

# The Dementia Difference

## A 2-day workshop on caring for people dying with dementia

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**BROADMEAD**  
Care Society

*Excellence in Care for  
Veterans and Seniors*

Operating The Lodge at Broadmead and Veterans Health Centre

# The Lodge at Broadmead

- Home to 225 people
- 60% Veterans
- 75% have Cognitive Impairment
- 100% have families
- Non-profit residential care [complex care]
- Committed interdisciplinary team
- Learning organization



2

# Our Dementia Care Program Journey

- Dementia care project – funded by Veterans Affairs Canada since 2003 – resulted in program development, education and research into best practice dementia care
- Second phase of the project we began to notice that the people moving into residential care were much frailer, more complex and closer to death
- To support our goal of aspiring to excellence in care we began to look at how we supported people with late stage dementia – and asked if we were doing the best we could for these people.



3

# A Decision

- We wanted to improve our care for people with late stage dementia who are ending their life with this chronic disease.
- We decided we wanted to build on our previous success with a facility wide education program on dementia and dementia care.
- Since we really are not wheel "reinventors" we searched for an education package on caring for people dying with dementia – we found none.



4

# A balanced focus

People come to TLAB to live



But people die here too



5

# Development

- Literature review: *Ambiguous Dying Syndrome*, prognostication, best practices
- Staff Input: Focus groups held with CNS and interdisciplinary team members
- Family Input: Interviews were held, either face to face or on the phone with a number of family members. Family members included: widows of people who had died previously at TLAB, children of people currently dying at TLAB and spouses of people currently living at TLAB.
- Exceptional Partners: Clinicians with expertise in Palliative care
- Linking Dementia and Palliative Care best practices [CHPCA]



6

## Development - Dementia Lens

Why is dying with dementia different?

(considerations of the end of life experience for a person with dementia)

- Social death preceding the actual death
- Misconception that dementia takes away the potential for the person to be creative or socially engaged
- Dying is often protracted – health problems build without concern
- Difficulty in ensuring optimum symptom control has been achieved
- Social networks that exhibit exhaustion & pessimism that any positive interaction can occur
- Assumption that the person with dementia has no capacity to express preferences

(Small, Froggatt & Downs, 2007)



7

## Facilitators

- The Lodge at Broadmead is always striving to build capacity in the staff working there.
- RN, LPN, OT and SW staff were selected to participate in a "Train the Trainer" – 3 day workshop to prepare them to co-facilitate the education.
- The internal training team has been instrumental in the revisions to the content and process over the first year of implementation.
- Trainers meet quarterly to debrief workshops, discuss new research and provide feedback to CNS as to how implementation of the content is happening [or not] in the Lodge.



8

## The Dementia Difference: A palliative approach to caring for people with late-stage dementia

Workshop Goal – To increase caregivers capacity to provide excellent care through to death, through the application of palliative care principles, specifically focusing on issues that are unique to caring for people with dementia.



9

## The Dementia Difference - Content

Day One

### Morning

**Introduction** – "a palliative approach" versus "he's palliative"

Palliative Care, CHPCA Square of Care

DEATH on the table

**Ambiguous Dying Syndrome** – Disease Progression,

**Ineffective interventions**

CPR, IV antibiotics, transfer to hospital, tube feeding

**Sentinel events** indicating death is nearing

"Could he/she be dying?"

### Afternoon

**Supporting Families** – Using the CHPCA Square of Care communication, communication, communication



10

## The Dementia Difference - Content

Day Two

### Morning

**Physical comfort** – Pain, Dyspnea, Delirium, Declining intake/Appropriate nourishment, Recurrent infections

### Afternoon

**Making moments meaningful** – activities for people with late stage dementia – BEING with

**Last days and hours** – what you will see, what you can 'do'

**Staff care** – the risk of being like family, how to avoid care burden



11

## The Dementia Difference - Implementation

- September 2007 – Feb 2008: 90 staff members.
- All staff are eligible to attend and the groups are interprofessional.
- The workshop is always co-facilitated.
- After the first year revisions were completed to the content and some of the learning activities were altered.
- Fall 2008 – another 90 staff have attended – we are reaching critical mass (total staff 300).



12

## Evaluation activities

- Pre/post knowledge test [T/F, MC]
- Single day participant comprehensive evaluations tools – each learning activity and content, as well as facilitator feedback
- Clinical Nurse Specialist observations when not facilitating
- Facilitator discussions [critical thinking and reflection]
- Participant focus groups one year after the initial launch

## Evaluation - Practice Changes

- Increased acceptance and communication about death – “discussions are easier” – more spontaneous and formal conversations about death.
- Decreased clinical nature of dying – staff feel they no longer have to follow a strict medical formula or hospital like routine when a person is dying.
- Increased knowledge and confidence – ‘pay more attention to the resident’s demeanor now’; have confidence to communicate their observations more readily with other team members.
- Increased attention to self-care – recognize and value self-care; “education makes everything easier”

## Evaluation - Practice Changes

Increase sense of “teamness” – interdisciplinary education increases support for each other, a greater understanding of each other’s roles and a sense of shared purpose.

Changes in communication with family – nurses in particular feel more confident when discussing care plans with family members.

Changes in language - “He’s palliative” means, imminently dying, actively dying, “doctors orders”, comfort “only”, etc.; Realization, he is not “palliative” he is a person. Use of ‘symptom management’ not just when a person is actively dying.

## Contact Information

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