End Stage Heart Failure
&
Deactivation of Implantable Cardioverter Defibrillators

Carolyn Brown
Heart Failure Nurse Specialist

What is Heart Failure?

A complex clinical syndrome

Results from any structural or functional cardiac or non-cardiac disorder that impairs the ability of the heart to respond to physiological demands for increased cardiac output

It is a progressive condition with symptomatic deterioration over an unpredictable period of time.

Heart Failure Facts

- 1-2% of UK population & 10-20% of the elderly
- Most common cause of hospital admission in patients > 65
- Admission often lengthy and costly to the NHS
- In the UK 1/3 readmitted within 12 months of discharge
- Patients report a greater reduction in QOL than any other long-term illness
- Worse prognosis than a patient with almost any form of cancer
  - 45% of patients admitted to hospital for the 1st time expected to die within 1yr
  - 75% dead within 5 years (MacIntyre et al 2000)
- Research literature suggests that 10% of patients in a heart failure nurse caseload require palliative care in a year
- 40-50% of patients die suddenly

Causes

- Ischaemic Heart Disease
- Hypertension
- Cardiomyopathies: dilated/hypertrophic/idiopathic alcohol, viral, post-partum
- Valvular Heart Disease
- Arrhythmias
- Pericardial disease - constrictive pericarditis
- Infection – rheumatic fever/myocarditis

Cardiovascular Co-morbidity

- Ischaemic heart disease 50% deaths > 65's
- Cerebrovascular disease
- Peripheral vascular disease
- Renovascular disease
- Hypertension
- Diabetes mellitus
- Hypercholesterolaemia

Non Cardiovascular Co-morbidity

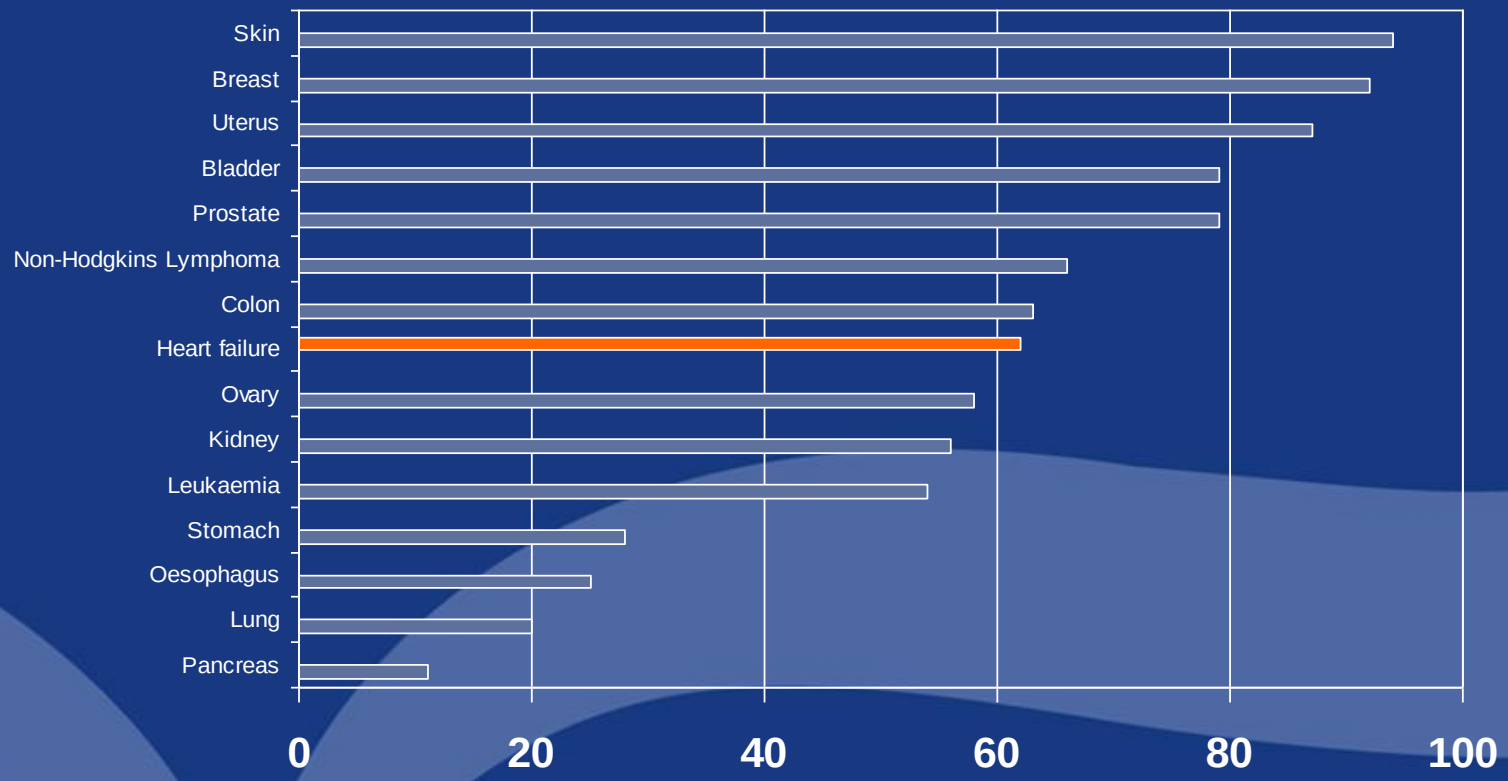
- COPD
- Locomotor problems
- Anaemia
- Chronic renal disease
- Cognitive impairment
- Immunosuppression
- Depression

NHS Dumfries & Galloway

“I've got heart failure; and this is what it feels like every morning".

BHF 2012

Poor Prognosis:1 year survival rate % (BHF 2002)



Common Symptoms

- Anxiety
- Depression
- Dyspnoea/ PND
- Gout
- Light-headedness/hypotension
- Muscle wasting and fatigue
- Nausea, altered taste and anorexia
- Oedema
- Pain
- Pruritis
- Confusion
- Fluid overload
- Insomnia

How do we know this is the beginning of the end?

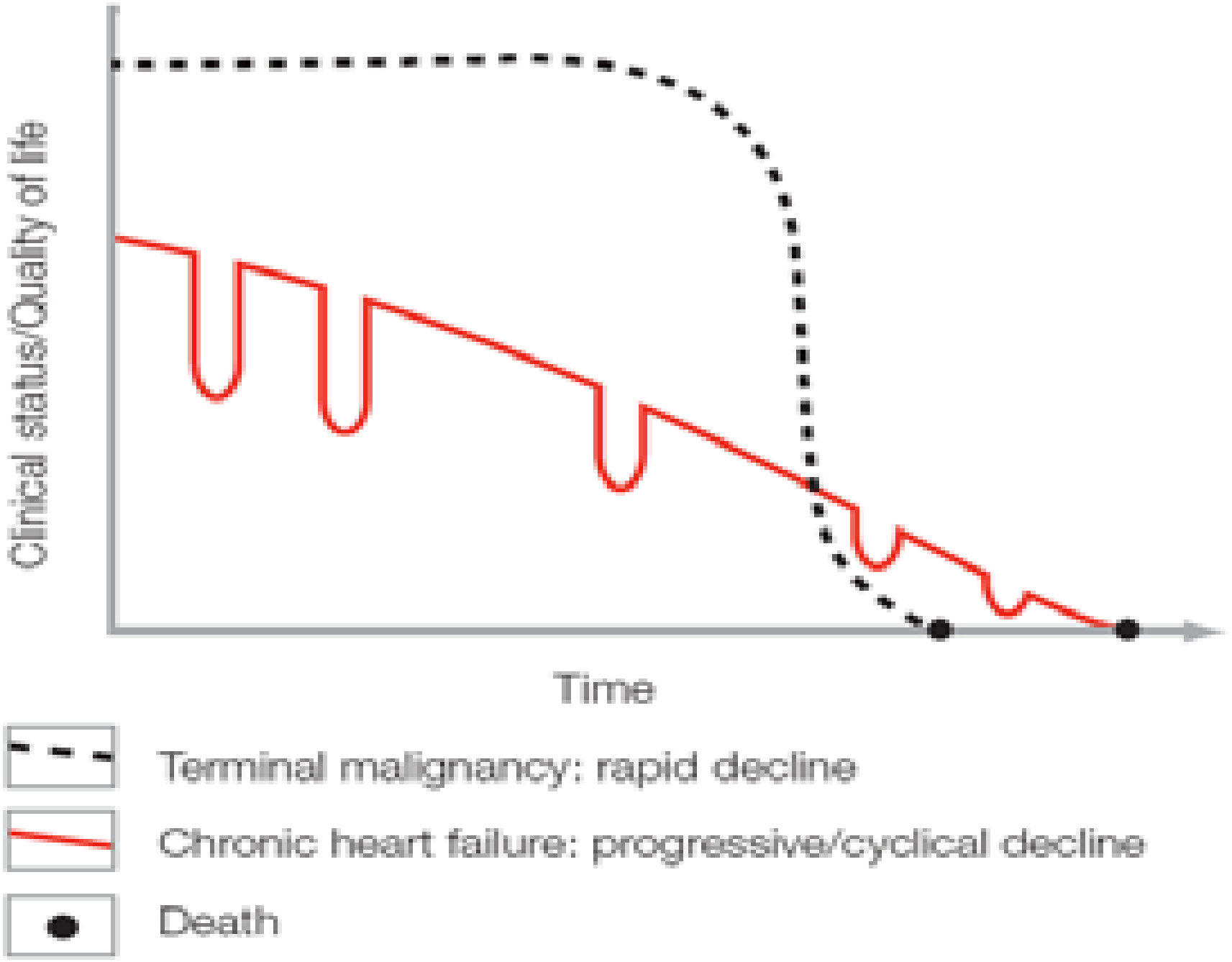
For many heart failure patients, the day that they die they will probably appear no more ill than any other day during their illness

This is in sharp contrast to patients who die from cancer as they are most likely to be the most ill they have ever been on the day of death.

(Lynn et al 1997)

Triggers to consider end of life care

- Continual symptoms despite optimisation of therapy
- Deteriorating renal function and resistant hyponeutraemia – no reversible cause
- Anaemia
- Frequent periods of decompensation
- Frequent hospital admissions
- Pain – effects 25 - 35%
- Dyspnoea – use of low dose opioids, relaxation techniques, oxygen if desaturate
- Cardiac Cachexia
- Hypotension & tachycardia at rest
- Increasingly withdrawn, bed bound, weak and exhausted
- Oedema – skin breakdown
- Unable to take medication/oral fluids
- Termination of treatment at patient's request
- Dependent on more than three activities of daily living
- Multiple shocks from ICD device


Clinical status/Quality of life
Time
Terminal malignancy: rapid decline
Chronic heart failure: progressive/cyclical decline
Death

Palliative Care includes provision of:

- Information for patients and carers – referred to relevant services
- Accurate holistic assessment of patients needs
- Co-ordination of care teams in/out of hours and across boundaries of care. Gold Standards Framework, Liverpool Care Pathway.
- Symptom control
- Psychological, social, spiritual and practical support
- Open and sensitive communication which should include discussion and documentation of resuscitation status
- Deactivation of ICD
- Preferred place of care

Barriers to palliative support

Organisational

- Time Constraints
- Uncoordinated care
- Lack of dedicated cardiology time
- Lack of carer support including day time, night and respite care
- Patient unable to have IV diuretics out-with hospital setting

Prognostic uncertainty

- Failure to identify patients requiring palliative care support
- Can be difficult to know when to take this approach – patient may be ill for many months or years with acute, often severe exacerbation

Perceptions of patients, carers and professionals about the role of palliative care

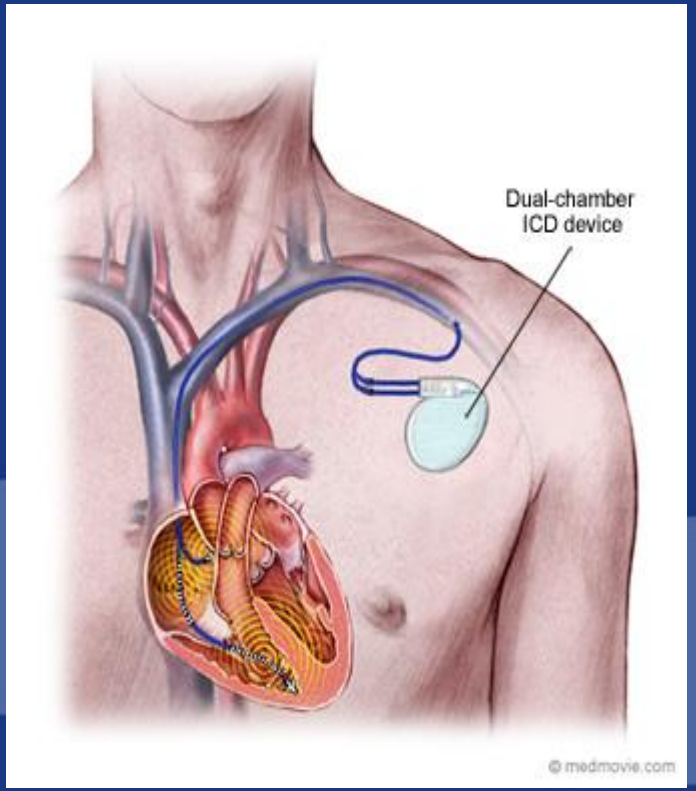
Palliative care

- Agreement by the multidisciplinary team.
- Patient and family discussion.
- Symptom control
- Care planning - discontinuation of inappropriate interventions
  - anticipatory care/ prescribing
  - decisions about resuscitation
  - Preferred place of care
  - Involvement of Palliative Care Team & referral to Macmillan Nurses

Implantable Cardioverter Defibrillators (ICD)

NHS Dumfries & Galloway

ICD is a form of intervention used for patients who have a life threatening ventricular arrhythmia or those who have been identified as being at risk of developing a life threatening ventricular arrhythmia.



Purpose of ICD

- Monitor the heart rhythm and respond to arrhythmia by – automatic administration of defibrillator shocks to terminate VF or fast VT
- Anti-bradycardia pacing often used after defibrillation shock as the heart returns to normal sinus rhythm
- Cardioversion of VT
- Anti-tachycardia pacing to terminate slower rate of VT
- Discussion re the purpose of ICD and possible requirement of deactivation of ICD should ideally be discussed prior to the procedure of insertion of device but this is very often not the case. Written information should be given to patient.
- Studies of physicians demonstrate that while they believe they should engage in these types of conversations with patients, they rarely do. Goldstein et al. J Am Coll Cardiol 2009

Care planning

- Clinicians should encourage patients to discuss their condition, patients quality of life, primary goals of management
- Care plan reviewed and documented in medical notes /patient held record
- Review of relevance of functioning ICD

Discussion to deactivate ICD

- Once DNACPR is in place
- Withdrawal of antiarrhythmic medications
- Terminal diagnosis
- Fits the ‘surprise question’ would you be surprised if this patient was alive in the next year
- Placed on Gold Standards Framework/ Liverpool care pathway.
- Imminent death
- Consent form and record of decision to withdraw ICD in patients health records.

Information when discussing deactivation of ICD

- Discussion with patient and family should emphasise
- The device will no longer be able to provide life saving therapy
- Turning off the device will not cause immediate death
- Turning of the device will not be painful nor will its failure cause pain
- The ICD will continue to provide bradycardia support if required. This is not painful or prolong life

- Majority of patients imminently dying from heart failure do not die from tachyarrhythmia's. A majority develop a malignant tachyarrhythmia such as VT/VF on the background of end stage heart failure due to metabolic or biochemical derangement and it is unlikely that activation of ICD will prolong life.
- Patients dying phase may be interrupted by multiple shocks from ICD which will be unpleasant of patients, family and staff. Harm from activation of ICD outweighs the benefits.

Deactivation

Ideally should be done when patient is well enough to attend the cardiology department when physiologists can re programme the device to deactivate tachycardia therapies. Painless quick procedure

Out of hours, patients home, hospice

- Planned deactivation at programmer at the patient's house
- Large donut magnet can be placed over generator externally and secured
- If magnet is removed the ICD is active again
- People with pace makers are not effected as long as they do not lean over magnet
- ICD magnet should not be removed until ICD has been deactivated after death. Relatives need to be aware that ICD needs to be removed prior to cremation

Deactivation Cont'd

- Each health board is encouraged to have in place their own ICD deactivation policy
- Temporary deactivation of ICD can be initiated preoperatively, intraoperatively, and for some patients under going radiotherapy

References

1. Scottish Government. Living and Dying Well, Scotland (2008)
2. British Heart Foundation. Implantable Cardioverter Defibrillators in Patients Who are reaching the End-Of-Life, London: (2007)
3. Human Rights Act (1998) - Adults with Incapacity Act (Scotland) (2000)
4. Lewis WR; Luebke DL; Johnson NJ; Harrington MD et al. Withdrawing Implantable Defibrillator Shock Therapy in Terminally ill Patients, American Journal of Medicine; 119 (10); 892-6; (2006)
5. "Implantable Cardioverter Defibrillators (ICD's) in Dying patients" www.arrythmiaalliance.org.uk
6. British Heart Foundation. Implantable Cardioverter Defibrillators in Patients who are reaching the End-Of-Life, London: (2007)
7. Berger JT. The Ethics of Deactivating Implanted Cardioverter Defibrillators, Annals of Internal Medicine;142 (8): 631-4; (2005)
8. British Medical Association. Quality in End-of-Life Care. London: (2010)