



Supportive care, Early Diagnosis and
Advanced disease research group

Palliative care of people with end-stage heart failure

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HospiceUK conference November 2016

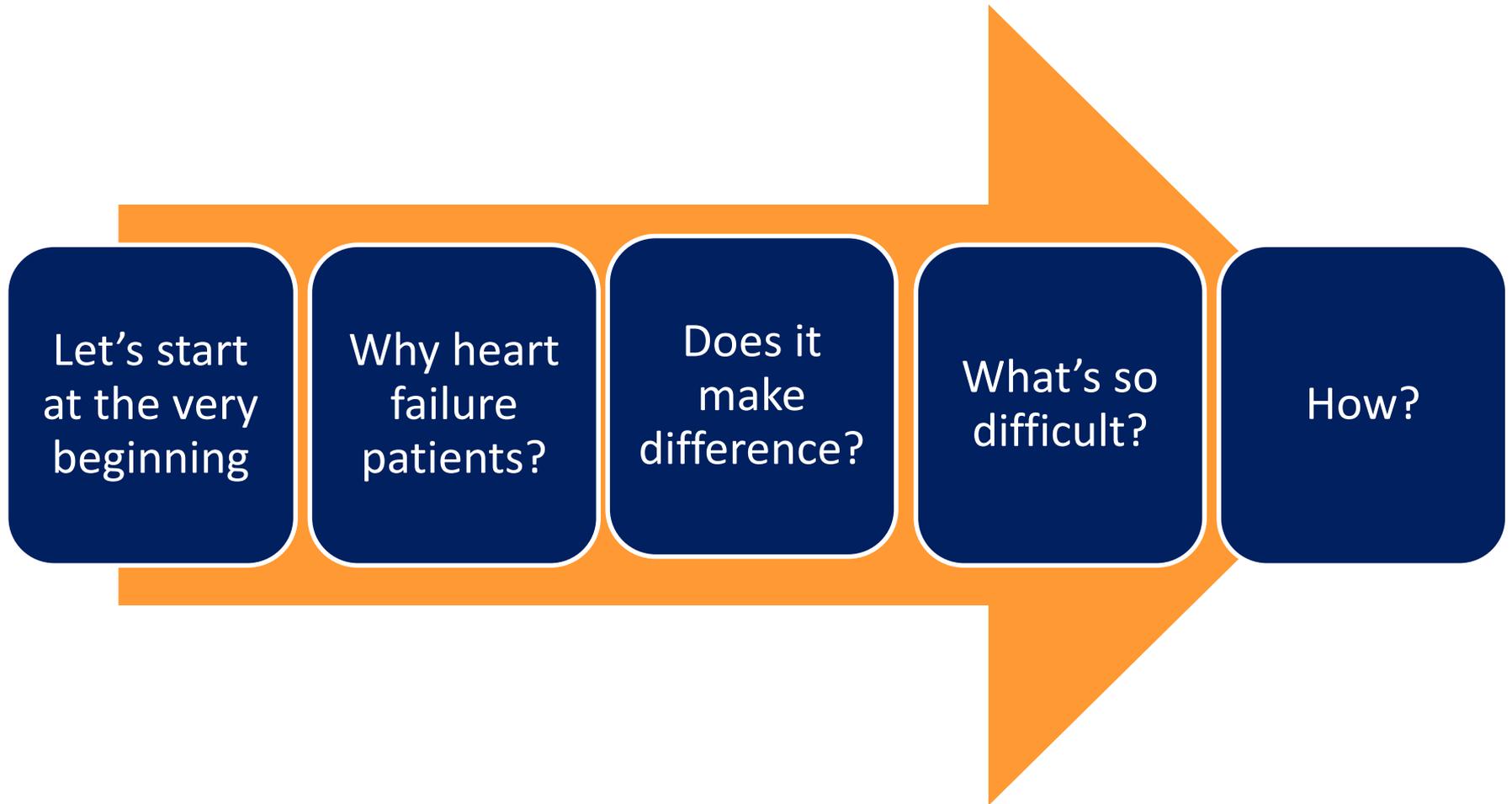


Saint Catherine's Hospice



THE HULL YORK
MEDICAL SCHOOL

Overview



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

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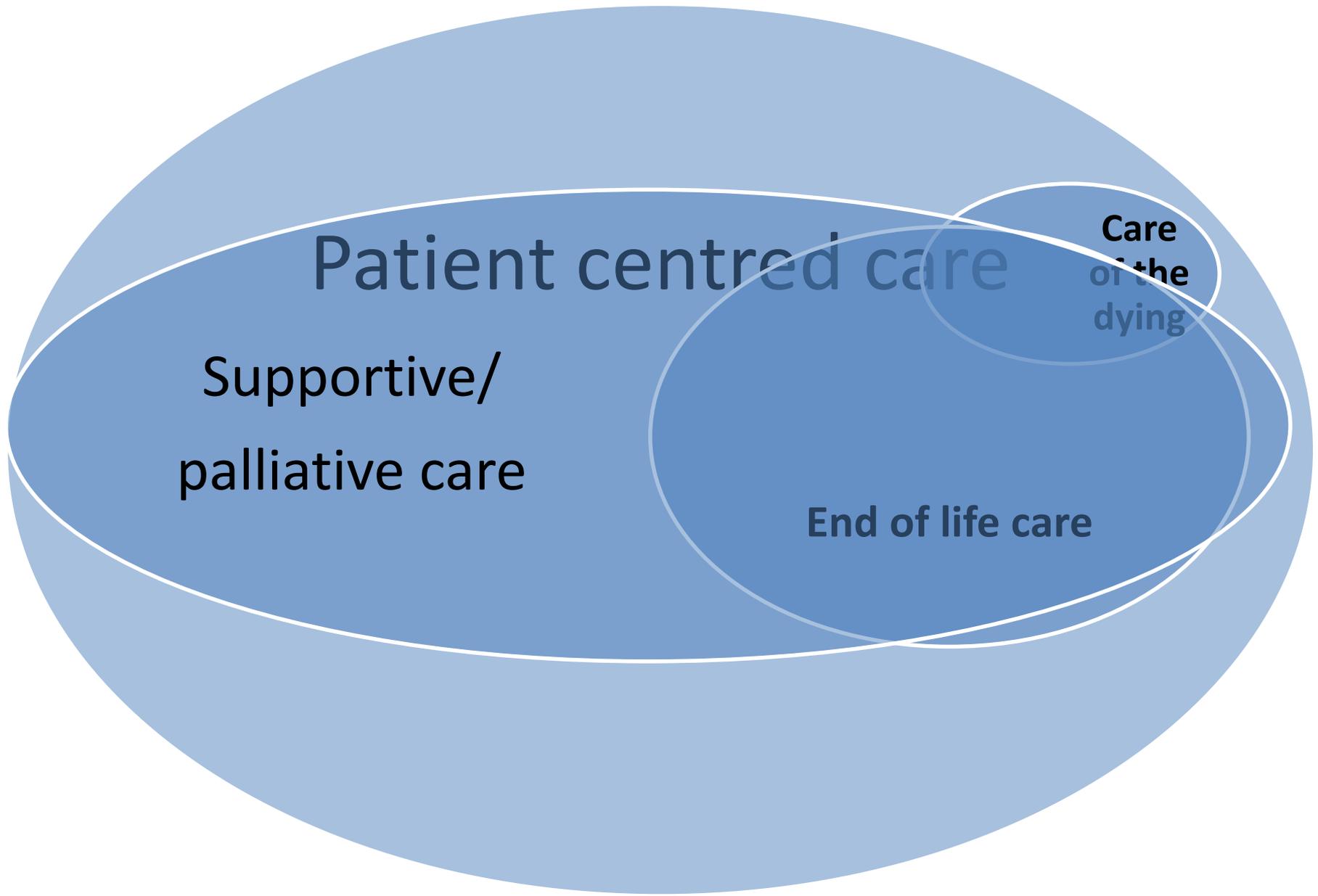
WHO 2002

terminology

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

Patient centred care

- NICE, ESC and AHA have recommended a patient-centred approach for CHF.
- An agreed global definition is lacking but include
 - respect for patients' needs, values, preferences,
 - patient-healthcare professional collaboration,
 - shared decision making



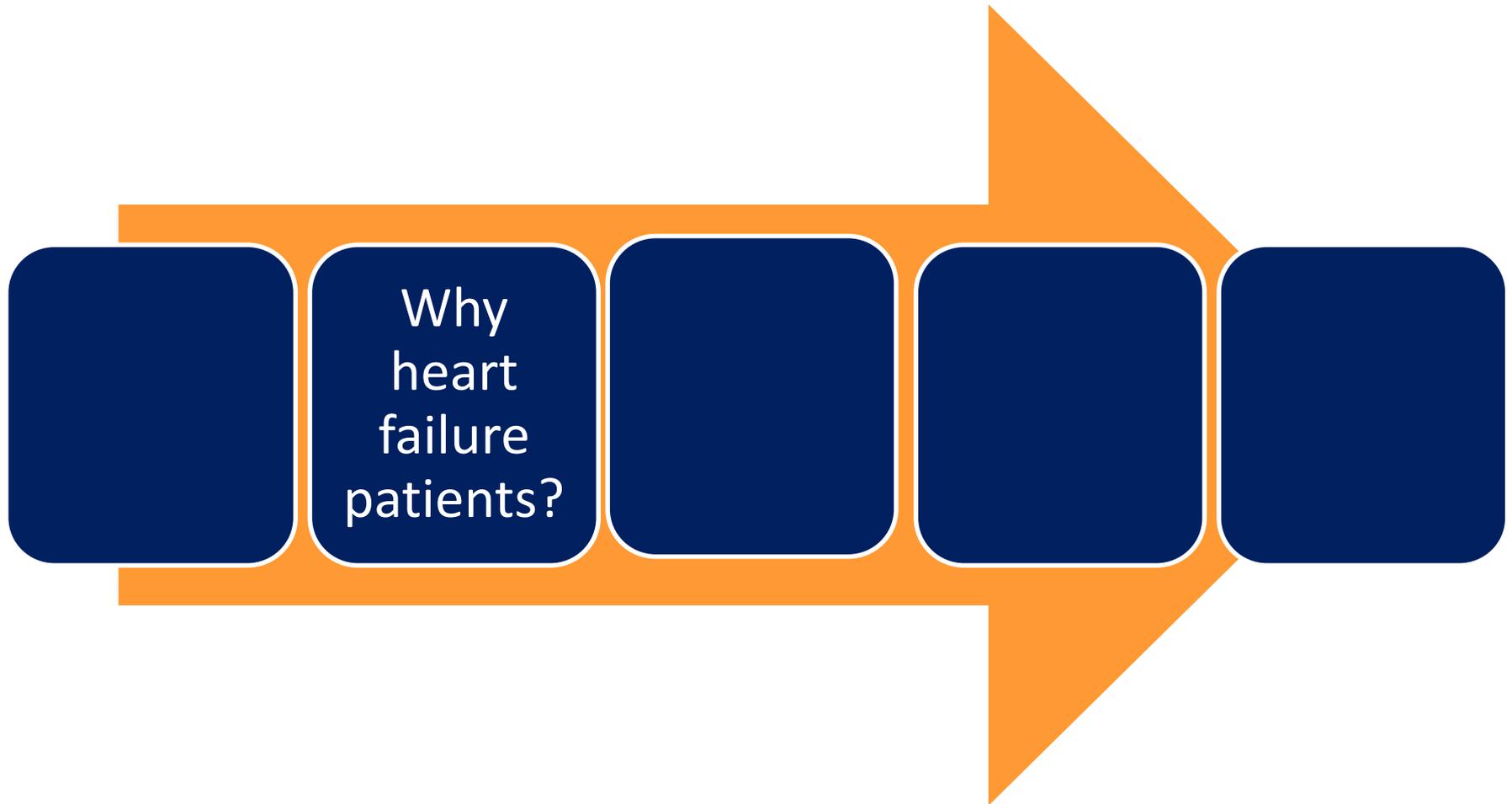
Patient centred care

Supportive/
palliative care

End of life care

Care
of the
dying

Overview



“However this communication simply must take place. Instead of serving as a reason to avoid conversation, uncertainty should be a trigger for exploration.”

- ... society
for Car
Associatio

Because they are symptomatic

- 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

Knowledge and communication difficulties

A Rogers et al BMJ 2000 321: 605 - 607

- Little lay understanding of disease
- Didn't understand importance of symptoms and when to call GP
- >50% talked about death and dying
- Socially isolation
- Confusion or short term memory loss
- Difficulties getting to appointments
- Perception that doctors didn't want to give information

“...they don't take you into their confidence...either they think you're stupid..or else not interested..”

Dying of lung cancer or cardiac failure:....

S Murray et al BMJ 2002; 325: 929 - 932

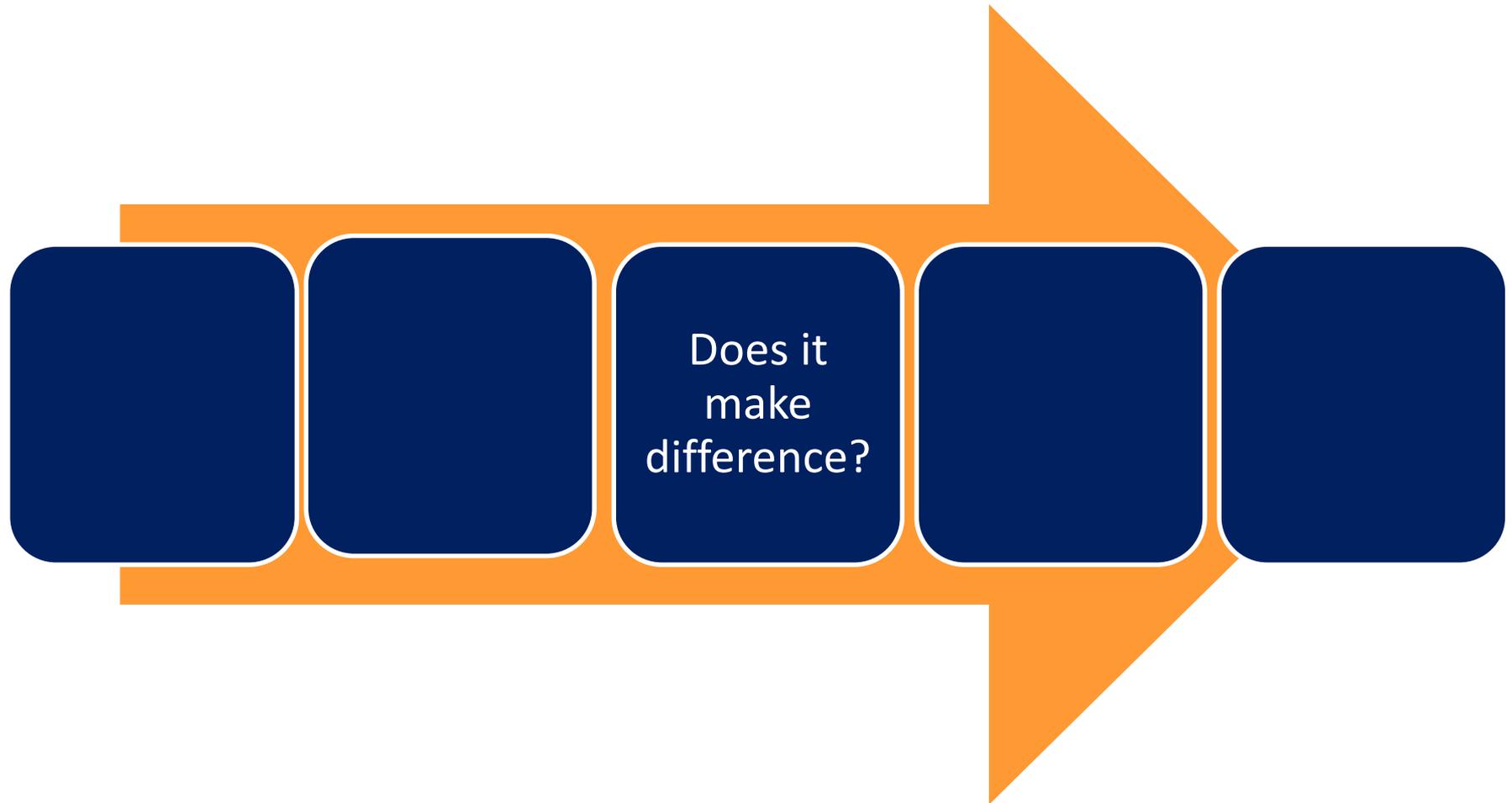
- Heart failure patients have:
 - a different illness trajectory
 - different concerns,
 - a poorer understanding of illness and prognosis,
 - less opportunity to address end of life issues
 - health, social and palliative care services are less readily available
- Care should be pro-active and designed to meet specific needs

GP research database records for deaths in 2009: 27, 689 evaluable decedents

- Nearly half of those dying with cancer also on palliative care register
- Only 7% dying with heart failure also of palliative care register
- Of those on the register, a third placed within a week of death

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

Overview



Does it make a difference? – evidence in heart failure

- Phase 3 RCT Brannstrom M et al EJHF 2014
- N=72
 - MDT – specialists in heart failure, pall care, OT, physio
 - Improved KCCQ $p=0.047$;
 - Reduction in total symptom burden $p=0.035$;
 - Increased self-efficacy $p=0.041$;
 - NYHA improved $p=0.015$;
 - Fewer rehospitalisations $p= 0.009$;
 - No difference in mortality

Does it make a difference? – evidence in heart failure

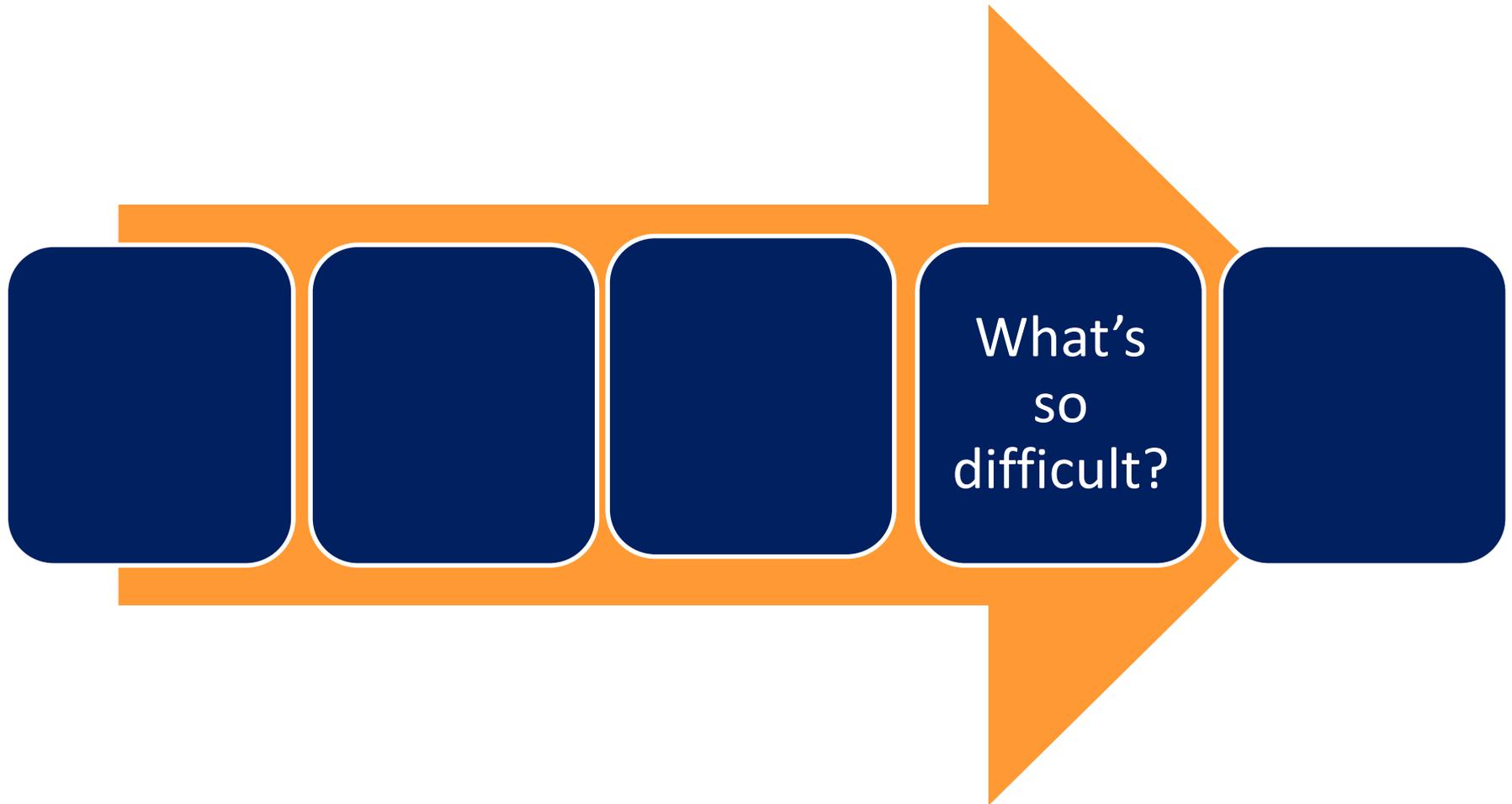
- Phase 3 RCT Sidebottom 2015.
 - IPs with acute HF (single site; N = 232)
 - PC consult and follow-up vs standard care
 - Primary outcomes
 - Improved symptom burden = 8.39 (PC) vs 4.7 (control) at 1 month ($p < 0.001$).
 - QOL score +12.92 points (PC) vs +8 (control) at 1 month ($p < 0.001$).
 - Secondary outcomes
 - ACP = only secondary outcome associated with PC (HR 2.87, $p = 0.033$)
 - no increased risk of inpatient 30-day readmission, hospice use, and death

Sidebottom A et al JPM 2015; 8: 134 - 141

Does it make a difference? – evidence in heart failure

- Phase 3 RCT Wong 2016
 - 3 site, N=84
 - end-stage heart failure after hospital discharge and referred for palliative service
 - Intervention – multi-professional palliative care service
 - primary outcome
 - readmissions within 4 and 12 weeks
 - Results;
 - lower readmission rate at 12 weeks; RR = 0.55 (0.35 to 0.88).
 - improvement in depression, dyspnoea and total ESAS score at 4 weeks.
 - Better quality of life – (McGill QOL) and chronic HF questionnaires.

Overview



Policy – identifying those in the last year of life

Haga et al Heart 2012

- 138 consecutive NYHA III/IV community dwelling patients
- Seattle Heart Failure Model:
 - 12% sensitivity; 99% specific
- GSF prognostic indicator:
 - 83% sensitivity; 22% specific
 - 86% met criteria for end of life care
 - 82% difficult refractory symptoms
 - 24% ≥ 2 admissions in last year for heart failure symptoms

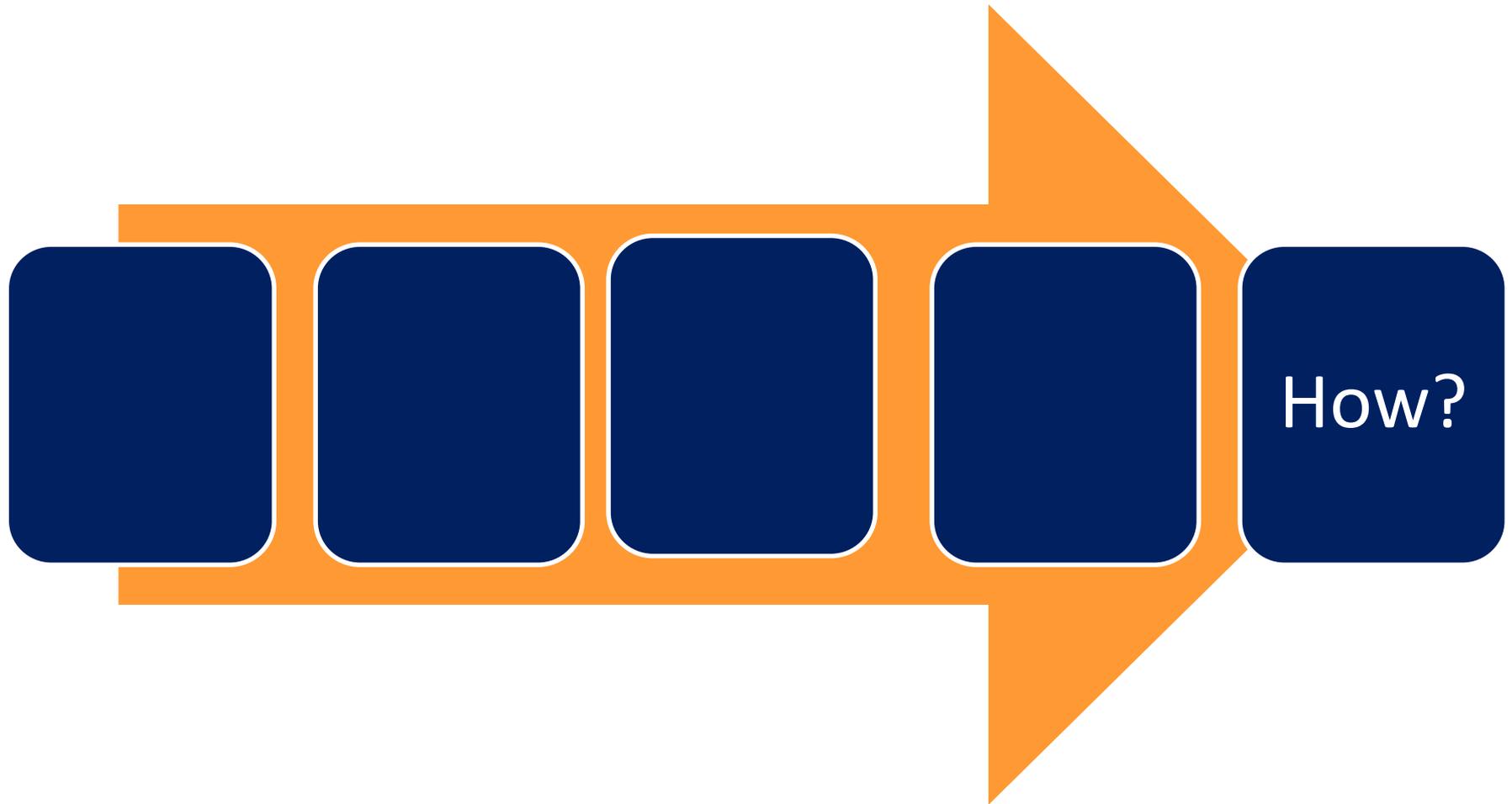
'Clinical Indicators: Heart Failure'

- NYHA functional class III or IV.
- Recurrent hospital admission for symptomatic / decompensated heart failure despite maximum or optimal tolerated therapy
- Deteriorating renal function
- Persistent hypotension
- Persistent hyponatraemia
- Progressing hypoalbuminaemia
- Difficult physical or psychosocial issues despite optimal tolerated therapy

Prognosis – the “holy grail”

- If we wait until
 - incontrovertible,
 - completely obvious,
 - irreversible,
 - no chance of stabilisation or improvement
 - deterioration
- The patient will be dead

Overview



Needs based care

- 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 (including across settings)
- Service configuration
- MDT cardiology and palliative care

Difficult conversations

- Uncertainty
- Misconceptions
 - 85% patients with ICDs believed that re-programming meant that the heart would stop (Stromberg 2014)
- The elephant in the room (Barclay et al 2011)
- Emerging evidence
 - Allows support for preferred place of care (Johnson et al BJC 2012)
 - “the way that its done”
 - Allows access to services and joined up care
 - Reframing hope

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

Full of practical, evidence based advice, *Heart Failure and Palliative Care: a team approach* encourages a multidisciplinary team based approach. It stimulates joint working between primary care, cardiology and palliative care teams – raising awareness of the problems associated with supportive and palliative care for heart failure patients.

Heart Failure and Palliative Care: a team approach offers invaluable advice for primary care, cardiology and other healthcare professionals including heart failure nurse specialists, consultants, and ward nurses.

'This second edition of *Heart Failure and Palliative Care: a team approach* is an asset for all teams involved in the care for patients with heart failure, and it can be seen as the basis for optimal care. The first edition of this book was received very positively by healthcare providers as one of the first heart failure-specific books about palliative care that addressed theoretical and practical knowledge. Its pragmatic approach opened the eyes of many 'cardiology people' and clarified the importance and relevance of palliative care for their heart failure patients. It also opened the eyes of many 'palliative care people' to see the complexity of heart failure and the need for an interdisciplinary team approach. This second edition of *Heart Failure and Palliative Care: a team approach* has the same pragmatic and realistic approach and is updated with the latest evidence and insights. In this edition palliative care for heart failure patients is placed in a wider international context and elaborates more on patient experiences and advance care planning.'

From the Foreword by Tiny Jaarsma,
Professor in Nursing Science, Linköping University, Sweden

HEART FAILURE AND PALLIATIVE CARE A TEAM APPROACH SECOND EDITION

EDITED BY JOHNSON, LEHMAN AND HOG

HEART FAILURE AND PALLIATIVE CARE

A TEAM APPROACH

Second Edition

