



Supportive care, Early Diagnosis and  
Advanced disease research group

# Integrated palliative care in heart failure

M Johnson

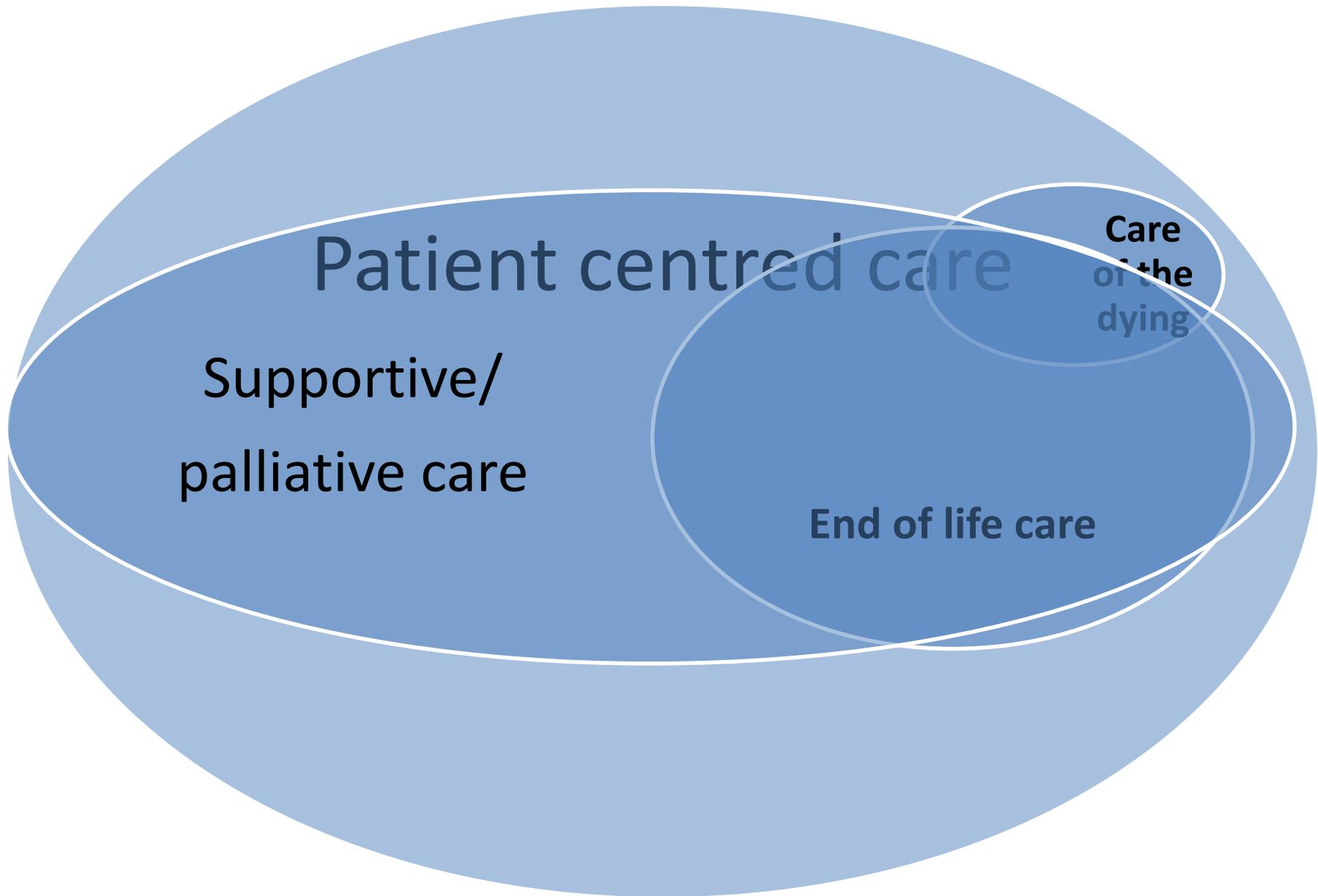
# What is palliative care?

- aims to help patients live as actively as possible until death;
- uses a team approach
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life

WHO 2002

# terminology

- End of life care
- Terminal care
- Care of the dying
- Palliative care
- Supportive care
- Patient-centred care



Patient centred care

Supportive/  
palliative care

End of life care

Care  
of the  
dying

# Because they are symptomatic

symptom	cancer	CHF
Pain	35-96%	41-78%
Fatigue	32-90%	69-82%
Breathlessness	10-70%	60-88%
Insomnia	9-69%	36-48%
Anxiety/depression	3-79%	9-49%

- Anderson H, et al *Palliative Med* 2001;15:279-286
- Nordgren L, Sorensen S. *Eur J Cardiovasc Nurs* 2003;2:213-7
- Pantilat et al. *J Card Failure* 2010;16:S88
- Weiss et al. *Lancet* 2001;357:1311-5
- Ng and von Gunten *J Pain Sympt Man* 1998;16:307-16
- Levenson et al. *JAGS* 2000;48:S101-9
- Solano et al. *J Pain Sympt Man* 2006;31:58-69

# Because currently they get too little, too late

Gadoud A, et al Palliative Care among Heart Failure Patients in Primary Care: A Comparison to Cancer Patients Using English Family Practice Data. PLoS ONE 2014, 9(11): e113188

# Because palliative care makes a difference

- Brannstrom M et al *Eur J Heart Failure* 2014
- Sidebottom A et al *Journal Pall Med* 2015
- Wong FK et al *Heart* 2016
- Improved
  - QoL
  - Symptoms
  - Self-efficacy
  - NYHA
  - Hospital admissions
- No difference in mortality

Because it is agreed that we should...

- **Palliative Care and Cardiovascular Disease and Stroke: A Policy Statement From the AHA/ASA. Braun LT et al 2016**
- ...and policy statements from European Society for Cardiology, NICE, Australian Heart Association

# When to involve specialist palliative care?

- Persistent, complex symptoms
  - Other support needed, including for family
  - Difficult things to talk through
  - Preference in place of care
  - Local service configuration
- 
- Problem based, *not* prognosis based
  - Extended team based, *not* “either/or”

Integrated care

# Why integrated care?

- “The right care, at the right time, in the right place, by the right person.”
- Most care can be provided by non-specialist palliative care clinicians
- However, the specialist palliative care team are useful for;
  - Education and support *re* symptom control and communication skills
  - Direct *additional* involvement for people with persistent and complex issues, or who wish to have the hospice as a place of care/death

# Integrated care is needs based,

- Systematic and regular holistic assessment
- Identify and triage needs of patient and carer
- Training and support for cardiology and primary care staff
  - What about cardiology/COE trainees/HFNSs/senior staff?  
Ismail Y et al British Journal of Cardiology 2015: linked Editorial Johnson MJ
  - Tools to help (Needs Assessment Tool- progressive disease:HF) Waller et al JPSM 2013
- Communication skills (inc across settings)
- Service configuration
- MDT cardiology and palliative care

# Example 1- palliative heart failure service

- Est 2000 Scarborough, district general hospital; urban/rural
- Palliative consultant led
  - Consultant cardiologist
  - Heart failure nurse specialists
  - Palliative care nurse specialists
  - Communication with primary care (written)
- Cross setting (hospice, hospital, community); multiple funders
- Multi-disciplinary team meeting
  - Referrals (access to all palliative care services)
  - Education & training
  - Local protocols (ICD reprogramming; subcutaneous morphine)

Core component 1: cardiology and palliative care

Core component 2: nursing and medical – with opportunities for joint consultation

Core component 3: communication with primary care

Core component 4: key role for heart failure nurse specialist

Core component 5: education and training

Core component 6: audit & evaluation

# Example 2- Caring Together Project

- Est 2011 Glasgow. Major regional tertiary hospital.

- Cardiology consultant led

- Consultant palliative physician
- Heart failure nurse specialists
- Palliative care nurse specialists
- Communication with primary care (written, nu

Core component 1: cardiology and palliative care

Core component 2: nursing and medical – with opportunities for joint consultation

- Cross setting (hospice, hospital, community): multiple funders

Core component 3: communication with primary care

- Multi-disciplinary team meeting mont

- Reconfigured cardiology service with c  
cardiology clinic, and medical ACP

Core component 4: key role for heart failure nurse specialist

- Evaluation

Core component 5: education and training

- Qualitative study
- Cohort: Palliative care needs of people admitted
- Two cohort study (palliative cardiology clinic; u  
service use, documentation of care plan

Core component 6: audit & evaluation

# One patient's story. Dennis

You are having a lot of problems at the moment with your breathing, pain, sleeping, family worries ....

I think it would be helpful if we asked my colleague Dr Johnson, and her team, to help us ... they will provide an extra layer of expertise to help improve your quality of life

I will continue to look after you, and you will carry on with all the best treatments we have for your heart failure, but I want to see if we can get you feeling a bit better....

- Dennis is 36, married with 2 girls aged 8 and 12
- NYHA IV due to IHD
- Can manage a few steps in the house – limited by pain and breathlessness

Dr Johnson works at the hospice, but she also sees patients here in the hospital, or in their own homes. Does mention of the hospice worry you?

# Dennis

- Discussed at the heart failure MDT
- Concurrent referral for transplant assessment
- Initial consult with myself followed by:
  - Refer day hospice (..and his wife needed a break!)
  - Hospital bed at home (poor sleep)
  - Analgesia for back pain (degenerative)
  - Physio/OT
  - Financial adviser (self employed)
  - Child and adolescent counsellor (family worries)
  - Simple cognitive behavioural therapy approach with anti-depressant for mood

# Dennis

- Mobility improved due to improved back pain and breathlessness management
- Sleeping better
- Rediscovered role in family (story writing!)
- Children less distressed, eldest now back at school, and youngest happy to be left in house with him
- Electric wheelchair for independence outdoors
- Psychologically improved (and wife happier too)
- Tolerating up-titration of ACE-I, now on target dose
- Discharged from SPC service
  
- End of life care? It might have been....

# Dennis

- Over the next 15 years, Dennis was reviewed by the palliative care team on several occasions
  - Consultant/HFNS out patient visits
  - Consultant/HFNS home visits
  - In-patient spells at hospice
  - Repeat spells in the day hospice
- Each time he stabilised, we discharged him
- Throughout this time he remained under the care of the cardiology team, supported by his GP and district nurses
- He died last year in the hospice

# A carer's verdict...

- “..when initially introduced to palliative care..and it is explained to you, the first emotion is one of utter relief that someone is offering a safety net in a time of crisis..”
- “..for the first time in a very long time, that feeling of frustration, helplessness and aloneness is dispelled.”

- “..in (my husband’s) case, it boosted his self-confidence and self-esteem, giving him a better quality of life...he was able to manage his disability without the constant need for hospitalisation, thus cutting out stress of some magnitude.”
- “.. It is difficult to separate his relief from mine, because by making his life more bearable, it made my task easier (even though it was still an ongoing 24 hour job), and because my life was made easier, he began to be more relaxed too.”