Palliative Care in Many Guises:

"Caring Together" Collaborative Working for persons living with and dying from advanced heart failure.

Images Courtesy of Internet

Yvonne Millerick & Jackie Wright

Partnership Working

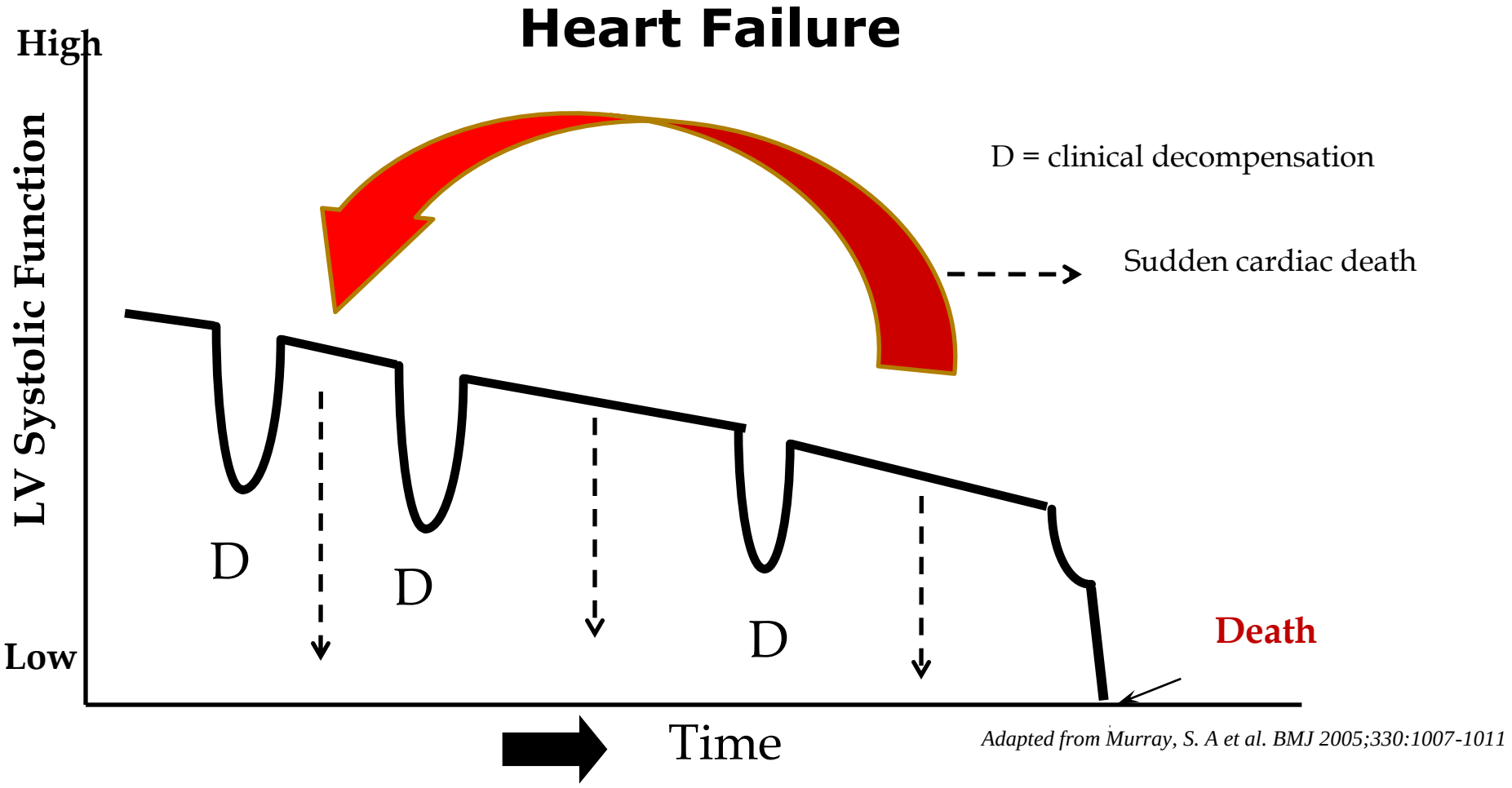
Double Act Begins...Jackie & Yvonne

Image Courtesy of Internet

The scale of the problem

- 10 million people across Europe
- 1-2% of adult population in developed countries
- Prevalence rising to >10% for aged 70yrs and over
- Most frequent principal diagnosis in hospitalized adults>65
- In the UK 1/3 readmitted within 12 months of discharge
- Poor prognosis and high morbidity
  - 1/3 die within one year of diagnosis
- £905 million 1.9% of NHS expenditure

Barriers to palliative care in heart failure



The Living Reality for Patients and Carers

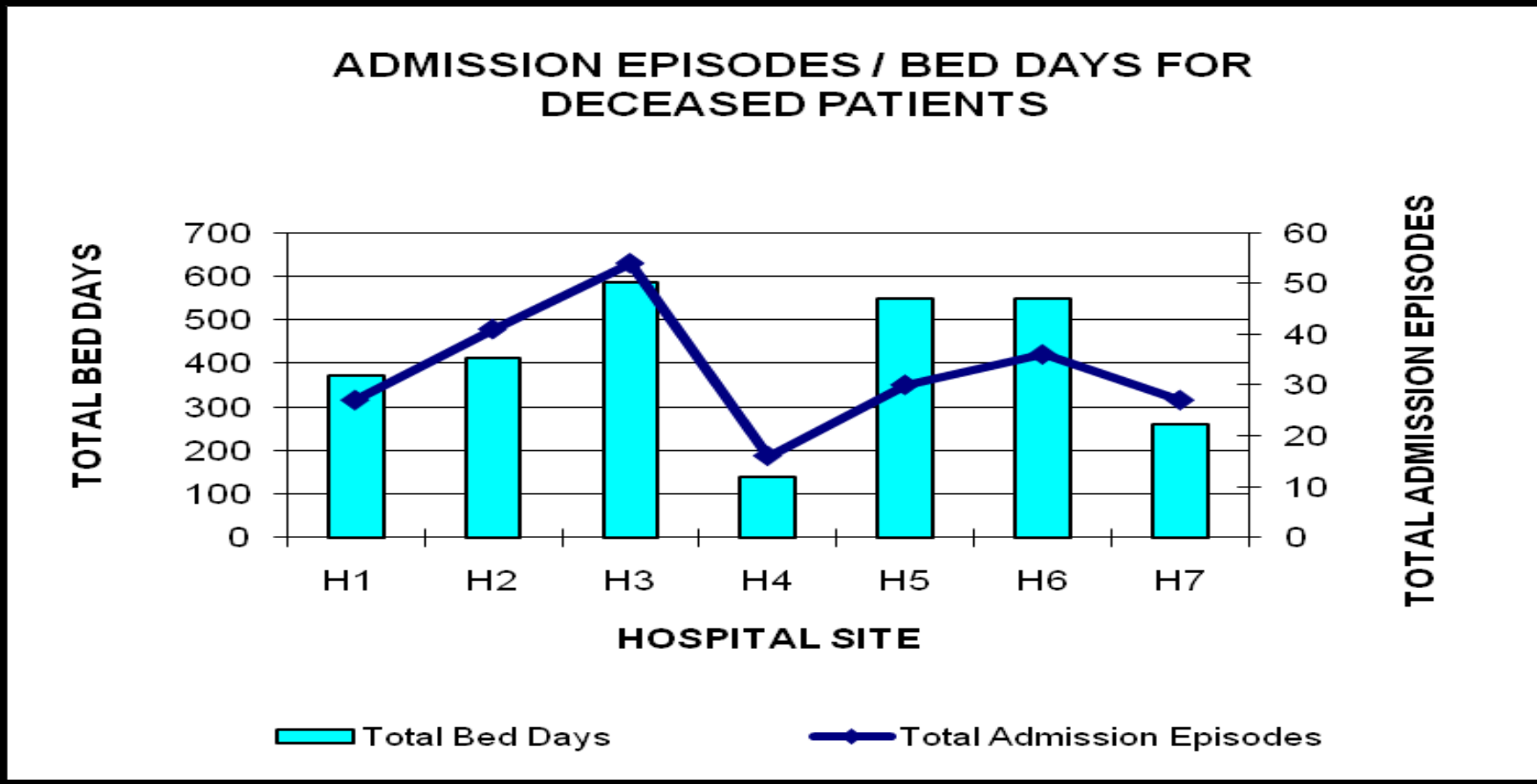
- **Patients with HF and carers are less likely to have:**
  - Access to social and palliative care services
  - Discussion about their illness and its poor prognostication
  - The opportunity to communicate Preferred care wishes including place of death

- **Patients with HF are more likely to:**
  - Be symptomatic compared to patients with cancer
  - Die in hospital

- **Audit Scotland: Review of all Palliative Care Services (2008)**
  - 90% of specialist palliative care was delivered to patients with cancer
  - 10% of specialist palliative care to be divided between all other non-malignant life threatening conditions.

Remme et al. Eur Heart J 2005; 22: 2413-21, Allen et al. JAMA 2008;299:2533-42, Anderson et al. Pall Med 2001; 15: 279-86
Murray et al. BMJ 2002; 325: 929-932

BHF: Heart Failure Palliative Care Project Glasgow & Clyde Experience 2011



Making Sense of the Different Perspectives

- Professional Approach
- Communication
- Patient Journey

Joe: Nurse Perspective

Background: 75 year old retired naval chef. Lived at home with his wife and teenage grand-daughter in a two bedroomed upper level flat with internal stairs.

Diagnosis: Moderate to Severe LVSD, Chronic Atrial Fibrillation, Coronary Artery Bypass Graft, , Previous MI, Primary Prevention ICD.

Heart Function & Supportive Care Clinic: Aim was to comprehensively assess his heart failure and general wellbeing.
Assessment: Symptoms/Social/Occupational/Psychological/Spiritual and Carer Support

What happened next? CANCER!!!!!

Multidisciplinary Working: Heart Function Supportive Care Clinic/MCCC Day Therapies/HFLN/PC

Joe continues to live with advancing heart failure in the knowledge he has the support of both Cardiology and Palliative Care.

Joe’s Perspective

- Joe liked us!! – Why?
- Time
- “Probed”
- We asked what he needed – we helped
- Devastated by cancer diagnosis
- “Heart failure was nothing”
- “Made links”

Additional Observation

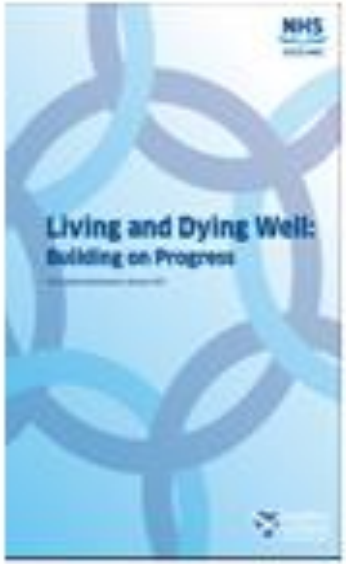
- The majority of the Cardiac patients were not complex.
- They had generalist palliative care needs that could potentially be met by generalists.
- Their trajectory can be very unpredictable.....
  some die suddenly and many others have a prolonged and exhausting trajectory.....
- The specialist palliative care model is not immediately transferrable to all patients with a non-malignant condition.

“There will not be a distinct terminal phase.....
.....We will have had a 50:50 chance of living six months, on the day before we died”

Image Courtesy of Internet

Joanne Lynn: Sick to Death and Not Going to Take it Anymore (2004)

ESC a position Statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology



Caring Together

Better end of life care for patients with heart failure”

NHS Greater Glasgow and Clyde

British Heart Foundation SCOTLAND

Marie Curie Cancer Care

Referral criterion

- Patients must be registered with a GP in one of the three CT pilot sites
- A confirmed diagnosis of heart failure
- NYHA classification III or IV
- Have distressing or debilitating symptoms despite optimal tolerated medical therapy
- Have supported palliative care needs

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Core Components of the models

- A comprehensive patient assessment: (Cardiological/Holistic/Anticipatory)
- Identification of an appropriate care manager: (Co-ordinate care provision)
- Training and education of professionals: (Train*ing Needs Analysis)*
- Joint working and professional development between palliative and cardiology teams, across different care settings
- Multidisciplinary working approach to enhance coordinated care delivery

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Caring Together Documents

Holistic Assessment Tool: encourages professionals to move away from condition specific information and to develop a greater awareness of holistic needs through the appraisal of physical, social, occupational, psychological and spiritual wellbeing.

The assessment process is complimented:

- ESAS Symptom Assessment Tool
- PHQ-9 and GAD 7
- Carer Strain Index

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Medical Anticipatory Care Plan

Caring Together Programme

DEPARTMENT OF MEDICAL CARDIOLOGY
Heart Function and Supportive Care Clinic

Glasgow Royal Infirmary
Level 3
Walton Building
84 Castle Street
Glasgow G4 OSF

Consultant:
Dr Karen J Hogg

Caring Together Medical Anticipatory Care Plan

Patient and Main Carer Details

NAME: DOB: CHI:

ADDRESS:

NOK Details *(Relationship)*: Main Carer Details *(Relationship)*:

Care Manager Details:

Diagnosis List:

Current Medications:

Changes to medications

Medications to stop:

Medication intolerance:

Device details: Applicable / Not applicable

Medical and Symptom Management Considerations:

Priorities of Care

NAME CHI

Current Place of Care:
Preferred place of care: 1.
2.

Device Status if appropriate:

DNA / CPR Status:

Intensive Care Referral: Not Appropriate

Central line access: Not Appropriate

Appropriate maximal medical therapy:

Inta-aortic Balloon Pump (IABP)	YES / NO
IV Inotropes	YES / NO
IV Diuretics	YES / NO
SC Diuretics	YES / NO
Oral medications	YES / NO

Transfer to hospital in the event of acute deterioration:Avoid if at all possible

Key Professional Services Currently Involved:

NAME - Consultant Cardiologist GRI

NAME – Care manager

NAME - GP

NAME - Other Consultant

Key Professional Services to be considered if condition or situation changes:

Significant Conversations

Patients Understanding of current situation:

Carers Understanding of current situation:

Helpful/Emergency Contact Numbers:

Cardiology GRI: .....

HFLN .....

DN .....

Consent

NAME CHI

Has patient agreed to sharing their personal details with other professionals (including for use in ePCS):

Yes / No / NA

Has carer agreed to sharing their personal details with other professionals:

Yes / No / NA

Has next of kin agreed to sharing their personal details with other professionals:

Yes / No / NA

This Medical ACP has been agreed by:

Consultant Cardiologist (Dr Karen J Hogg) Sec: Donna Sharpe - 0141-211-4833 Donna.sharpe@ggc.scot.nhs.uk

Signature:

Date:

Care Manager (Print Name):

Signature:

Date:

All components of this Medical ACP have been discussed and agreed with the patient and family members (where applicable).

Date Completed: **Review Date:** Weekly
Recommend as appropriate

This patient has attended a heart failure and supportive care clinic.

This patient has met the criteria for Caring Together and should be considered for entry onto the appropriate palliative care registers

For further information on the Caring Together Programme:
Telephone: 0141 557 7552
Email: caringtogether@mariecurie.org.uk

Pub. date: April 2011
Review date: March 2012
Issue No: 04
Author: Caring Together Programme Team
www.mariecurie.org.uk/caringtogether
www.bhf.org.uk/caringtogether

Developed from previous work undertaken as part of British Heart Foundation heart failure palliative care project: the Glasgow and Clyde experience (2006-2010).

NAME CHI

An Integrated Model

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Background:

30 year old single mum of 3 young children, previous history of drug abuse. 3 young children previous history of drug abuse

Presents May 2011: Out of hospital arrest, Anterior STEMI, Angioplasty LAD
(Cardiogenic Shock/intra aortic balloon pump & short term LVAD)
Moderate-severe LVSD

Jun 2011–Oct 2012: Inpatient/Outpatient attendance at Advanced Centre for optimisation of cardiological treatment (evidence based pharmacology & ICD insertion)
Assessed as unsuitable for Cardiac Transplantation.

Nov 2012: Consented to inclusion to cardiac study in an attempt to sustain life.
Developed complications resulting in cardiac arrest.
Miraculously survives.....

Dec 2012: Referred to Caring Together for Supportive Palliative Care.
Sadly died peacefully at home 4 weeks later with her family present .

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Physical Wellbeing

Symptom Burden: Edmonton Symptom Assessment Score (ESAS) = 54
Main symptoms: generalised pain, fatigue, tiredness, weakness, nausea, poor appetite, pruritis, poor quality sleep, breathlessness, PND, orthopnoea, low mood, thirst, dry mouth and cachexic

Functional: Housebound & bed bound secondary to extreme weakness, exhaustion, high symptom burden and difficulty managing the stairs

Completely dependant on her mum who not only cared for Anne, also cared for the children etc

Used wheel chair during short visits outside of the home

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Social + Occupational Wellbeing

- Own home was completely unsuitable
- Living with her mum in a 2 bedroom home with internal stairs making it impossible to use the downstairs living accommodation
- Sleeping arrangements unsuitable

Assessment Outcomes:

- Escalated to top of the priority housing list
- Full removal undertaken by housing dept and provision of new beds
- Full social work care package implemented
- Guardianship assistance from social work for kids
- Occupational assessment and provision of aids implemented
- DS 1500 Terminal illness application processed
- Grant awarded £2000 from Lord Provost Fund

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Spiritual Wellbeing

- Explored understanding of current illness situation, its impact and likely progression.
- Discussed concerns around the illness, what might happen and what should definitely not happen based upon her wishes etc
- Explored the hopes and fears that she had now for herself and for her family
- Explored her goals and desires regarding what was important for her to achieve now and in the immediate future.

(Association of Hospice and Palliative Care Chaplains: Standards for Hospice and Palliative Care Chaplaincy)

Psychological Wellbeing: Hospital Anxiety Depression Score (HADs)

A=7,D=11

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Anticipatory Care Discussions

- Preferred place of care
- Preferred place of death
- DNA CPR
- ICD Deactivation
- Medical Anticipatory Care Plan
- Palliative Care Register
- ePCS/eKIS
- Guardianship

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Pharmacological Management

Ramipril 1.25mgs od
Furosemide 40mgs od
Aspirin 75mgs od
Oromorph 1.25ml (x6 doses/24hrs)
Esomeprazole 20mgs od
Loratidine 10mgs od
Lactulose 15mls nocte
Senna 2 tabs nocte
Ondansetron
Oral Balance Gel

Drugs Discontinued: Bisoprolol, Spironolactone,

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Carers Assessment

Carer Strain Index = 24 (high score)

Further discussion took place with mum to make certain that she understood what was expected from her regarding the home being identified as the preferred place of care and death.

Additional support services were offered

Bereavement follow up visit

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Partnership Working

- Care Manager: Heart Failure Specialist Nurse
- Heart Failure Medical Team/Cardiac Physiologist
- Specialist Palliative Care
- District Nurse and GP
- Pharmacist
- Health Visitor/Schools
- Social Work/Welfare Rights Officer
- LTC Financial Inclusion Partnership
- Housing Association
- Charitable Organisations
- Funeral Directors

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Communicating across care settings

1 Caring Together: Medical Anticipatory Care Plan

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Reflection

What worked well:

Assessment of holistic needs through comprehensive assessment

True Partnership working

Facilitation of care preferences with actual place of care and death

Communication across different care settings

Person centred approach integrating who and what was important to Anne as well as what should, would and would not happen in the event of Anne's condition changing.

What worked less well:

Very late integration of a palliative care approach

Partnership working could have been considered much earlier

Communication between care settings was one way

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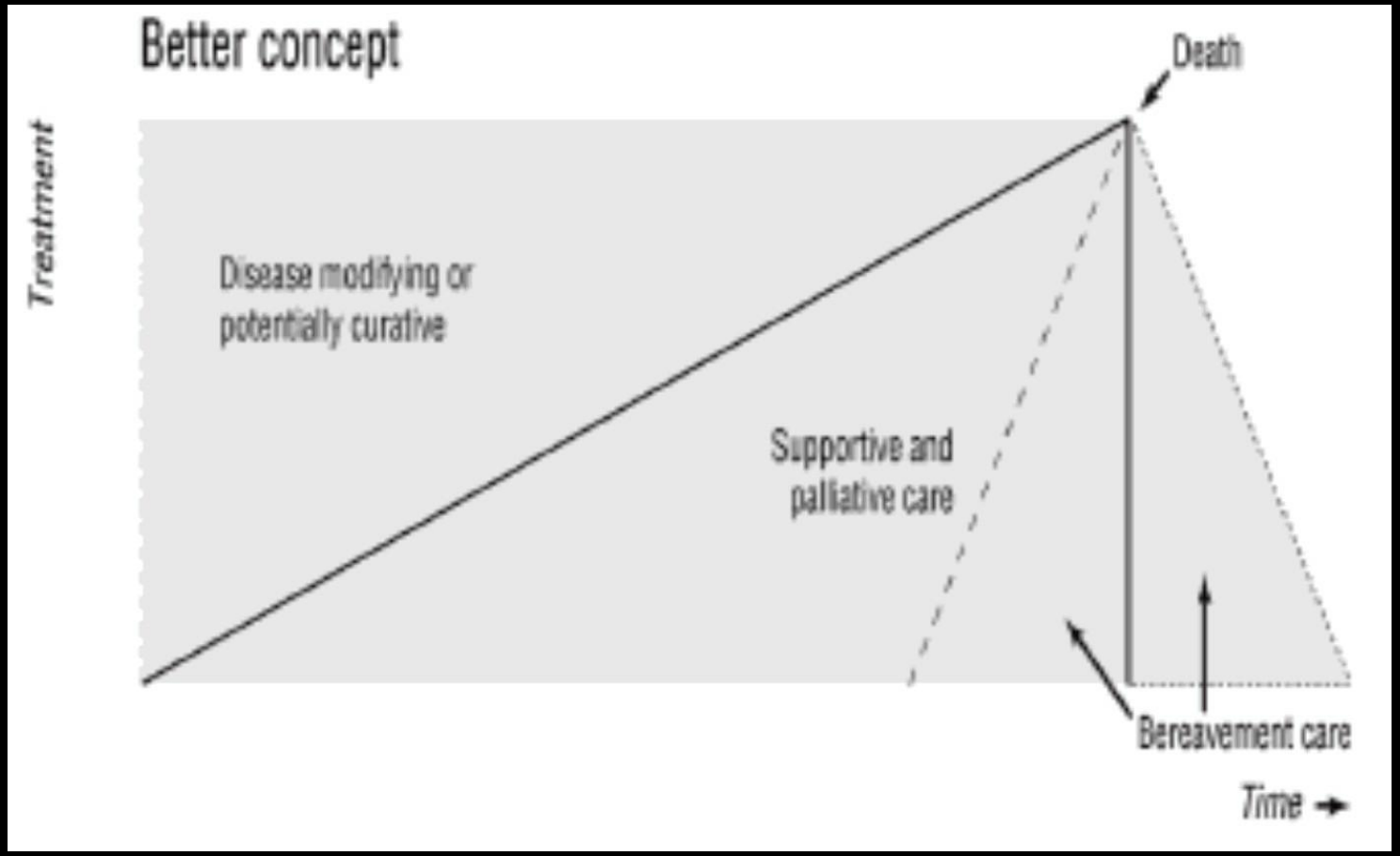

Appropriate care near the end of life Murray et al 2005. Adapted from Lynn & Adamson 2003

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Thank you: Question Time?