Palliative Care for Heart Failure. Service Development in West Hertfordshire

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History

- 2003- Need for symptom control for patients with advanced heart failure recognised by consultant cardiologist and approach made to palliative care doctor
- 2004- first heart failure nurse appointed
- 2004- referral criteria developed and HF patients more regularly seen by palliative care consultant
- 2007- grant awarded by St James Place Foundation/ Help the Hospices to support development of the Hearts and Minds project
To develop a palliative care service for patients with heart failure in the community

- Symptom control
- Psychological support
- Carer support
- Support in end of life decision making
- Reduce hospital admissions
- Foster open communication
- Promote recognition of palliative care needs
History 2007 to 2014

- Recruitment of a specialist community heart failure nursing team.
- Palliative heart failure MDT started with representation from the Hospice of St Francis and the community heart failure team
- Development of collaborative relationship between palliative care consultant and consultant cardiologists
- Further development of MDT to include consultant cardiologist and GP as well as community palliative care teams
Currently

- Weekly meetings in the Acute Trust with the consultant cardiologists and their teams to actively seek out heart failure referrals and make decisions about direction of care
- Monthly palliative care heart failure meetings held in the community
- Consultant in Palliative Medicine with an interest in heart failure working in the Acute Trust, in the Hospice and in the Community
- Telephone advice available to heart failure nurses at any time from above consultant.
Improvements

- Heart failure nurses are better able to provide generalist palliative care
- Palliative care specialists have a better understanding of the complexities of the management of heart failure
- Consultant cardiologists are more likely to consider a more palliative approach
Improvements

- More heart failure patients being referred to palliative care
- More heart failure patients with Advance Care Plans
- More patients with DNACPR orders
- More heart failure patients achieving their preferred place of care
- Some heart failure patients understanding that they might have a choice about the care that they receive
- Fewer inappropriate transfers to ITU for haemofiltration
Improvements

- Increased heart failure patient referrals to Hospice services
- Increased admissions to Hospice inpatient units for parenteral diuretics/symptom control
Difficulties

- Expectation that palliative care HCPs will take over from heart failure services
- Reluctance to discontinue medications
- Surgical mindset of some cardiologists
- Prognostic paralysis
- Repeated close shaves giving impression of immortality
- Reluctance of patients to engage with hospices
Difficulties

- Lack of resources
  - Support of consultant cardiologist and palliative care consultant not commissioned
  - Pressure of workload
  - Competing demands from other non-cancer patient groups
  - Need to keep abreast in a specialty that is continuously progressing and has a good evidence base

- Chaos within the cardiology department in the Acute Trust
- Reluctance of community teams including GPs to take on responsibility for new treatments at home
Difficulties

- Complexities of managing end stage heart failure drugs- polypharmacy
devices- increasingly common
- Fear of making the patient worse by stopping drugs
- Fear of upsetting the cardiologists by stopping the drugs
The Case of MR FE

- A 72 yr old man with IHD and severe heart failure. CRT-D in place
- Presented for discussion at the community palliative care MDT
- Severely symptomatic, worsening renal function.
- Diagnosed as dying
The Case of MR FE

• Decision made to turn off ICD
• Admitted to Hospice for end of life care
• Drugs reviewed
• Focus on symptom control, holistic care and support for his family

AND THEN........
The Case of MR FE

• As we stopped his drugs, his BP improved.
• His kidneys started to function better
• He started to sit out of bed and then mobilise
• After three weeks in the Hospice with his ICD switched back on, he went home

• He had another 3 years of good quality life, seen regularly by the community heart failure nurses sharing care with palliative care nurses
The Case of MR FE

- Finally admitted to the Hospice.
- Much more unwell. Peripheral oedema ++. Renal impairment
- Reversible causes sought and treated
- ICD turned off
- Continued deterioration
- Died peacefully, 2 weeks later
If We Don’t Do It

- Inappropriate hospital admissions
- Inappropriate investigations in dying patients
- Inappropriate interventions in dying patients
- Families bereft and feeling guilty about how loved ones have died
- Patients dying in hospital where they may not receive the care that they deserve
Future Challenges

- Ensuring equitable access to palliative care for all of those with life limiting illnesses including heart failure
- Getting our services commissioned by CCGs who are strapped for cash
- Continuing to keep the specialists on board despite turnover in the workforce
- Continue to fight against the revolving door of heart failure admissions
- Development of evidence base
Why Bother?

- We have a moral obligation to offer equitable care whatever the difficulties and whatever the life limiting diagnosis.
- NICE guidance demands that heart failure patients have access to palliative care.
- It is not good enough to say that we do not have the resources. This is just a feeble excuse.
- Educate yourselves and take on the challenge.
- Work together with your local cardiology teams.
- Be determined and persistent and things will change.
The Way Forward

- Have courage!
- Overcome prognostic paralysis
- Work together
- Learn from each other
- We all have a responsibility for this work
- Communication, communication, communication!
- Hospice Enabled Heart Failure Care publication 2017