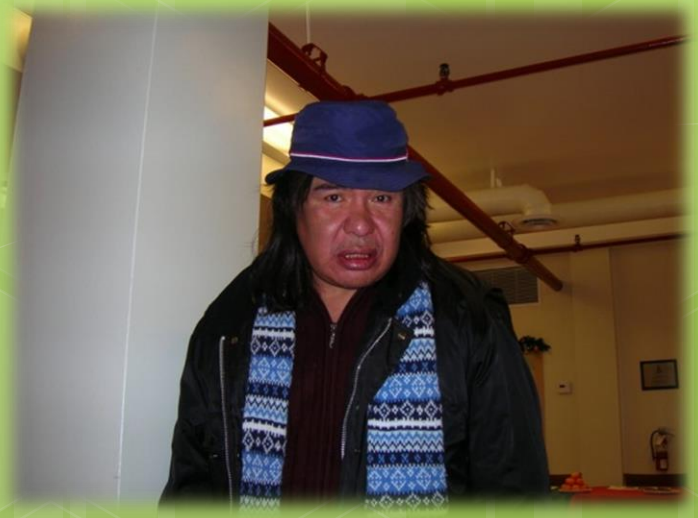


Providing End of Life Care to the Ottawa's Homeless

Marg Smeaton, Health Service Manager, Ottawa Mission

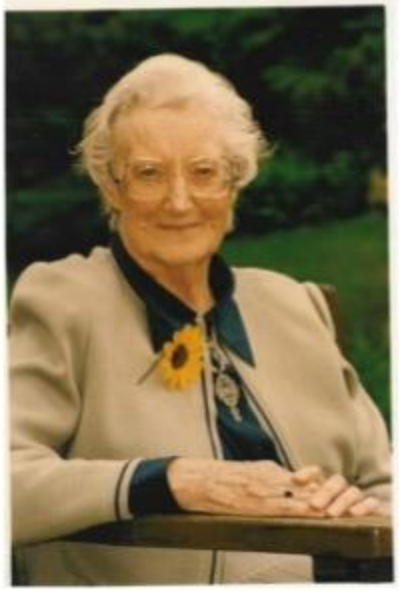
Wendy Muckle, Executive Director, Ottawa Inner City Health

Why the Homeless Have a **Right** to Palliative Care?

- Age adjusted life expectancy 25-30 years less than housed Canadians
- Usually have had difficult lives, poor coping skills,
- Higher burden of illness
- Lack of natural caregiving systems,
- Lack of appropriate housing impedes benefit from health care
- Severe mental illness imposes complexity on plan of care

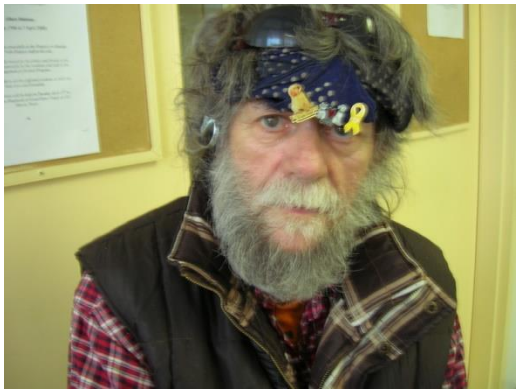
DAME CICELY SAUNDERS

- "You matter Because You Are YOU...& To The Last Moment of Your Life And We Will Do All That We Can To Help You To LIVE until You die"



Who deserves a good death more than someone who has had a difficult life ???

Benefits?

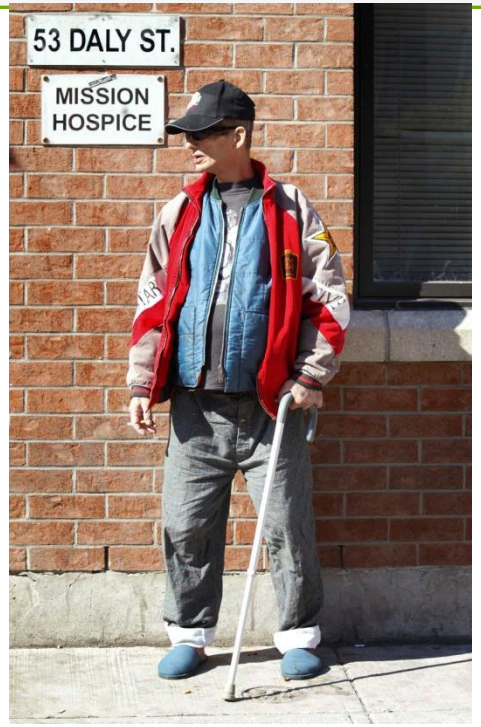


- Cost effective ($125 per day vs $3000 in hospital)
- Consistently demonstrated cost savings of $3:1
- Significant reduction in ER utilization
- Longer life expectancy than in shelter or on the streets
- Reconnection to family and social supports (restoration of position in society)

Do you Need a Hospice?

- It's nice but. . .
- End of life care is defined by meeting need and respecting life choices not by a bundle of care
- Need to address the need by adherence to values and not succumb to "rules" about palliative care

In the Beginning. .



- Mission Hospice opened in 2001 at the height of the AIDS crisis
- Established to provide accessible palliative care to homeless
- Main barriers to accessing main stream palliative care were drug use and trajectory of the disease (AIDS)

Palliative Care Context

- Strongly rooted in middle class white values
- Efforts to differentiate palliative care from other kinds of health services have created certain "rules/norms" which define palliative care which may be at odds with values of the homeless
- Take the best and give back the rest. . . . Remember who we work for!

Challenges to the "Mainstream" Palliative Care System

- Culturally very different from what many providers are familiar with
- Value system often at odds with mainstream palliative world
- Poor tolerance for rules and rigid requirements
- Behavior and lifestyle may be at odds with care provider system and practices
- Lack of connection to usual "gate keepers" to access care
- **Talking less important than "doing"**
- **Need** for palliative care occurs much earlier in the disease trajectory

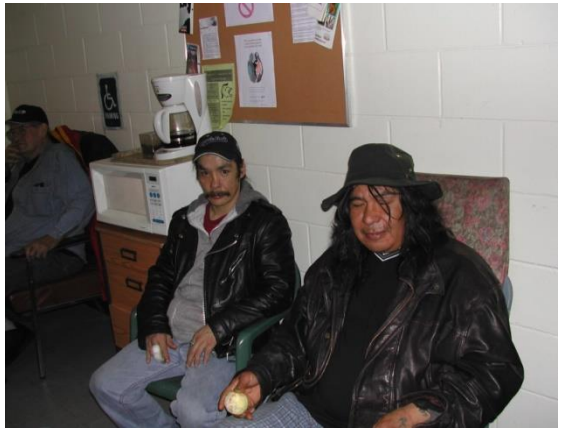
A Different Model of End of Life Care

- Initial response to the AIDS crisis among the homeless in 2000
- Unbearable suffering of homeless people who use drugs led to Mission Hospice
- Vision of a place to live at the end of life which respected the life style and values which included their community
- "The Good Old Days"

What Did Our Clients Want?

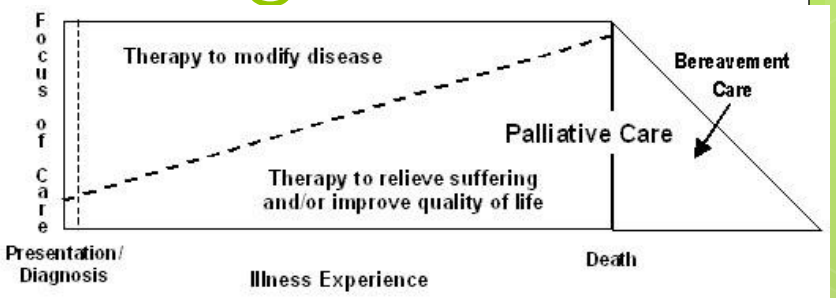
- To Die within their own community and culture
- To have their lifestyle respected and accommodated
- To have dignity and to have their symptoms controlled
- To be remembered as important to their community

Meet Triple Therapy



- Hospice care shifted to cancer and chronic diseases
- Age of death increased
- HIV clinic changed the face of AIDS for the homeless
- ***But, people now living longer but living with more diseases and therefore <u>more suffering</u>***
- ***Success from a survivalist lens but failure from a quality of life perspective***

?? The Unknown Challenges to Palliative Providers



- When "the surprise question" applies to almost everybody
- When the trajectories of different disease processes fail to fit in the graph

Evidence and Data

- Validation of the SPICT tool in our setting demonstrated potential benefits to developing a chronic palliative care program
- Lacks sensitivity to complexity imposed by mental illness and lack of housing
- Many of the tools and measures commonly used in mainstream palliative care are not very useful in the homeless setting

A Different Model of End of Life Care?

- Care based on need to reduce suffering not on life expectancy
- Trajectory is flexible-not just one chance for end of life care
- Focus on living well and dying when other options are exhausted??

Rooted in Values of Compassion and Respect for Respect for Street Culture

What Is Street Culture?

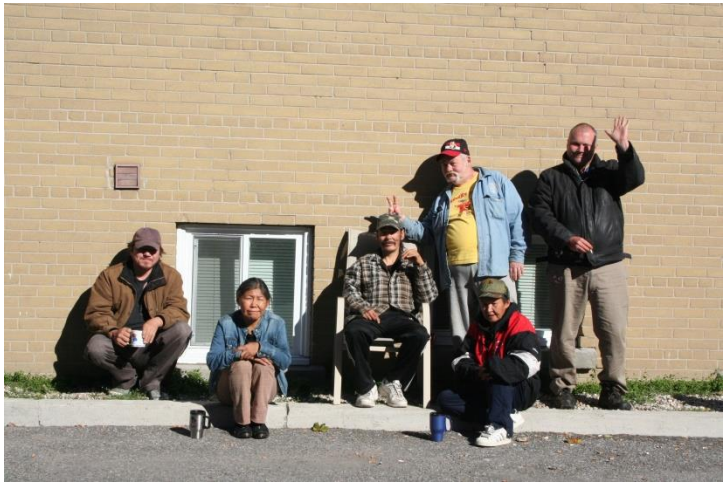
- Rooted in alienation from mainstream society
- Automatic assumption of discrimination
- Lack of hope for a brighter future
- Survivalist values
- Inclination to violence as a way of solving conflict
- Adhering to "Code of the Street"
- Lack of faith in police and justice system which often translates to other mainstream systems
- Primary issue is **respect**- hard won, easily lost and highly valued
- Lack of fear of dying, could die at any time and accept this as normal –high tolerance for risk

- What imposes suffering on the lives of our patients
- What can “we” do to minimize suffering and extend quality of life and longevity
- Challenge of how to integrate chronic palliative care in a resource limited setting

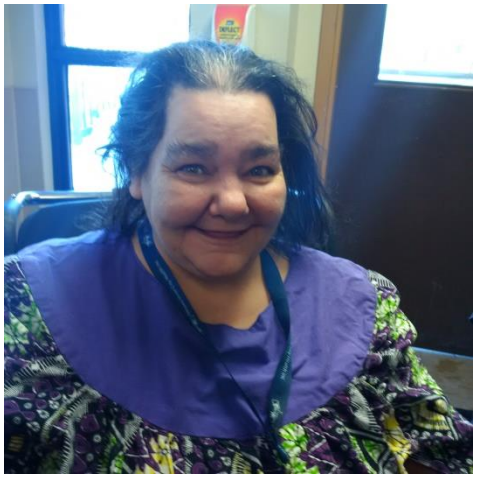
Focus on **Suffering**

End of Life Care-the Next Generation. .

- 14 Acute palliative care beds
- 7 chronic palliative care beds
- Enhanced chronic palliative care services in supportive housing
- Health literacy project to engage clients in improving their own health outcomes



Take Home Message



- The benefits of end of life care to the homeless need to be defined by need vs models of care or funding
- End of life care needs to part of the care provided to people who are or have been homeless
- Benefits to individual obvious, benefits to health care system, community, family (especially children) less apparent but just as important