

Fifty shades of dying: the challenge of maintaining goals of care in chronic heart failure

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Trustee,

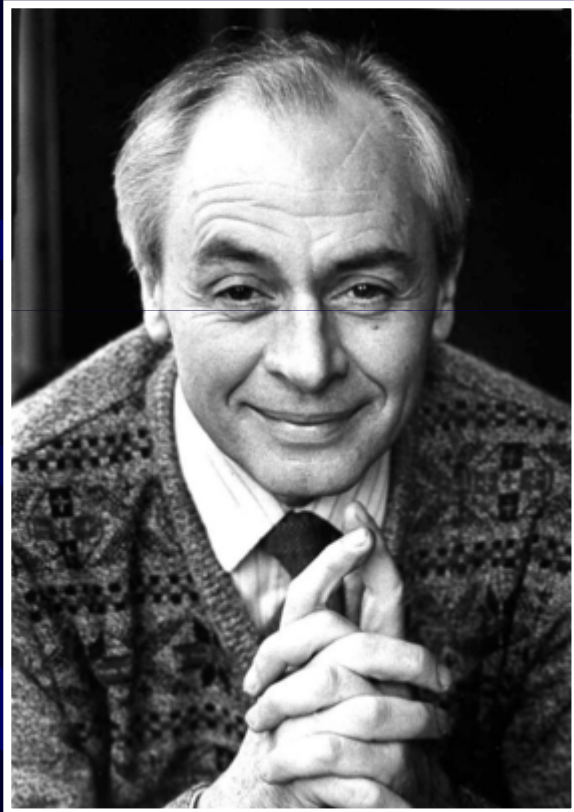
National Council for Palliative Care, London



Beardmore Conference Centre

18th Sept 2015

Chasing immortality?



“Life is a sexually transmitted disease and the mortality is one hundred percent”

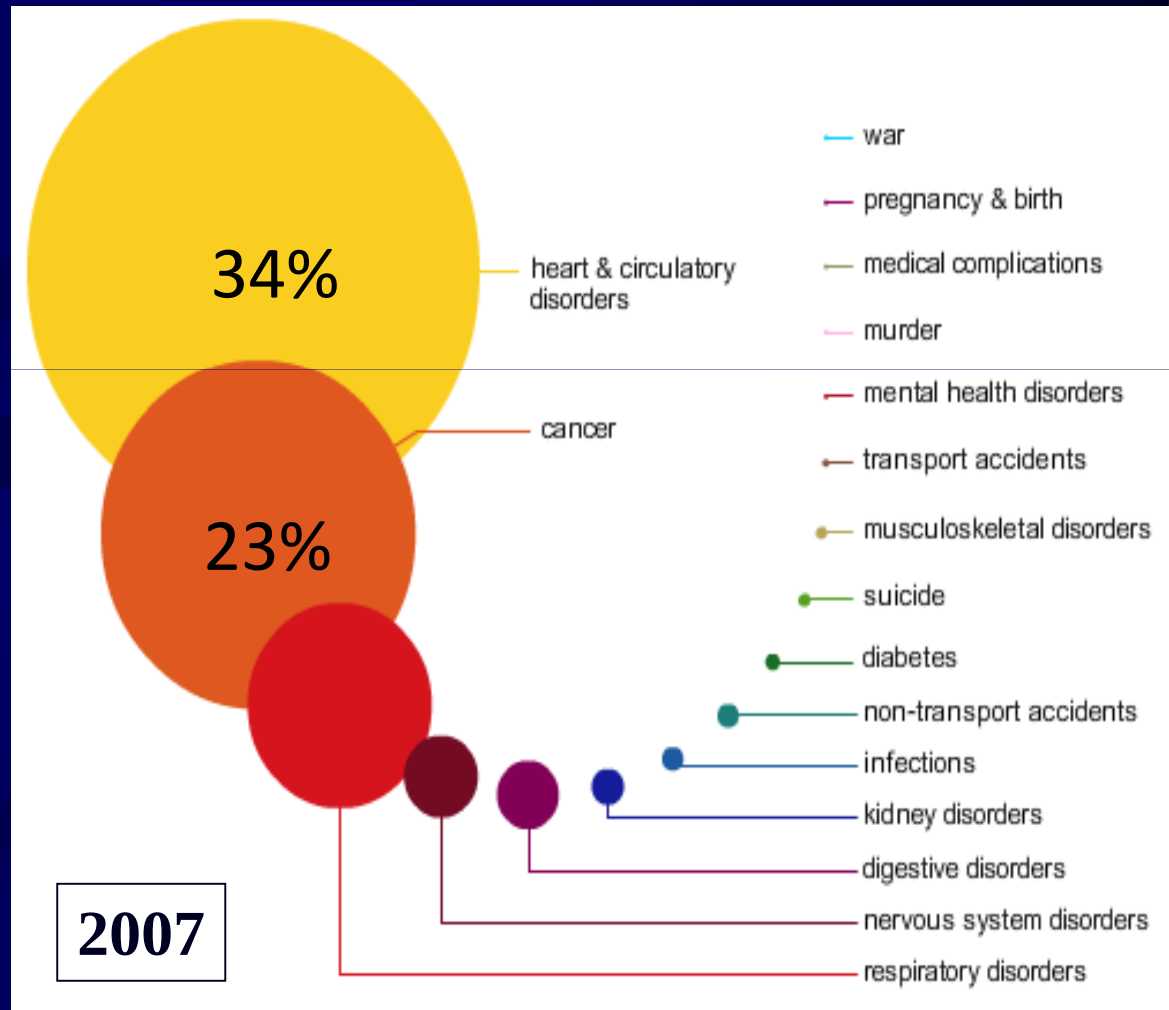
R.D. Laing

CVD – mortality market share

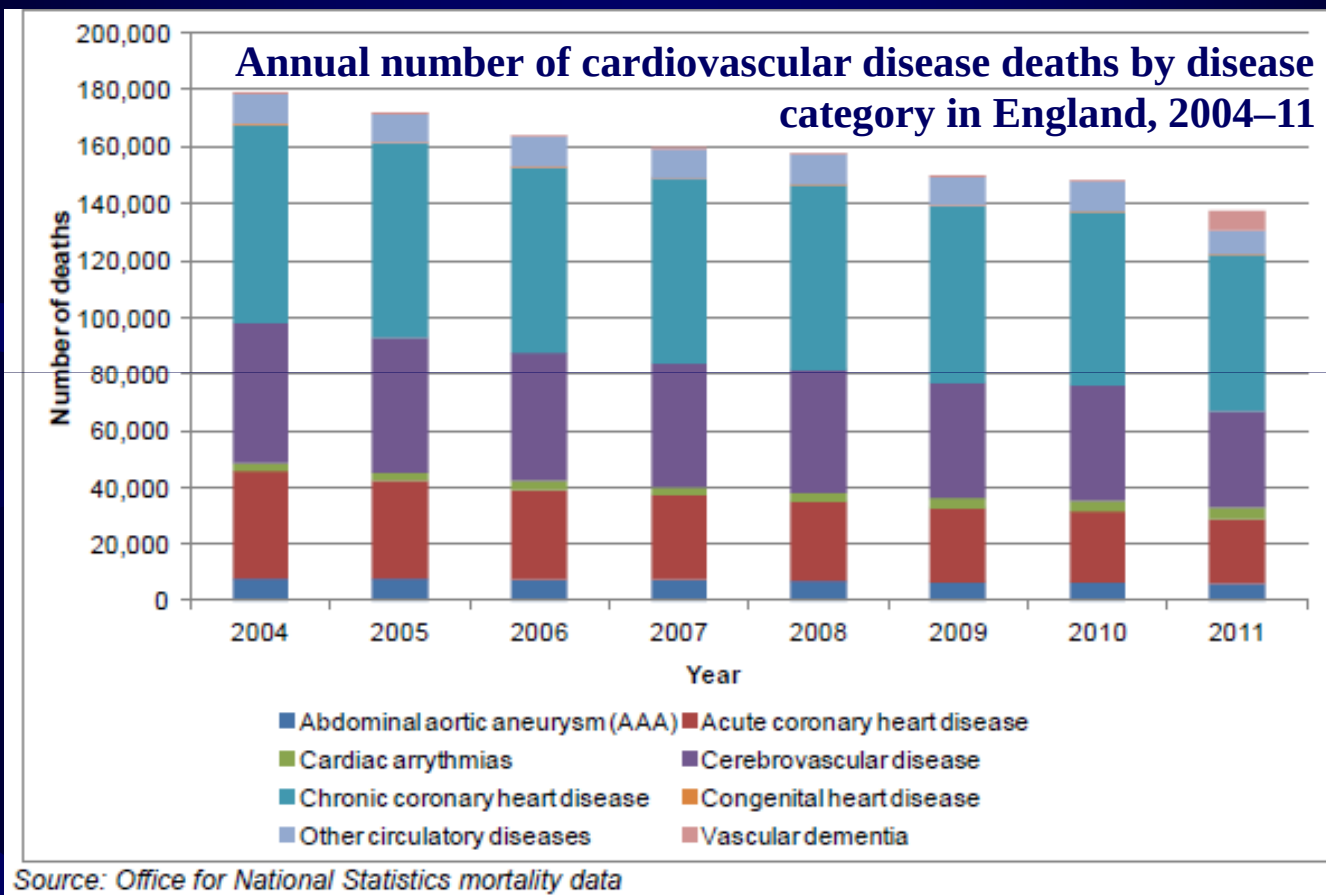
Cardiovascular disease - leading cause of death in England, resulting in 158 500 deaths - 34% of all deaths

Cancer responsible for 23% of all deaths

Atlas of Risk – NHS, 2009
(Courtesy of Pfizer)

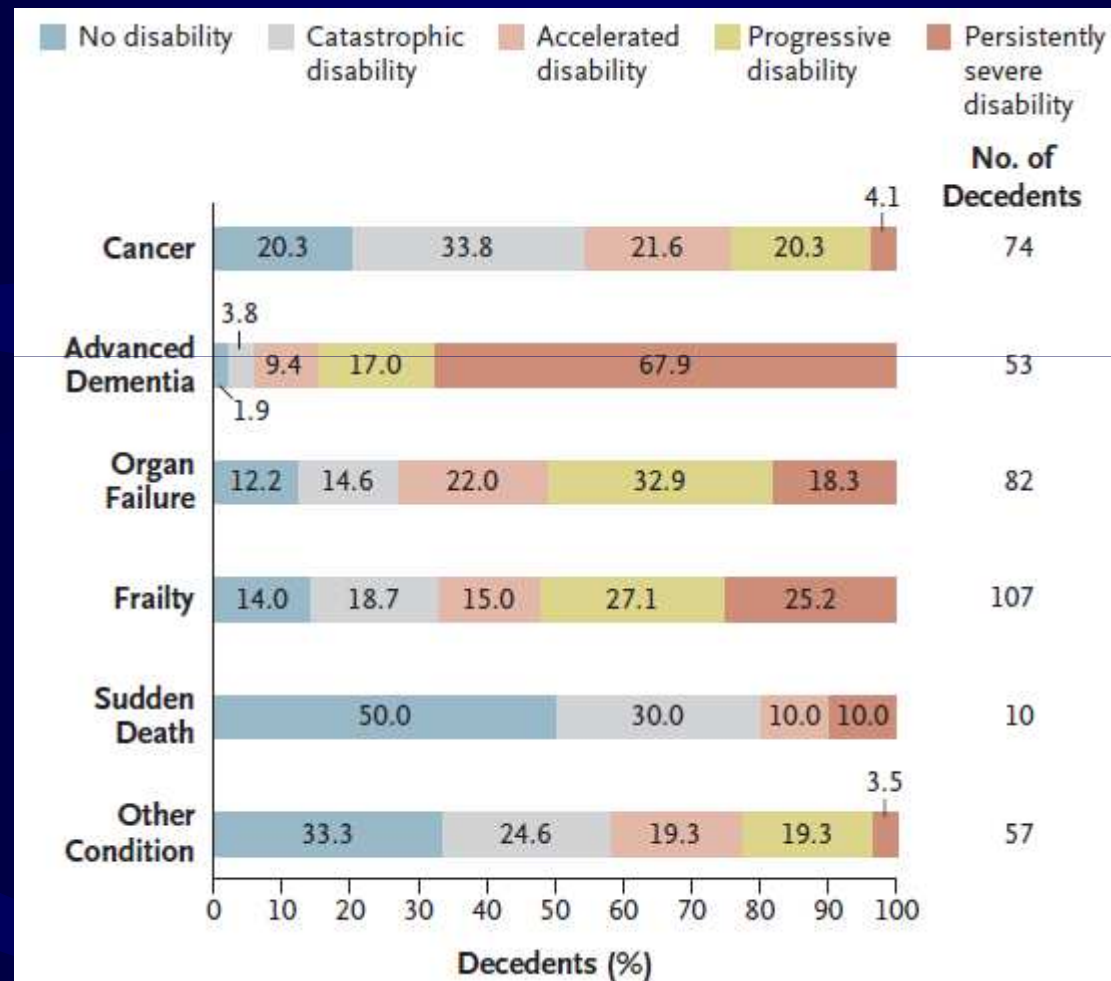


Deaths from cardiovascular diseases in England - implications for end of life care



Trade-off: A fragile survivorship

Trajectories of disability in the last year of life



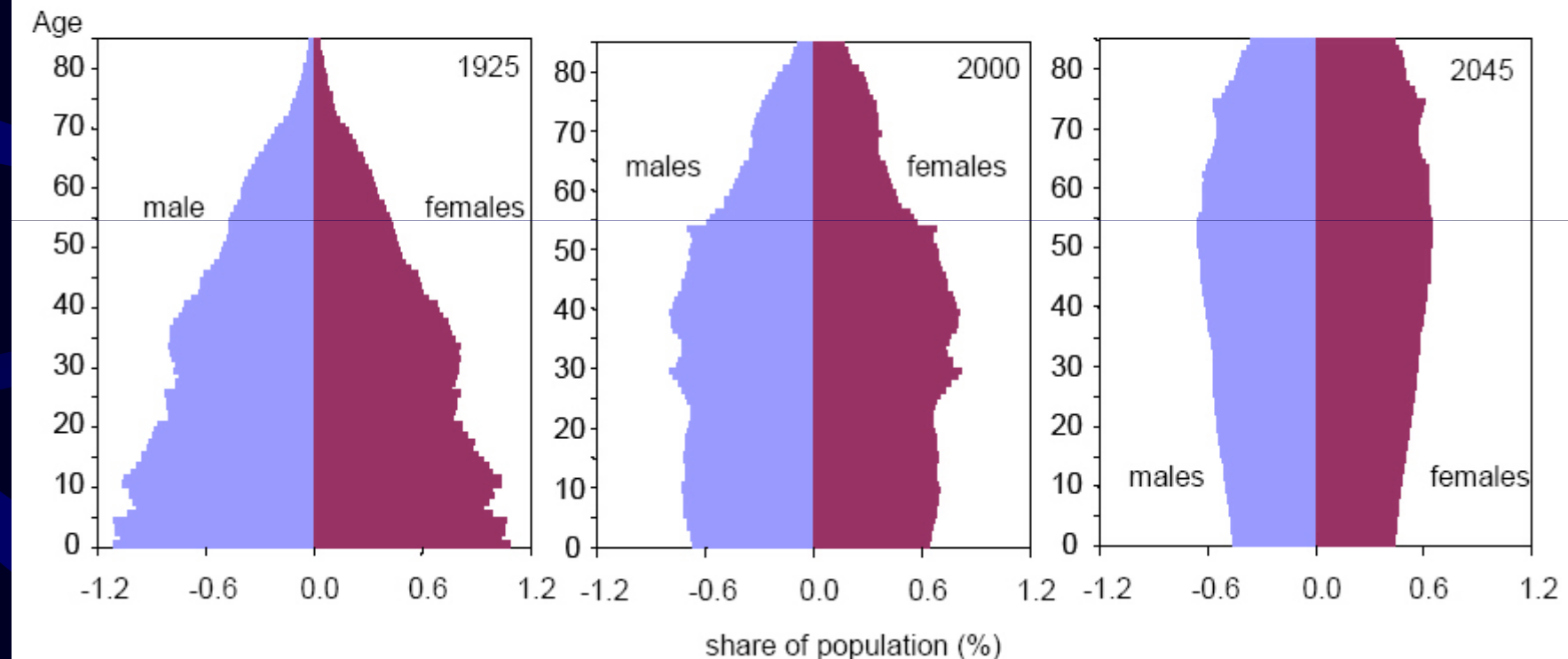
Gill TM. *NEJM* 2010;362:1173-80.



Population dynamics



From pyramid to coffin

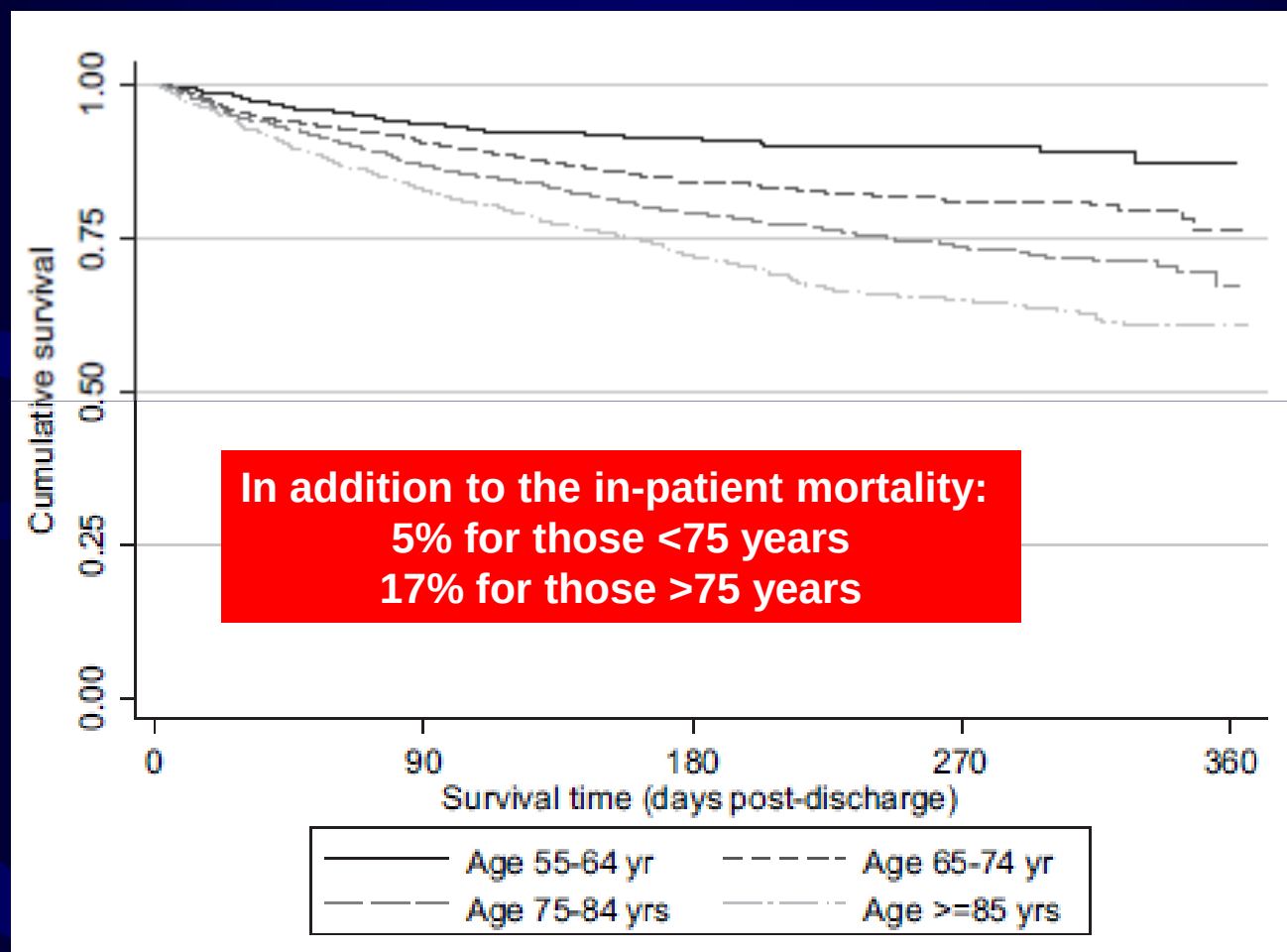


**UK 2001: Healthy life expectancy – men 67 of 76 years
women 69 of 80 years**



Parliamentary Office of
Science & Technology

National Heart Failure Audit 2008-09



Cleland JGF *et al*, *Heart* 2011, 97:876-86.

Reality of dying from CVD in the elderly



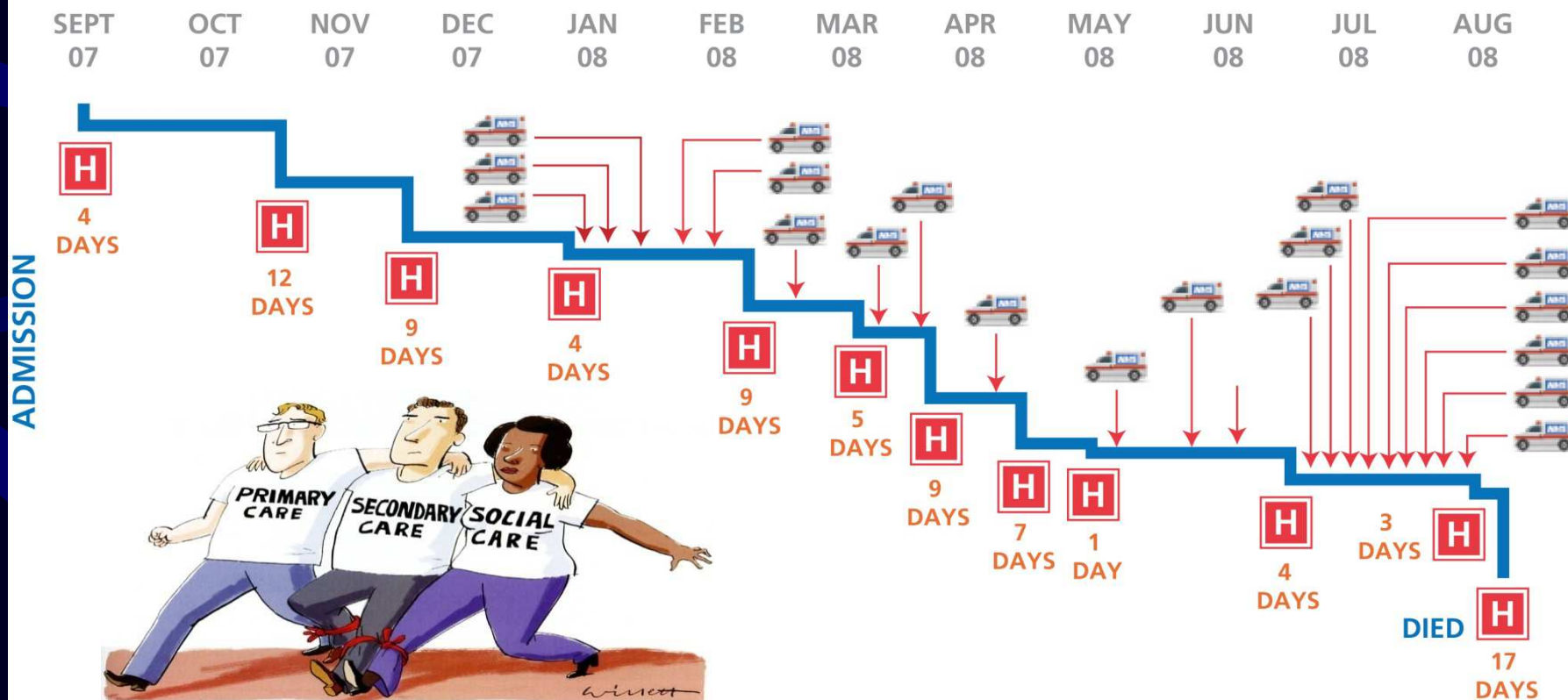
- Heavy burden of symptoms: multifactorial
- Multiple chronic medical conditions
- Progressive losses: independence, autonomy
- Substantial care needs: often overwhelming for family caregivers
- Lengthy period of decline: uneven course
- Difficulty with prognostication
- Poor care coordination

HF - good clinical navigation essential

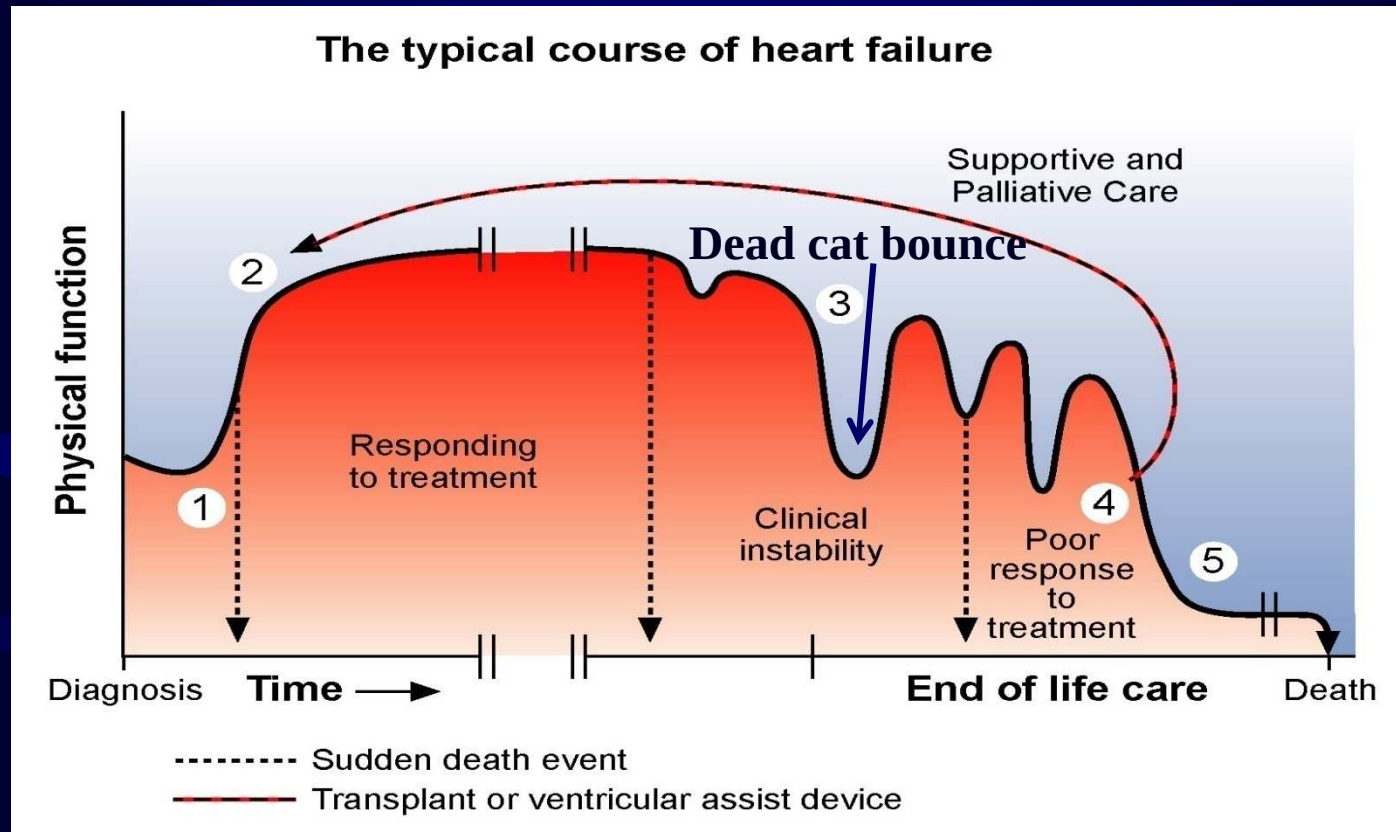
Case History: Nora P.

There are potential savings of £20,000+ if these admissions and A&E attendances were avoided

Centre of excellence



The heart failure disease trajectory



Phase 1 – initial symptoms

Phase 2 – plateau after diagnosis / early management

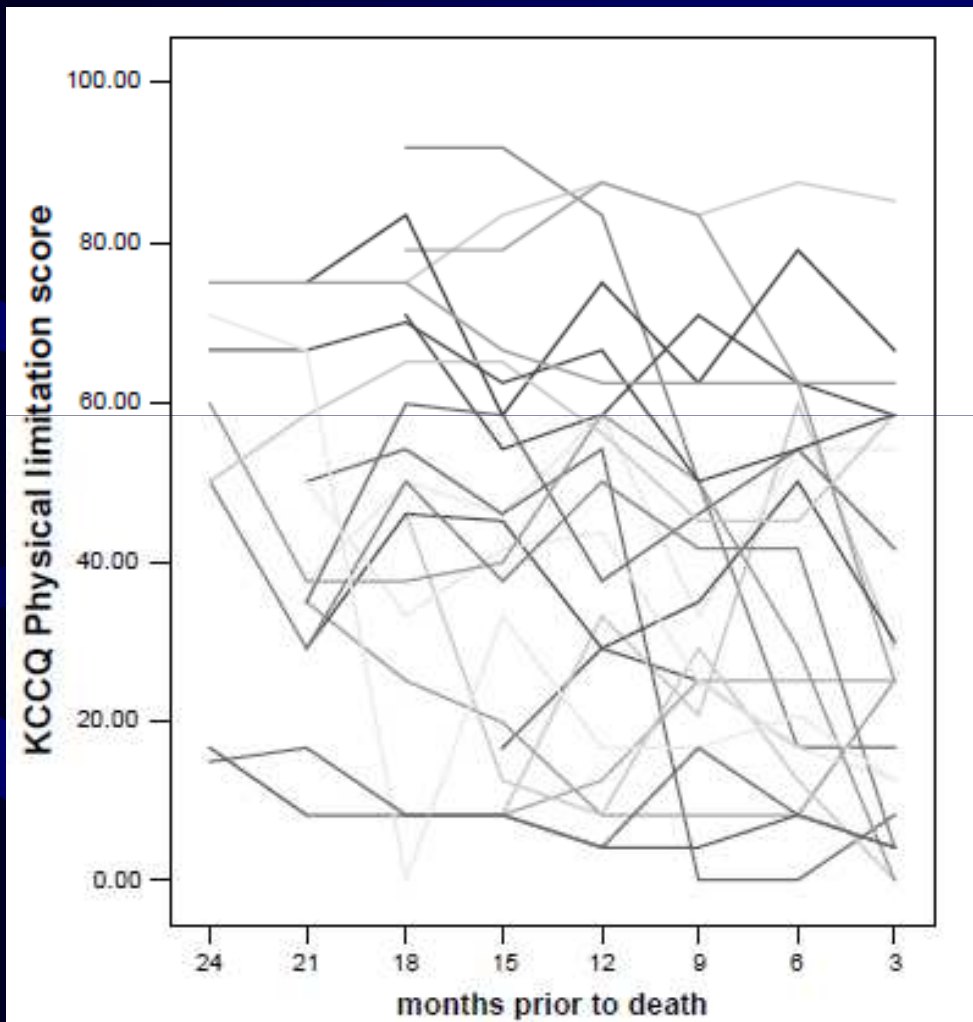
Phase 3 – declining functional status, exacerbations respond to rescue

Phase 4 – stage D HF

Phase 5 – end of life

Modified from Goodlin SJ JACC, 2009, 54:386-96

Every HF patient's trajectory is unique

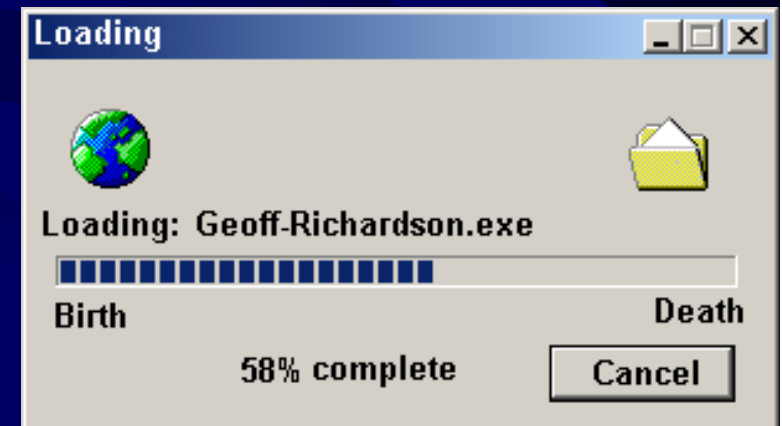


Trajectories of physical decline (KCCQ) in heart failure patients over 24 months prior to death (n = 27)

Gott M et al. *Palliat Med*, 2007, 21: 95-9

Care transition pointers

- Deteriorating despite optimal therapy for HF and comorbidities
- Increasing functional dependence
- Increasing fatigue
- Low ejection fraction
- Recurring hospitalisations
- Emotional distress
- Carer fatigue
- Patient request



O'Leary N et al. *Eur J Heart Fail* 2009, 11: 406-11

HF care – a protocol driven paradigm

Challenges to initiating PC

- The culture of HF care favours a medical model and is treatment focussed.
- Evidence based intervention is often the default position.
- Patients' preferences may be unexplored or they may be disempowered by technicalities or lack capacity.
- A structure of sub-speciality silo working.
- There is a reluctance to discuss prognosis in the face of uncertainty.

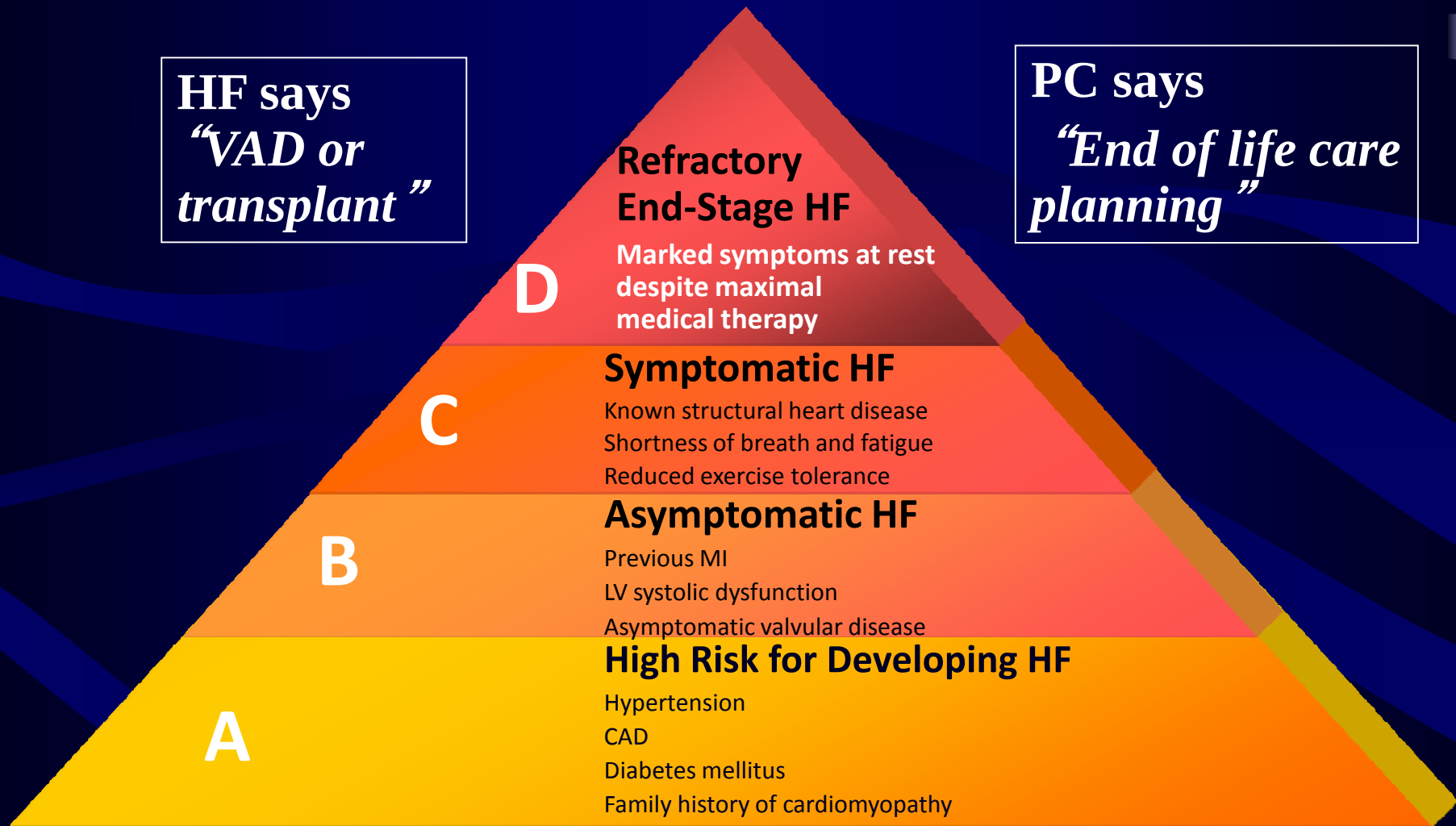


Spencer Tunick

What happens in Stage D?

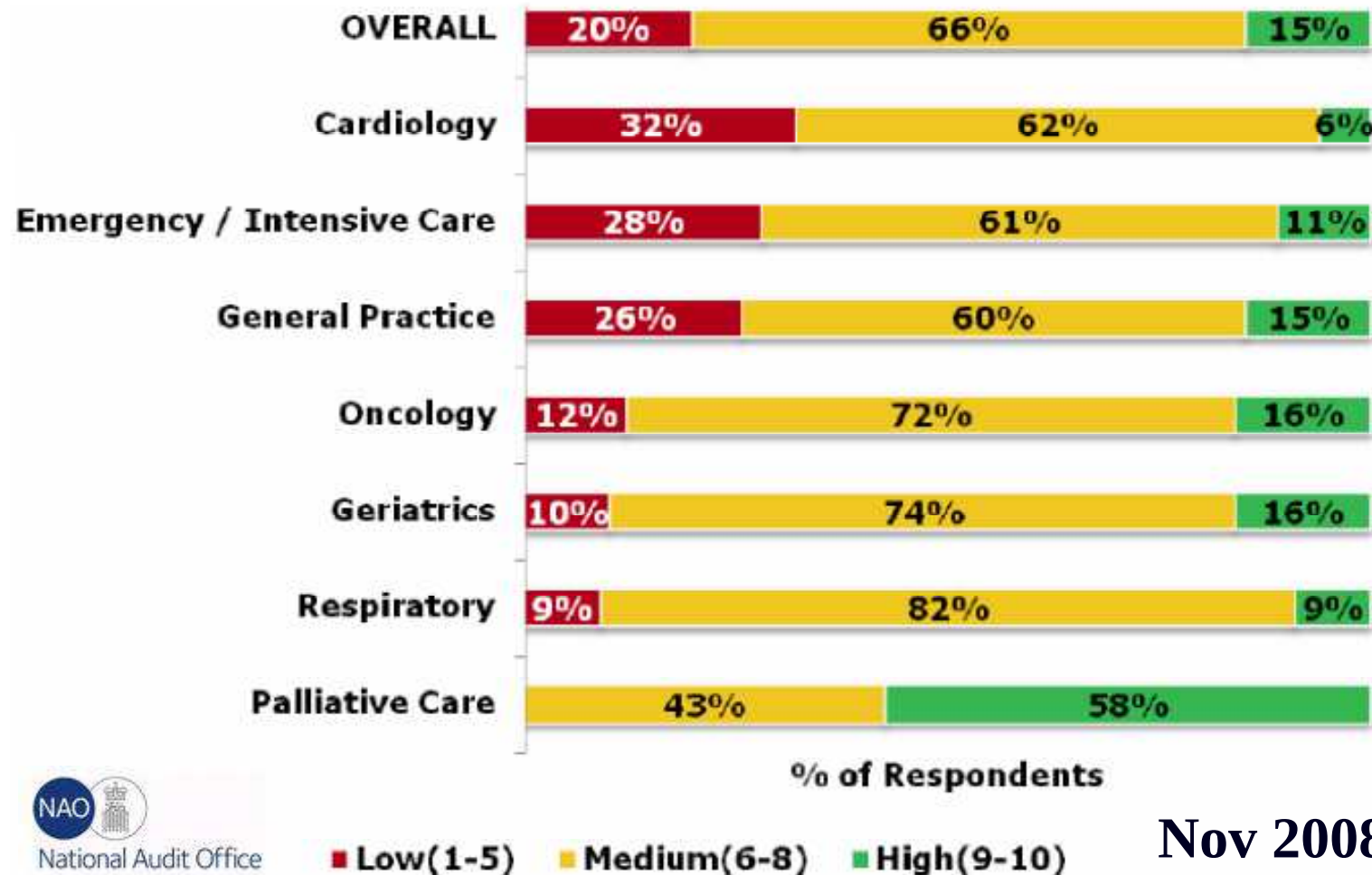
HF says
*“VAD or
transplant”*

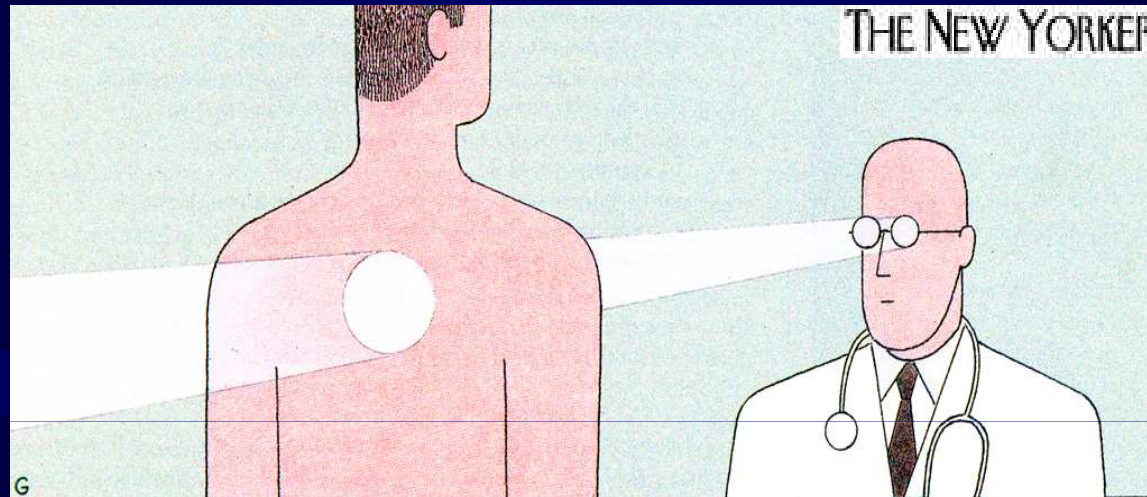
PC says
*“End of life care
planning”*



Hunt SA et al. *JACC* 2001;38:2101–13.

Doctors' confidence in delivering end of life care





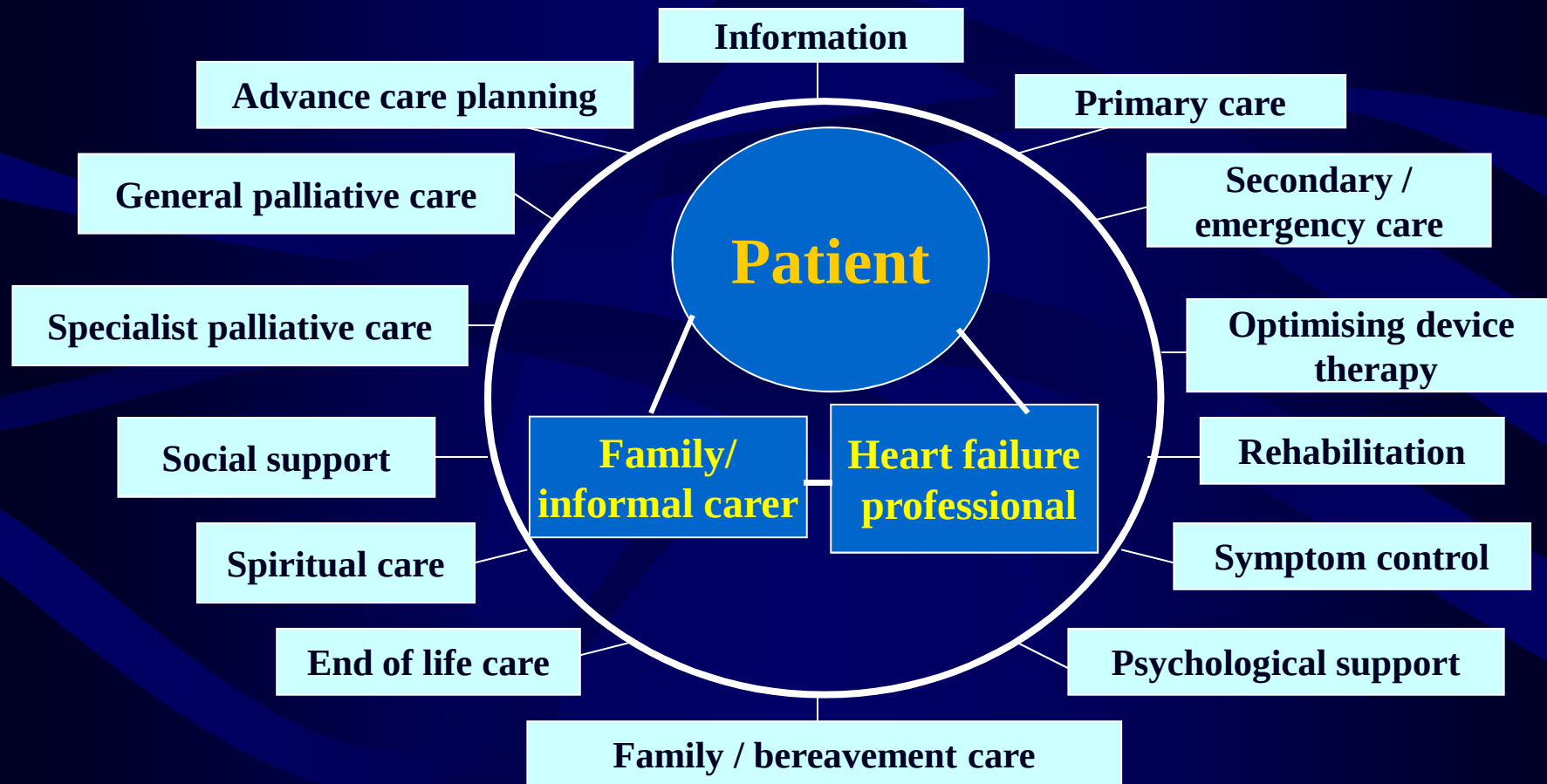
Cardiology Consensus

- Optimise heart failure therapy
- Foster better links with GIM, geriatrics, palliative care, primary care
- Develop a MDT approach

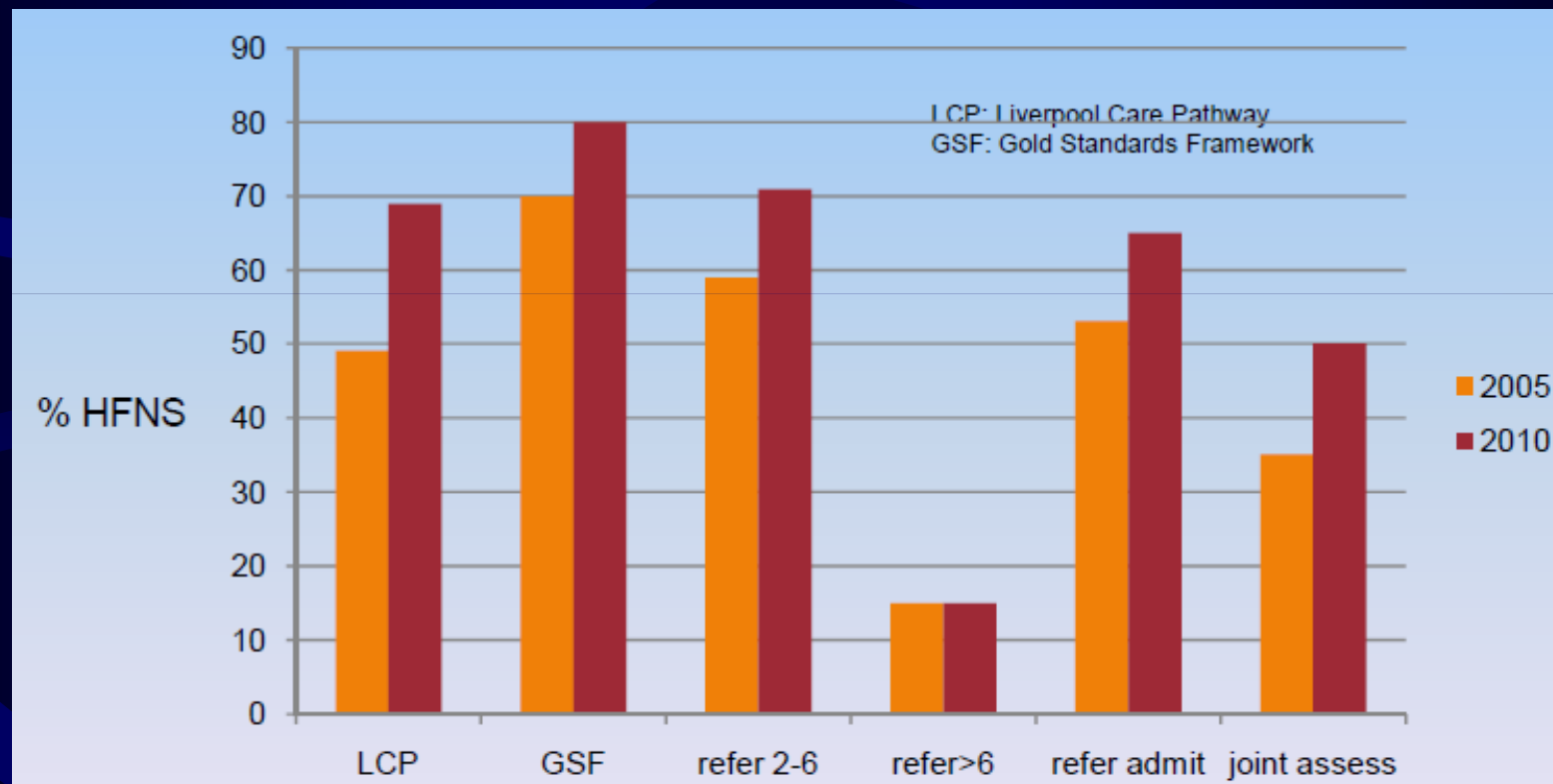
Feb 2007

A multidisciplinary approach to individualize HF care

ESC HFA workshop, Copenhagen, Nov 2007



The engagement of heart failure specialist nurses with palliative care services: A comparison of surveys across the UK in 2005 & 2010.



European Society of Cardiology

Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology

Tiny Jaarsma*, James M. Beattie, Mary Ryder, Frans H. Rutten, Theresa McDonagh, Paul Mohacsi, Scott A. Murray, Thomas Grodzicki, Ingrid Bergh, Marco Metra, Inger Ekman, Christiane Angermann, Marcia Leventhal, Antonis Pitsis, Stefan D. Anker, Antonello Gavazzi, Piotr Ponikowski, Kenneth Dickstein, Etienne Delacretaz, Lynda Blue, Florian Strasser, and John McMurray on behalf of the Advanced Heart Failure Study Group of the HFA of the ESC



***Eur J Heart Fail* , 2009, 11: 433-43**

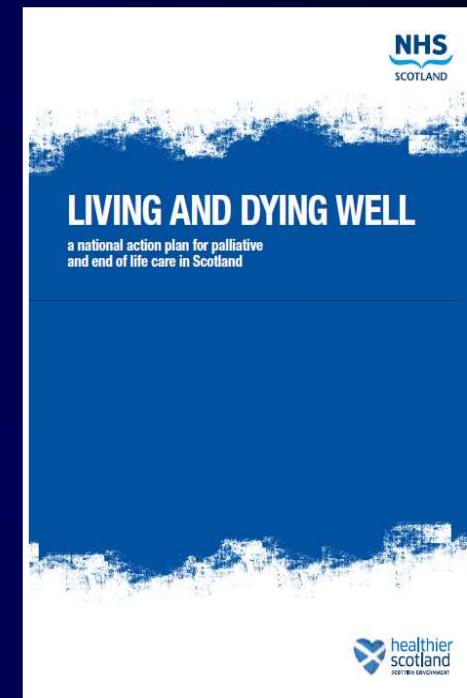
Scottish initiatives



Feb 2007



March 2008



Oct 2008

ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012



Key components of HF palliative care service

- Frequent assessment of patient's physical, psychological, and spiritual needs
- Focus on complete symptom relief from both HF and other co-morbidities
- Advanced care planning, taking account of preferences for place of death and resuscitation (which may include deactivating ICD)

HF = heart failure; ICD = implantable cardioverter-defibrillator.

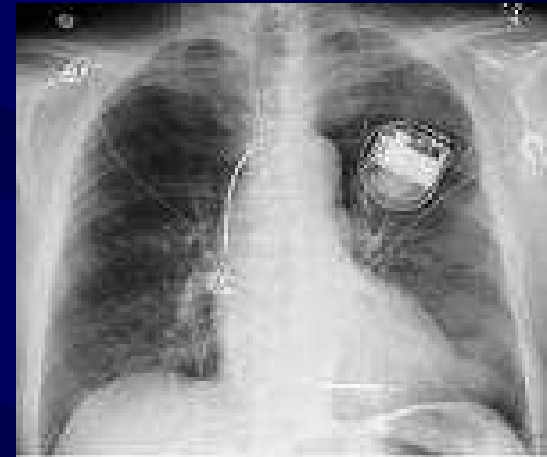
London ICD patients' perspective: should EOL issues be discussed?

- Yes 92%
- No 8%

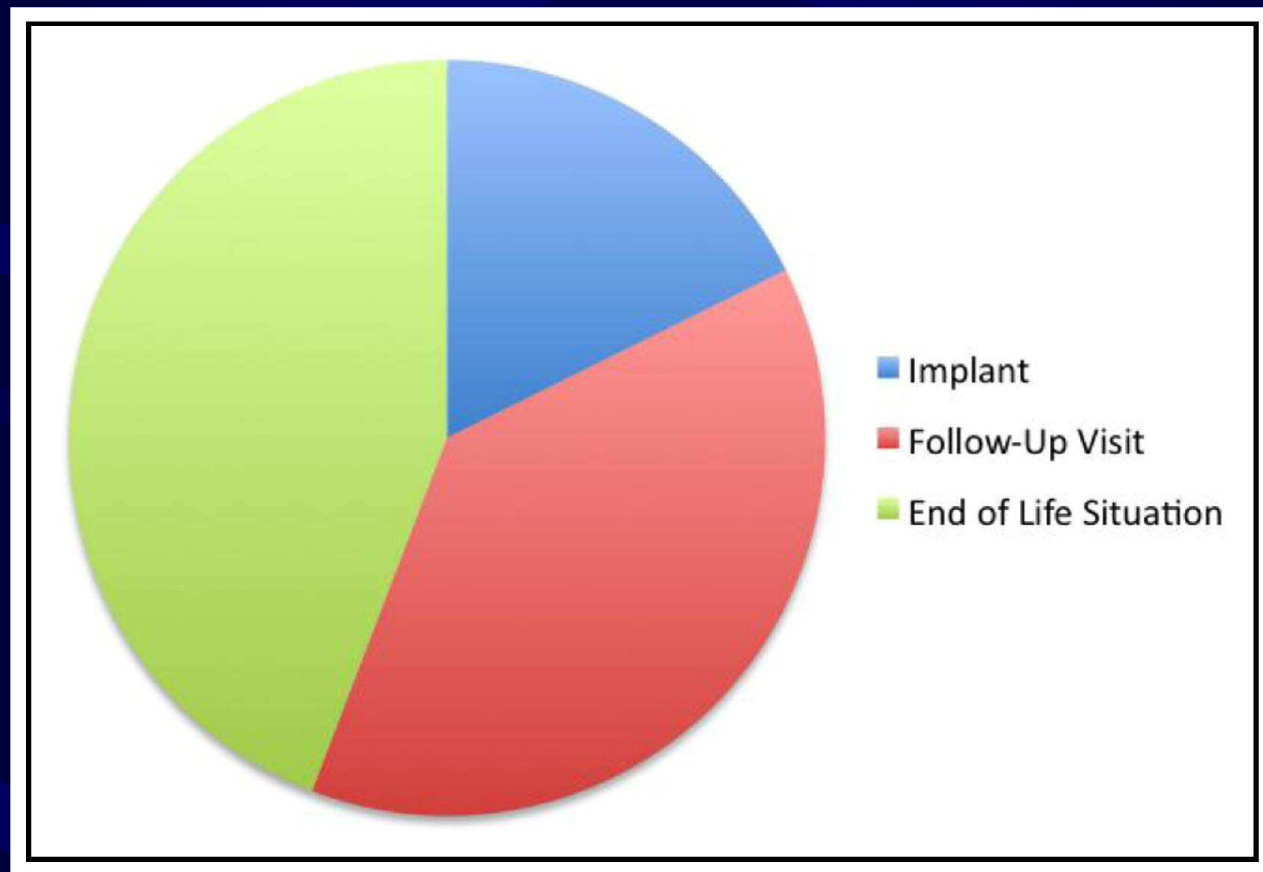
n = 38

When?

- Before implantation 43%
- Less than 1y after implantation 29%
- At least a year after implantation 21%
- Only when really ill 7%
- Only in last few days of life 7%



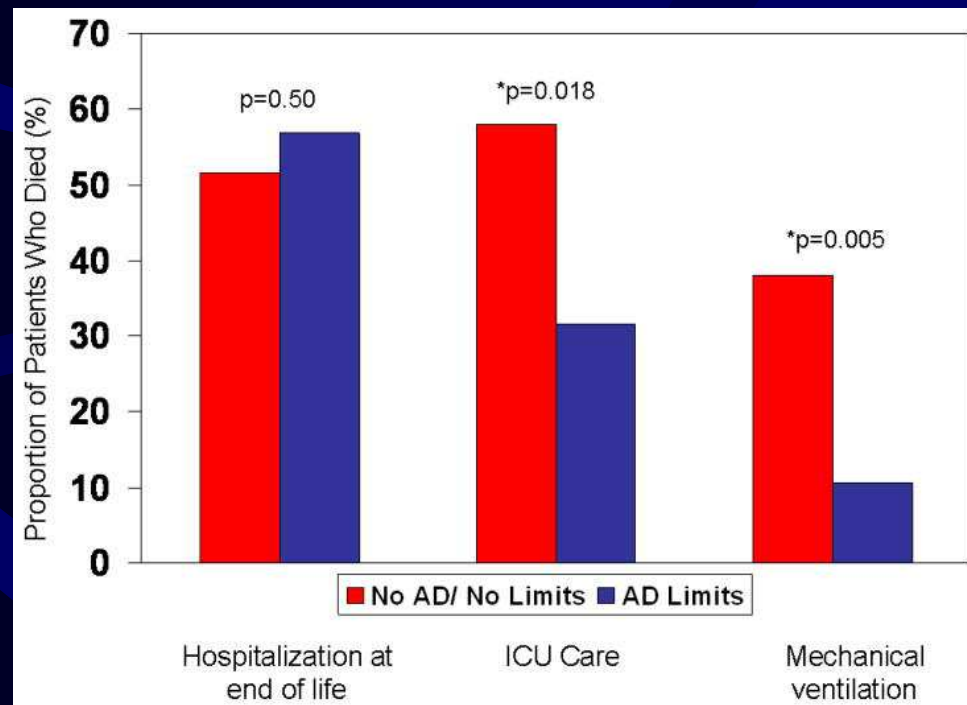
ICD recipients: When should an advance directive for deactivation be discussed?



n= 278

Advance directives in community patients with heart failure

Olmsted County, MN



n = 608, NYHA 3/4
27% mortality at 1.8 y

<u>Advance directive</u>	41%
Proxy	90%
CPR	41%
Mech ventilation	39%
Haemodialysis	10%

Dunlay SM et al, *Circ Cardiovasc Qual Outcomes* 2012, 5:283-9



European Consensus Statement

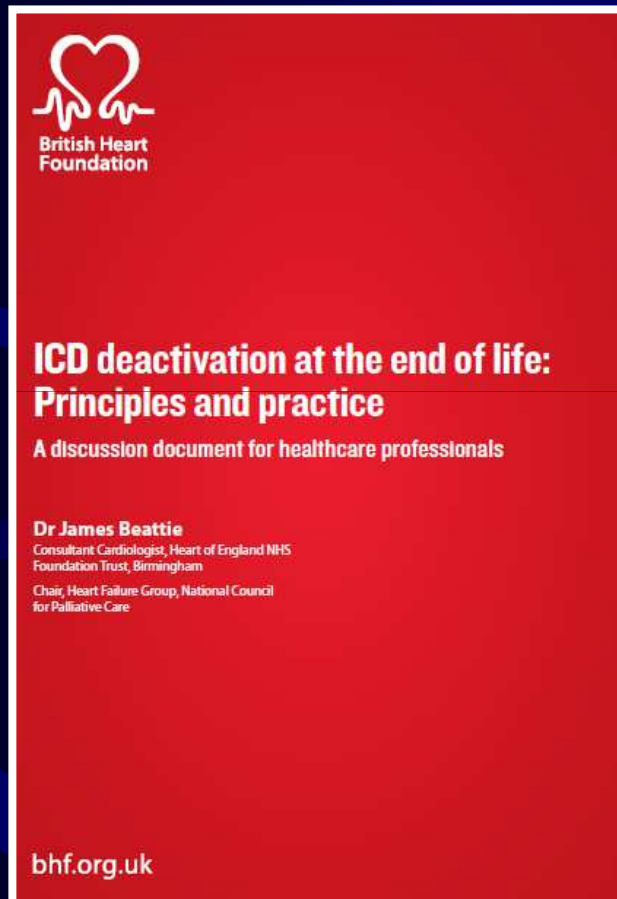


EHRA Expert Consensus Statement on the management of cardiovascular implantable electronic devices in patients nearing end of life or requesting withdrawal of therapy

Luigi Padeletti^{1*}, David O. Arnar², Lorenzo Boncinelli³, Johannes Brachman⁴, John A. Camm⁵, Jean Claude Daubert⁶, Sarah Kassam⁶, Luc Deliens⁷, Michael Glikson⁸, David Hayes⁹, Carsten Israel¹⁰, Rachel Lampert¹¹, Trudie Lobban¹², Pekka Raatikainen¹³, Gil Siegal¹⁴, and Panos Vardas¹⁵

Europace 2010, 12:1480-9

Device guidance documents

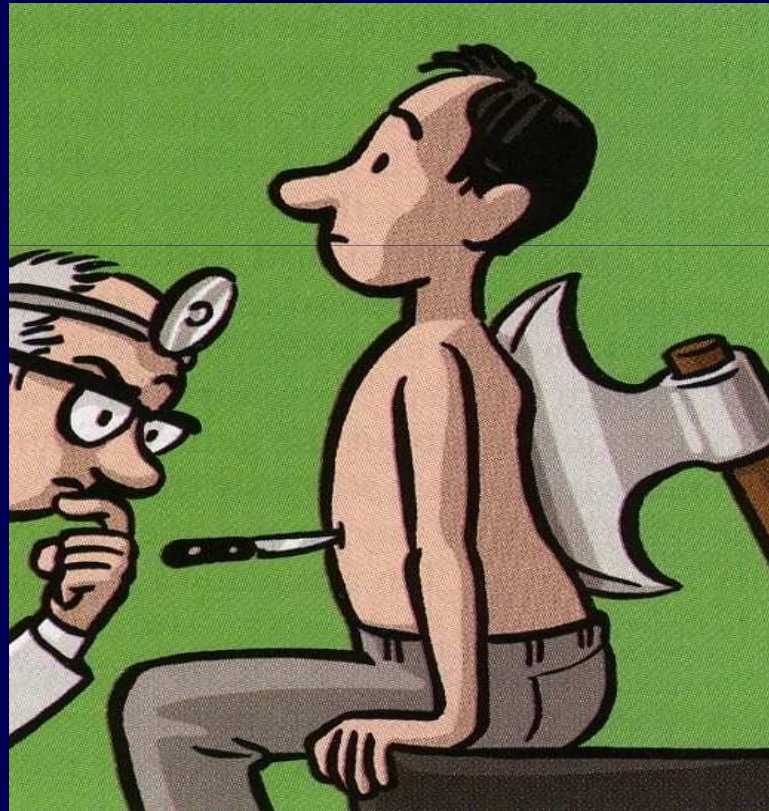


September 2013



March 2015

Tweaking therapy: Do we miss the big picture?



‘Ironic technology?’

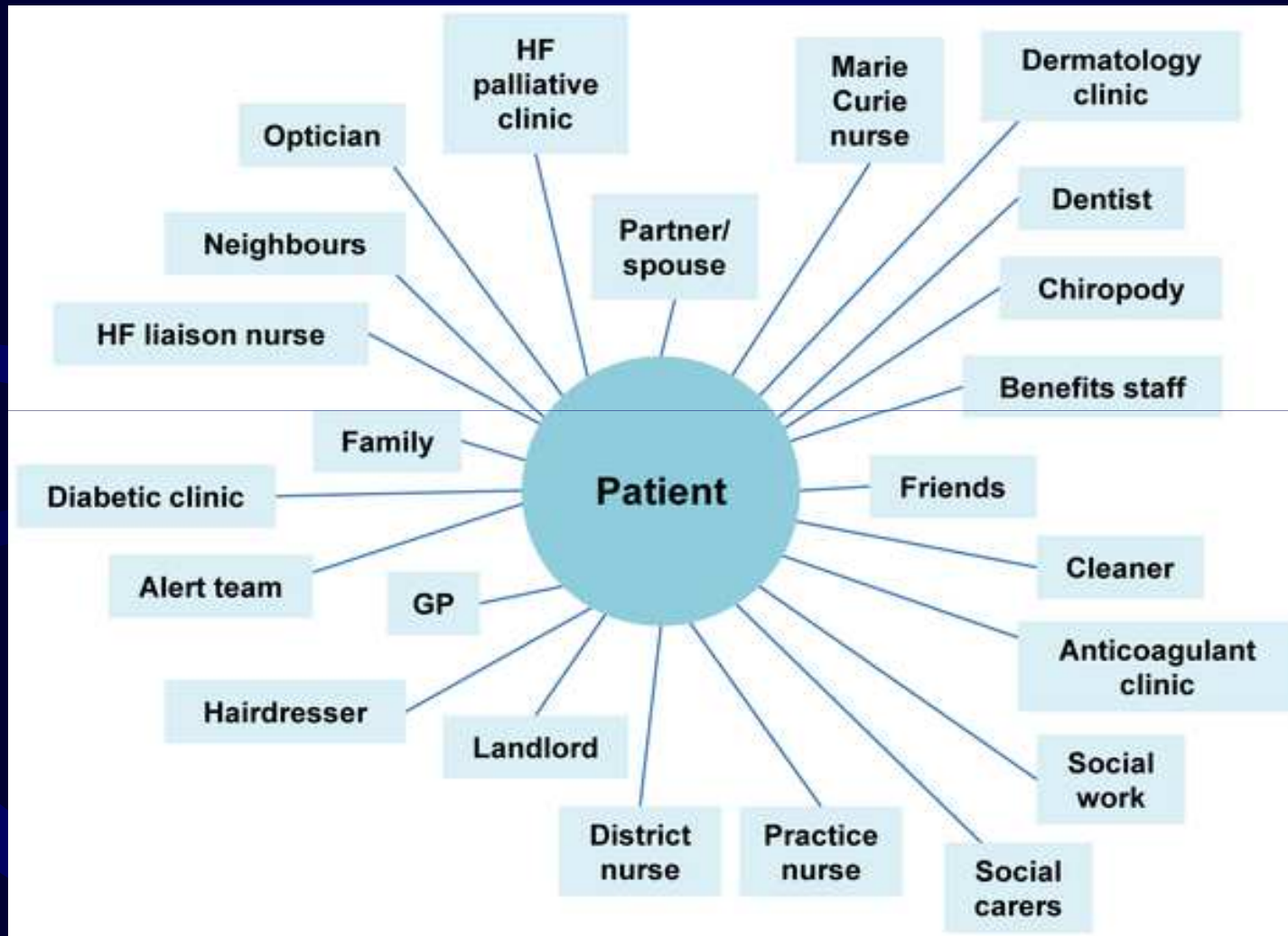
“I have an ICD and a pacemaker. It’s prolonged my life a little bit. But the longer it prolongs my life, the more things happen to me that it can’t correct. So the question is, do you want to have those effects, or do you want to end it all?”



—86 year old man.

Kaufman SR. Soc Sci Med 2011, 72:6-14.

Complexity of required care and support contributes to the heart failure disease burden



Browne S, et al. (2014). PLoS ONE 9(3): e93288. doi:10.1371/journal.pone.0093288

‘Caring Together’

A pioneering model of palliative care for those with advanced heart failure which:

- **Meets the needs of patients and carers**
- **Complements the optimal management of heart failure**
- **Promotes equity of access to palliative care for heart failure patients**
- **Enables increased choice of place of care for patients**
- **Improves coordination of care among stakeholders**
- **Ensures solutions are sustainable**



AHA Scientific Statement



Decision Making in Advanced Heart Failure

A Scientific Statement From the American Heart Association

Endorsed by Heart Failure Society of America, American Association of Heart Failure Nurses, and Society for Medical Decision Making

Larry A. Allen, MD, MHS, Co-Chair; Lynne W. Stevenson, MD, Co-Chair;
Kathleen L. Grady, PhD, APN, FAHA, Co-Chair; Nathan E. Goldstein, MD;
Daniel D. Matlock, MD, MPH; Robert M. Arnold, MD; Nancy R. Cook, ScD;
G. Michael Felker, MD, MHS; Gary S. Francis, MD, FAHA; Paul J. Hauptman, MD;
Edward P. Havranek, MD; Harlan M. Krumholz, MD, SM, FAHA; Donna Mancini, MD;
Barbara Riegel, DNSc, RN, FAHA; John A. Spertus, MD, MPH, FAHA; on behalf of the American
Heart Association Council on Quality of Care and Outcomes Research, Council on Cardiovascular
Nursing, Council on Clinical Cardiology, Council on Cardiovascular Radiology and Intervention, and
Council on Cardiovascular Surgery and Anesthesia

Circulation. 2012, 125: 1928-52

Who are the stakeholders in decision making?

- Patient
 - Autonomy, quality of life, individual needs
- Family
 - Proxy decision makers, quality of life
- HF physician
 - Risk management concerns
- Medical / nursing professions
 - Standards, protocols
- Hospital
 - Policies, accreditation, affiliations
- State
 - Resource allocation, legal regulation

Culture



Heart failure: Fifty shades of dying



Key Messages

- Uncertainty is intrinsic to progressive HF
- Health professionals need to ensure that treatment is personalised, remains appropriate, and held within an ethical framework.
- Goals of care and therapy need to be reviewed regularly and openly with patients and families to ensure best interests are maintained.
- This demands multidisciplinary consensus development to facilitate the prospective withdrawal of any redundant / futile therapies as the focus of care changes to symptom relief towards the end of life.

The Goldilocks principle



The challenge: Getting the balance just right each time