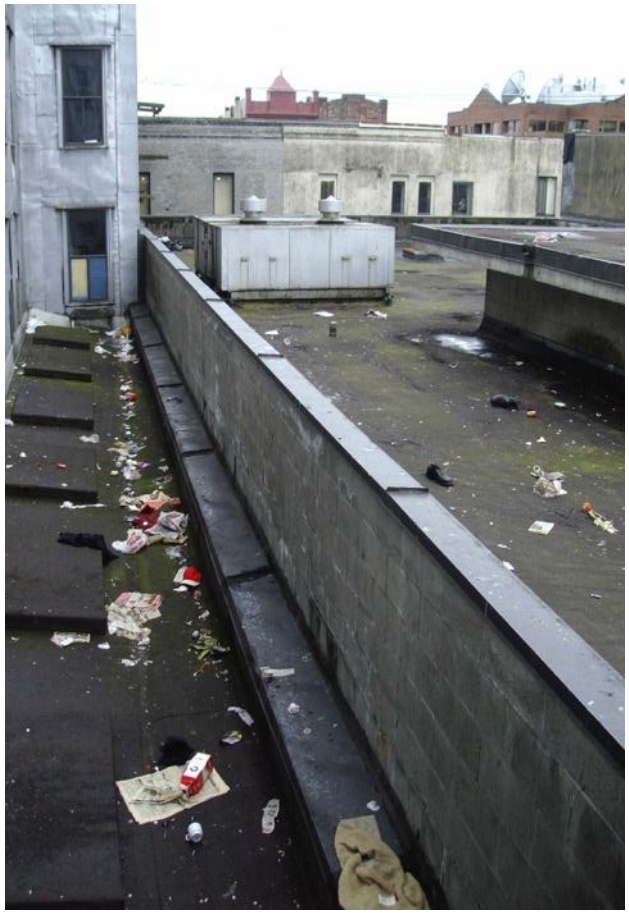
- Syphilis -TB
- Cardiomyopathy
- Septic joints
- Ulcers and Abscesses
- COPD
- Cancers
- Renal and hepatic failure

Attitudes as irritants

HIV disease as major irritant

- Medically, temporally variable
- Different faces in this population
- Variable trajectory
- Chronic disease
- Acute cause of morbidity/mortality
- Subtle/atypical
- Catastrophic

Symptom Management



‘Laura’

Pain Management

- Self-medicating/late presentation of illness
- Are they getting what you give?
- Control the analgesia
- Long-acting agents e.g. Duragesic/Kadian
- Daily dispensing breakthrough doses
- Observed ingestion as much as possible

Pain Management

As good as it gets?

- Frequent contact – daily
- Reliability
- What do they want from us? Know the culture
- Support the patient but not the‘habit’
- Seeing past the behaviour to the individual within
- Flexibility

Medication Adherence

Judgements

- “Look at her: she made $400 last night on the street and you’re telling me she’s palliative?
- Why doesn’t she die? Her CD4 is <10; she has MAC; CMV; lymphoma; pneumonia?
- I’m 20 now; will I make it to 30?
- “If I go to hospital, I know I’ll die!”

Judgements

- It’s not safe; we don’t go to ‘those’ places
- I won’t take ‘them’ in my car
- They have to meet ‘us’ 1/2 way
- Let’s get the pharmacy to ‘drop off’ the pills

End of Life

Primary Diagnosis??

- Social determinants of health
- Social determinants of healthcare

Spiritual Care
Who am I? Why?

- How do you define suffering in the context of serial losses?
  - Life events are experienced relative to trauma(s)
  - Limited opportunity to meet developmental milestones
  - Limited attachment, multiple homes, prison time

- What does hope look like?
  - “Hope is to see in the eyes of others that you are understood” (Henri Nouwen)
  - Starts with validating an individual’s experiences

Who Cares Anyway?

- What is the person's unique capacity to survive?
  - Autonomous right to live at risk
- What is "unfinished business" ? Does it need to remain unfinished?
- How will the anticipated death impact others in the community? (ripple of despair)

Case Example

- Joe was 47, lived in a SRO/walk up 4 th floor, dripping sink, swinging lightbulb, metal bed, rats for pets.
- Unrelieved back pain, IVDU polysubstance
- Never knew his life story
- dx HIV- opportunity, hope for better QOL
- Friend died
- Despair, refused all help, building too unsafe to put in evening checks
- Overdosed
- My hope is he felt a sense of control in his choice to die

Take Home Message

- If traditional pall care needs lead time to develop a relationship.....Triple that time needed to engage a marginalized person with MH and addictions
- Learn to practice trauma informed care

  http://trauma-informed.ca/wp-content/uploads/2013/10/Trauma-informed_Toolkit.pdf
- Have someone in your agency follow up on “no shows” if their address is DTES, have mental health or addictions diagnosis or “red flags” of medication misuse
- Self care is essential. Vicarious trauma happens

You Can Refer/Seek Help Here…

- **DCHC: (604) 255-3151**
  - ask for the resource nurse, or Barb Eddy
- **VCH Home Hospice: (604) 263-7255**
  - ask for Dr Burgess

Ethics of Access

“You matter because you are you.”

— Dame Cicely Saunders

Acknowledgments of Partners in EOL Care

Community of the Downtown Eastside

THE BLOOM GROUP
Community. Services. Together.

Vancouver CoastalHealth
Promoting wellness. Ensuring care.

Home Hospice Program
Pender / North AOA Programs

Vancouver Native Health Society