Care at the End

Transitioning to a palliative approach for frail elders at home

November 12, 2015
Dr. Jay Slater

Vancouver, BC

jay.slater@vch.ca

Disclosures

- No real or perceived conflicts of interest
- No commercial support or interests

Acknowledgements

- Vancouver Coastal Health Home VIVE and Home Hospice Programs
- Vancouver Division of Family Practice
- PATH (Palliative and Therapeutic Harmonization) Clinic, Halifax

Objectives

- Identify challenges in home-based palliation of frail elders
- Describe the “tool kit” for providing home-based palliative care
- Apply a palliative approach to common conditions at end-of-life, with cases

Outline

- Background
  - Home VIVE program
  - Vancouver context
- Tool kit
  - System supports and Day-to-day tools
- Cases
  - Challenges in prognostication and decision-making
  - Symptom management
- Discussion and summary

Home ViVE
(Home Visits to Vancouver's Elders)

- Longitudinal primary care practice
- Exclusively home-based
- Interdisciplinary team
  - 6 part-time FP's
  - 2 full-time NP's
  - 3 RN's
  - 1.5 Physio, 1 OT, 2 Rehab Assistants
  - MOA, administrator

Goals

- Maintain or improve function, independence and safety
- Manage chronic diseases, respond to acute changes
- Support patients' and caregivers' choices
- Avoid or delay hospitalization
- Avoid or delay residential care admissions
- Provide good palliative care at EOL

Demographic

- Age over 80
- Moderately or severely frail (Clinical Frailty Scale)
  - Medical and/or psychiatric impairment
- High MAPLe (Method of Assessing Priority Level) and CHESS (Changes in Health, End-stage disease and Signs and Symptoms) scores - RAI-HC

How do we measure frailty?

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

DALHOUSIE UNIVERSITY *Inspiring Minds*

Home ViVE

- High intensity / Low volume practice
  - Home visits average 20-30 minutes
  - 'Stable' patients seen by MD every 4-8 weeks
  - Palliative or patients with acute changes in status seen more often
  - Other team members may also be involved
  - 24/7 availability
- Deaths 20% per year
- Home deaths approximately 40%

Toolbox

- System Supports
  - Provincial programs
    - Advance Care Planning
    - BC Palliative Care Benefits
    - Expected Death at Home
- Local supports
  - Home Health
  - Home Hospice program
  - Geriatric programs

BC Palliative Care Benefits Program

- Life expectancy 6 months or less
- Expanded drug coverage
  - Medications for pain and other symptoms
  - Some OTC meds
- Medical supplies and equipment
  - Catheters, continence products, dressings, CADD pumps, needles/syringes
  - Walkers, wheelchairs, hospital bed, mechanical lift, commode

Expected/Planned Death at Home

- DNR form completed
- Notification of Expected Death at Home form
  - Done before the death
  - Allows Funeral Director to remove a body from home **without** pronouncement (not required by law in BC, but commonly requested by families)

Local palliative supports

- Home Health
  - Community RN's, Home support workers
- Home Hospice Program – consultative model to support primary providers
  - Home-based patients
  - Nursing home residents
- Palliative drug box
- In-home shift care nursing in last days

Top 5 Drugs in the Palliative Box

- Hydromorphone
- Glycopyrrolate
- Methotrimeprazine
- Haloperidol
- (Lorazepam)

Grouping	Description	Percent (Based on study in Western Canada, 2005)
Sudden Death	Accident, fall, trauma, sudden cardiac	2.9
Terminal Illness	**Cancer, CRF**	**28.4**
Organ Failure	**COPD, CHF**	**33.8**
Frailty	**Dementia, MS, Parkinson's**	**29.3**
Other	Not in other groupings	5.6

Shifting to a Palliative Approach

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

http://www.who.int/cancer/palliative/definition/en/
(World Health Organization, 2012)

Who might benefit from a Palliative Approach?

- The Surprise Question
  - *"Would you be surprised it this person died in the next 6-12 months?"*
- Not sure? Use general or disease-specific prognostic indicators
  - Gold Standards Framework
  - iPal tool (ipalapp.com)
  - SPICT

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

4th Edition October 2011

Why is it important to identify people nearing the end of life?

'Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care'

(GSF National Primary Care Snapshot Audit 2010)

About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-co-ordinated, high quality care.

This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such clarifying their particular needs, offering advance care planning discussions prevention of crises admissions and pro-active support to ensure they 'live well until they die'.

Predicting needs rather than exact prognostication. This is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

Definition of End of Life Care
General Medical Council, UK 2010

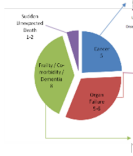
People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Three triggers that suggest that patients are nearing the end of life are:

1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?
2. General indicators of decline - deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.

Average GP's workload – average 20 deaths/GP/year approx. proportions



Typical Case Histories

1) Mrs A – A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline

2) Mr B – An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and coping alone in future. Decreasing recovery and likely erratic decline

3) Mrs C – A 91 year old lady with COPD, heart failure, osteoarthritis, and increasing signs of dementia, who lives in a care home. Following a 'bit' she grows less active, eats less, becomes easily confused and has repeated infections. She appears to be 'skating on thin ice'. Difficult to predict but likely slow decline

iPall – Advanced Disease

Palliative Care Assessment Tool

Providence HEALTH CARE

Identify who would benefit from a palliative care approach

1) ASK yourself

- Would I be surprised if this patient died in the next 6-12 months? **YES** or **NO**

2) LOOK for one or more *general* clinical indicators

- Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating
- Multiple hospitalizations in the past 6 months
- Patient needs more care at home or is in a residential care facility.
- Patient has multiple comorbidities causing symptoms/functional decline

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

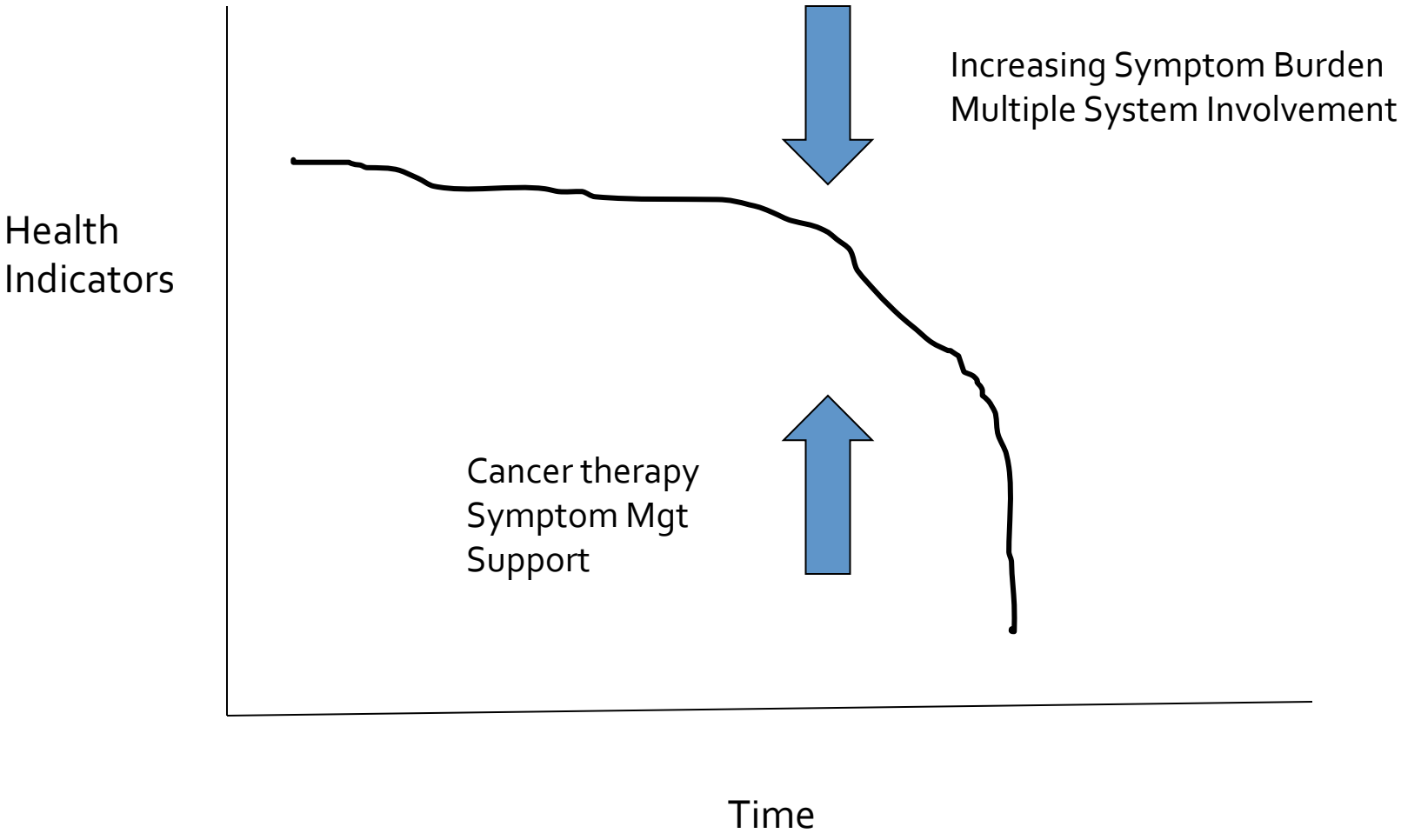
Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2015

General Clinical Indicators

- Decreasing activity and functional status declining
- Increasing need for support
- Progressive weight loss >10% in 6 months
- Repeated admissions (crises)
- Advanced disease, **multi-morbidity**, decreasing response to treatment
- Low serum albumin

Cancer Trajectory



Cancer Trajectory

- The most important predictive factor in cancer is performance status and functional ability
  - Patients spending more than 50% of the time in bed / lying down have a prognosis estimated to be about 3 months or less

A Circle Of Care
Victoria Hospice
SOCIETY

Palliative Performance Scale (PPSv2)

version 2

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 with 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/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
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	-	-	-	-

Dora

- 93 year old woman, living on her own since husband's death 20 years ago
- Hx of orthopedic injuries in an MVA 1975
- OA knees
- ?CHF
- Decreased mobility since 2000, attending Adult Day Program and requiring increasing home support over the years

Dora

- Cognitively intact, strong-willed, “would rather die than go to a nursing home”
- Increasingly house-bound 2009, no consistent primary care, enrolled in Home VIVE program
- Early issues with leg edema, cellulitis, skin ulcers
- Interventions included OT and Physio, wound care (RNs) and medical mgt

Dora

- May 2013 she revealed that she had “an infected L nipple”, wanting topical antibiotic but refusing exam
- Eventual exam suspicious for breast cancer
- June 2013 mammogram and core biopsy – which was unfortunately non-diagnostic
- Patient refused anything more other than analgesia (Acetaminophen, Codeine, Hydromorphone)

Dora

- Over the following months the lesion progressed to fungating destruction of the nipple and increasing ulceration
- Dressing changes painful “8/10” needing Sufentanyl, background pain requiring Hydromorphone and Gabapentin for neuropathic component
- Worsening mobility

Dora

- Autumn 2013 patient refused assessment at BC Cancer Agency for possible XRT or hormonal treatment
- Wound occasionally foul, draining, bleeding, significant time required for daily dressings
- February 2014 intermittent SOBOE, exam suspicious for L pleural effusion, limited activity and spending more time in bed due to fatigue
- March 21, 2014 severely SOB, caregiver called 911

Dora

- In ER started on oxygen, otherwise she refused pleural tap or admission
- She clearly wished a palliative approach and she was aware that she was nearing the end of life
- Thoracentesis done at home (1 litre) with some symptomatic benefit
- Continued rapid deterioration, bed-bound, sleeping more, minimal intake, diminished urine output

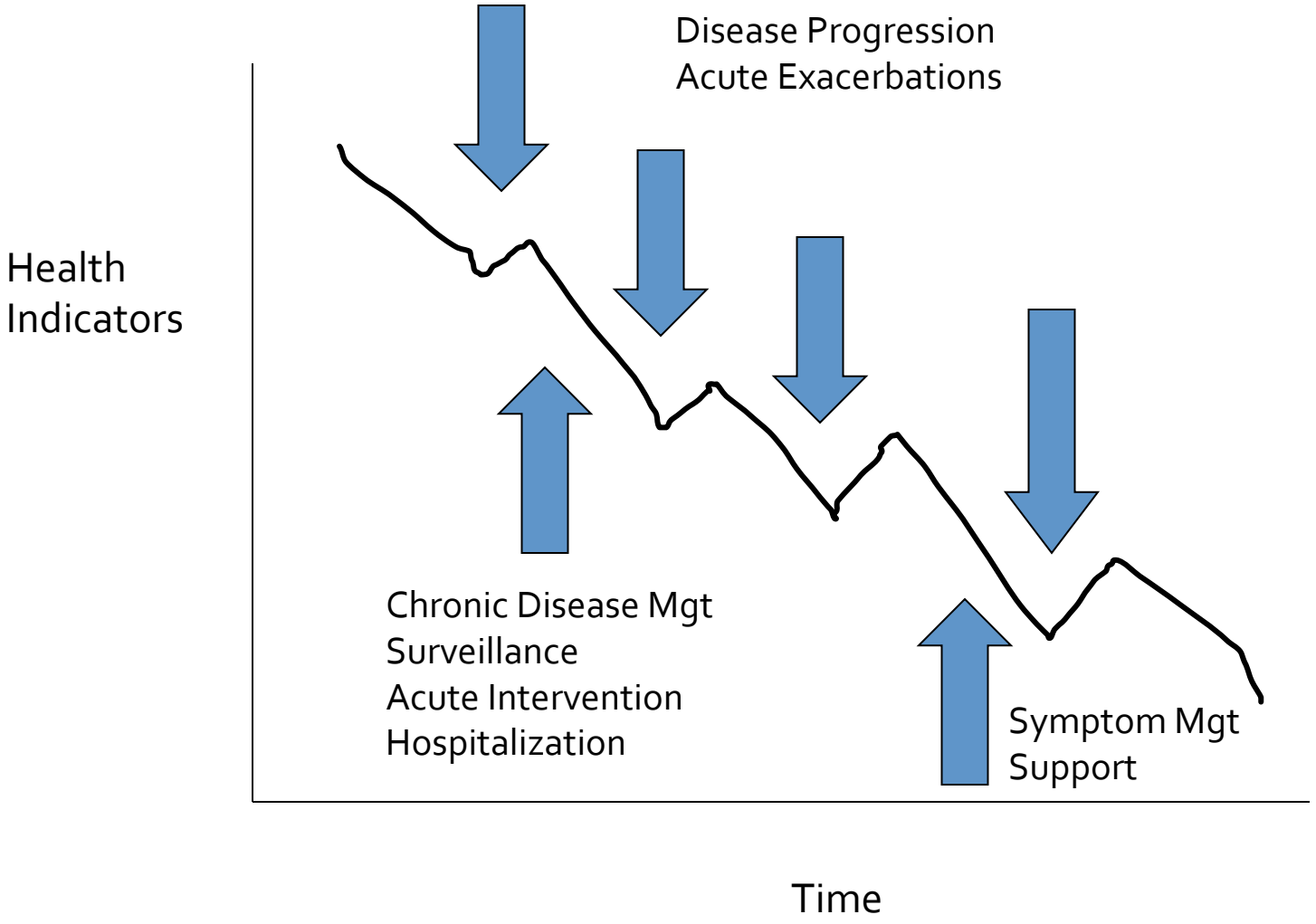
Dora

- Daily visit from RN, frequent MD visits
- Shift care nursing initiated April 4, palliative drug box (s/c meds)
- Died comfortably April 7, 2014

Dora

- Challenges
  - Respecting autonomy, negotiating care
  - Pain management including (background and 'incident' pain)
    - Hydromorphone regular and prn, Sufentanyl, Gabapentin
  - Dyspnea management
    - Hydromorphone, Lorazepam and thoracentesis
  - Difficult wound care, odorous and bleeding
    - Charcoal dressing, Tranexamic acid topically

Chronic Disease Trajectory (2-5 years)



Chronic Disease Trajectory

- “There will not be a distinct terminal phase. The week we die will start out like any other and some unpredictable calamity will occur. Amongst those of us with advanced heart failure, we will have had a 50-50 chance to live for 6 months on the day before we died”
    - Lynn, J (2004) Sick to death and not going to take it anymore

Specific Clinical Indicators

- CHF
  - NYHA Stage 3 or 4, SOB at rest or minimal exertion
  - Repeated hospital admissions with CHF symptoms
  - Symptoms persist despite optimal therapy

Specific Clinical Indicators

- COPD
  - Severe disease (FEV1 <30% predicted)
  - Repeated hospital admissions (3 in past year)
  - Requires long-term oxygen therapy
  - SOB walking 100 m on the level, house-bound
  - Signs and symptoms of R heart failure
  - More than 6 weeks of steroids in past 6 months
  - Anorexia, weight loss, complicated pneumonia

Brenda

- 86 year old woman, retired clerk, war bride from England, widowed 1995
- Lives in apartment with 24/7 private caregiver support
- Unable to get out to see FP, referred to Home VIVE program January 2013
- Recent hospitalization for severe epistaxis, INR 6

Brenda

- Hx includes Pulmonary Fibrosis, prior PE, DM-2, CHF, AVR, Depression, Anxiety, OA, Falls. She is cognitively intact
- She had been on Palliative Benefits for 2 years already. Fluctuating course mostly due to the respiratory symptoms.
- Numerous hospitalizations with associated complications (C. diff, Delirium, Deconditioning)

Brenda

- O2 prn for ambulation in the apartment, uses walker
- Financial concerns about paying for private care vs moving to assisted living and also having to buy the equipment that had been provided under the Palliative Benefits program
- Hydromorphone for severe hip OA pain, very sensitive to dosage changes (confusion)

Brenda

- Debate between Cardiologist and Respirologist as to the cause of her SOB. Clinical suggestion of LV failure though Echo does not confirm this and her bioprosthetic aortic valve works well. Patient is sensitive to volume changes from diuresis. Lung disease apparently stable on CT but her **SOBOE is worse**….
- General deterioration in function

Brenda

- Hospitalized January 2014 with UTI, pneumonia and septic shock due to Group B Strept bacteremia -> Delirium
- Goals of care discussion, she does not want more hospitalizations -> resume Palliative Care Benefits Feb 2014
- Diuretics (Lasix and Zaroxolyn) titrated to patient's weight. Hydromorphone short- and long-acting for symptom management, Ativan prn, continuous O2

Brenda

- Describes feeling awful and anxious much of the time, becoming dependent for ADL's. More SOBOE. Diuresis makes her breathing easier but fatigues her due to volume shifts
- Family meeting March 24, 2015 to review fluctuating situation, approach to symptoms management and difficulty prognosticating
- Family and caregivers burning out

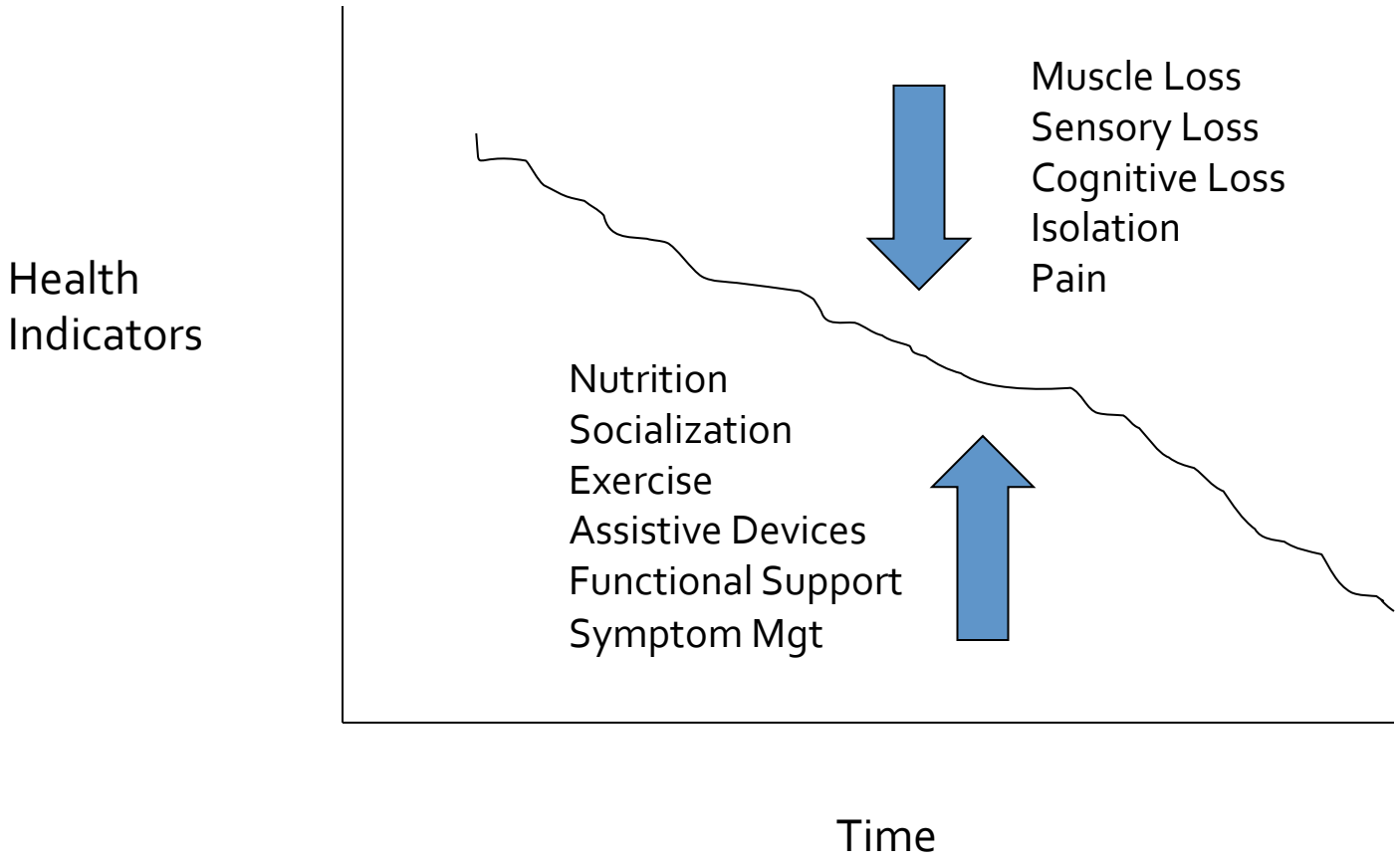
Brenda

- Fell out of bed early hours of March 26, caregiver attended and found her to have expired. She probably had a sudden cardiac event and died prior to falling

Brenda

- Challenges
  - Prognostication, Advance care planning and goals of care conversations
  - Numerous crises requiring quick response
  - Management of symptoms (opioids, benzo, diuretic) and complications (antibiotic associated diarrhea, fluid retention on steroids)
  - Longitudinal support for patient, family and caregivers

Frailty/Dementia Trajectory



Frailty / Dementia Trajectory

- Degree of dementia corresponds to degree of frailty
- Prolonged time course of inevitable deterioration (6-10 years)
- Advanced dementia has many of the symptoms of other life-limiting illnesses
- High likelihood of eating problem, aspiration pneumonia and/or febrile illness (CASCADE study)

Specific Clinical Indicators

- Frailty
  - Deteriorating function, multi-morbidity
  - At least 3 of the following: Weakness, slow walking speed, significant weight loss, exhaustion, depression, low physical activity

Specific Clinical Indicators

- Advanced dementia – when to consider a palliative approach
  - Unable to walk without assistance
  - Incontinence
  - Unable to do ADL's
  - Barthel score <3
  - No consistently meaningful conversation
  - Any 1 of the following: Weight loss, UTI, severe pressure sore, recurrent fever, reduced intake, aspiration pneumonia

Margaret

- 86 year old woman widowed since 1977
- Referred to Home VIVE in November 2010
- Had been living alone until recently, felt to be unsafe and incapable. Now in son's home with 24/7 care
- Dementia (mixed Vascular and Alzheimer's) with BPSD, symptoms present for "about a year"

Margaret

- Using ER for primary care
- Hx CVA's, CAD, CKD, Hypothyroid, Smoker, OP with spinal compression fractures and chronic back pain
- At intake MMSE 16/27, patient on Quetiapine and Risperidone for BPSD

Margaret

- Continued ER visits July 2011 (dizziness), May 2012 (back pain), Sept 2014 (UTI)
- Admissions June 2013 UTI and back pain, Oct 2014 UTI and delirium, Dec 2014 agitation and paranoia
- PATH training subject Nov 2013, Goals of care include palliative approach, dementia has progressed to “severe”

Margaret

- Several “near misses” over the years, palliative meds initiated then stopped
- At present dementia staged as “very severe” – totally dependent, mostly non-verbal, intake reduced, episodic choking
- Palliative care benefits – hospital bed, lift, supplemental caregivers, palliative drug box again in the home

Margaret

- Challenges
  - Prolonged course to advanced dementia has made it difficult for family to see dementia as a life-limiting illness and shift from crisis care to a palliative approach
  - Patient has had very difficult behaviours at times making it challenging to provide care at home

Practice Points

- Pain is common in elderly patients
  - Chronic non-cancer pain (ex. Neuralgias, Joint Pain), Cancer-related pain
- Pain is often under-reported, under-diagnosed and under-treated
    - Auret and Schug 2005, Drugs and Aging
- Patients with dementia experience no less pain than other older adults
    - AGS 2002

Practice Points – What works

- Establishing a trusting relationship
- Identifying the ‘circle of care’ including substitute decision maker
- Assessing and communicating prognosis and options for care
- Facilitating advance care plan and goals of care conversations ‘upstream’. Review in a crisis
- Being responsive and available