H·Y·M·S

THE HULL YORK
MEDICAL SCHOOL

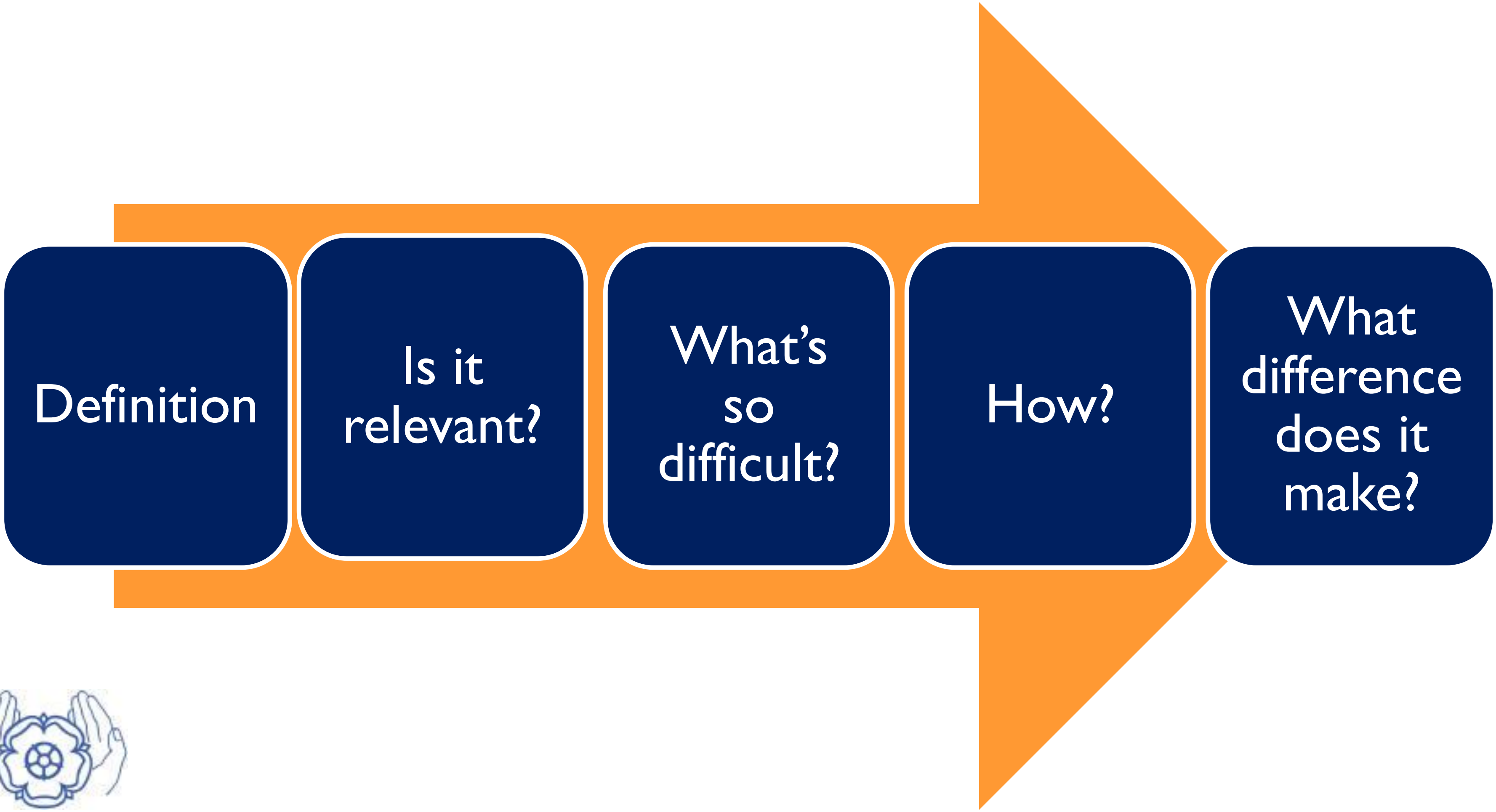
What is Palliative Care?

…is it relevant to patients with heart failure?

M Johnson

ST CATHERINE'S
HOSPICE

Overview



- Definition
- Is it relevant?
- What's so difficult?
- How?
- What difference does it make?

What is palliative care?

- “… an *approach* that improves the quality of life
- … *relief of suffering* by means of …
- *assessment and treatment of pain and other problems*; physical, psychosocial and spiritual….”

WHO 2002

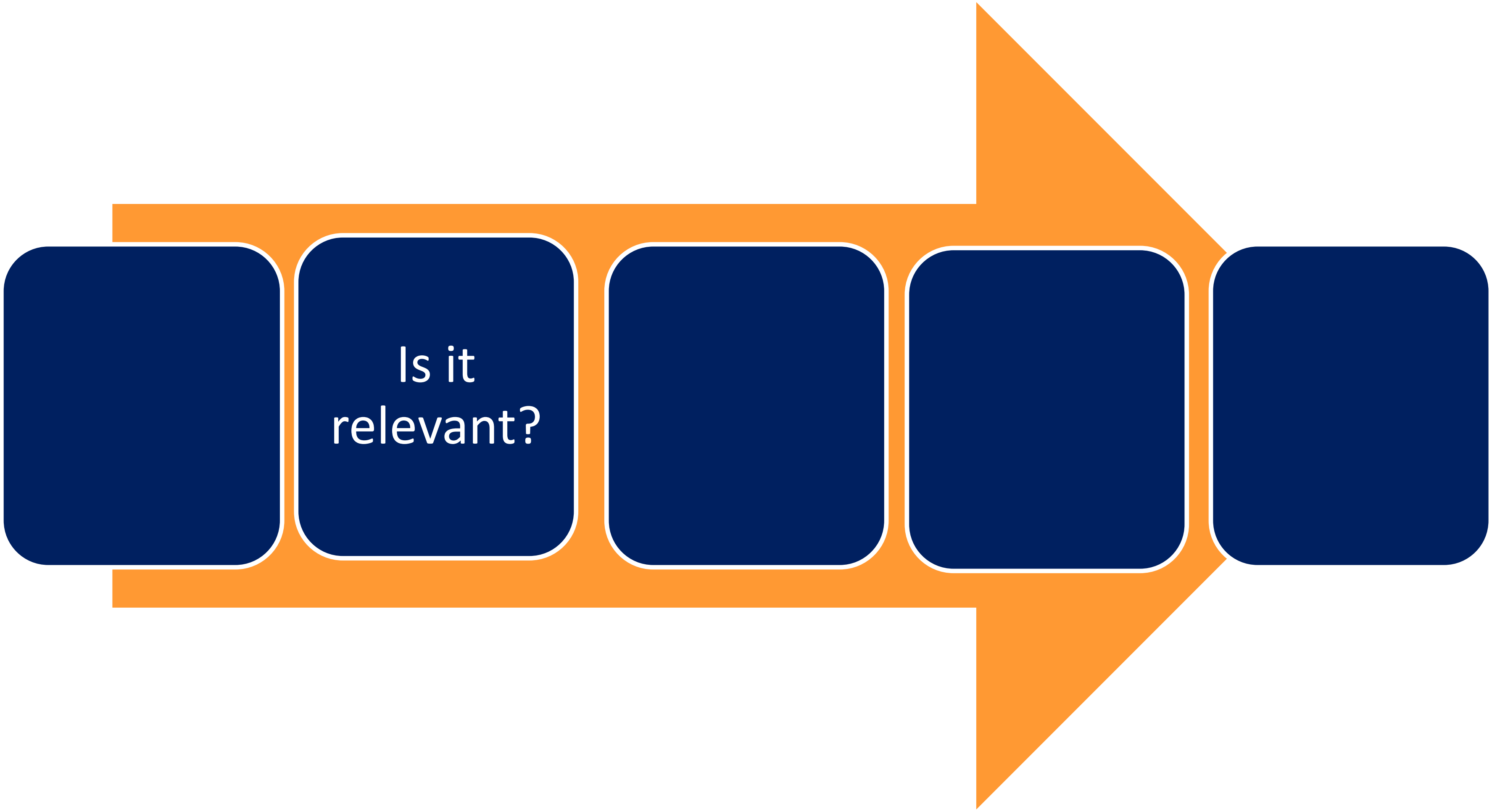
What is palliative care?

- 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 doesn’t help

- End of life care
- Supportive and palliative care
- Survivorship “living with and beyond”
- Dying
- The broader concept of advanced disease



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Palliative care is…

- *… an approach that improves the quality of life*
- *… relief of suffering; assessment and treatment of pain and other problems; aims to help patients live as actively as possible until death;*
- *uses a team approach*

- *is applicable early in the course of illness, with other therapies that are intended to prolong life*

Heart failure patients…

- *Quality of life is important*

- *Have a symptom burden similar to cancer patients, that lasts for longer for many, with less access to support services*
- *Have needs that require multi-professional team*
- *Have needs that fluctuate throughout their course of illness, some of which require palliative expertise (within the cardiology team, in primary care, or the palliative care teams as needed)*

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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*

Quality of Life Hobbs FD et al Eur HJ 2002

- Sub -study of ECHOES community prevalence study
- SF36 health status questionnaire completed by 5961 (97% of those screened)
- 3850 healthy randomly picked, and 426 with LVSD
- In all domains (physical psychological and social), patients with heart failure of any cause scored markedly lower than the general population and in most domains lower than those with other chronic illnesses, mental or physical.

Dying of lung cancer or cardiac failure:….

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

- Heart failure patients have a different illness trajectory from those with lung cancer
- Such patients and carers have different concerns, a poorer understanding of illness and prognosis, and less opportunity to address end of life issues than those with lung cancer
- Health, social and palliative care services are less readily available to those with a non-cancer diagnosis
- Care should be pro-active and designed to meet specific needs

Knowledge and communication difficulties

A Rogers et al BMJ 2000 321: 605 - 607

- Little lay understanding of disease; aging; inevitable; nothing can be done
- Didn't understand importance of symptoms and when to call GP
- >50% talked about death and dying without any prompting by researcher
- Become socially isolated
- 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.."

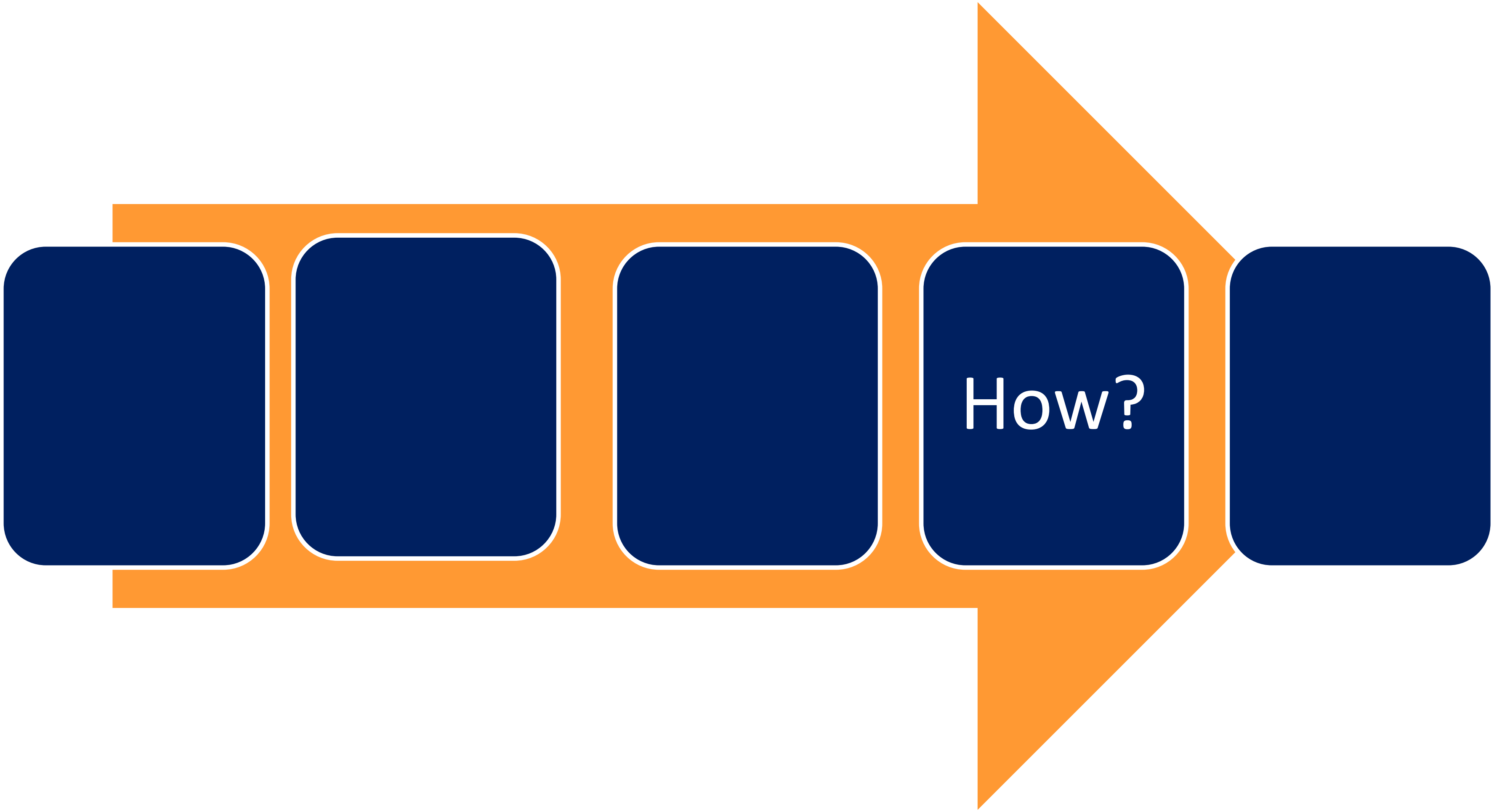
What if these issues are not addressed?

- Physical symptoms remain unmanaged
- Less understanding about the illness and stage
- Less access to supportive and palliative care services
- Less opportunity to contribute to plans for end of life and place of care
- Large and prolonged caregiver burden, with less support
- Poor communication and co-ordination of care

What’s so difficult?

What’s so difficult?

- Palliative care = imminently dying (“make ‘em cry, let ‘em die”) rather than a core generic skill for all health care
- Cycle of decompensation and restoration, therefore a palliative approach is delayed till it is too late (prognostic paralysis)
- Tendency for clinicians to look for further treatment options even when these are futile
- Honest discussion about limitations of treatment in the face of uncertainty is hard – and when they may not understand how bad things are
- Fear of taking away hope/not enough time
- Poor communication between primary and secondary care



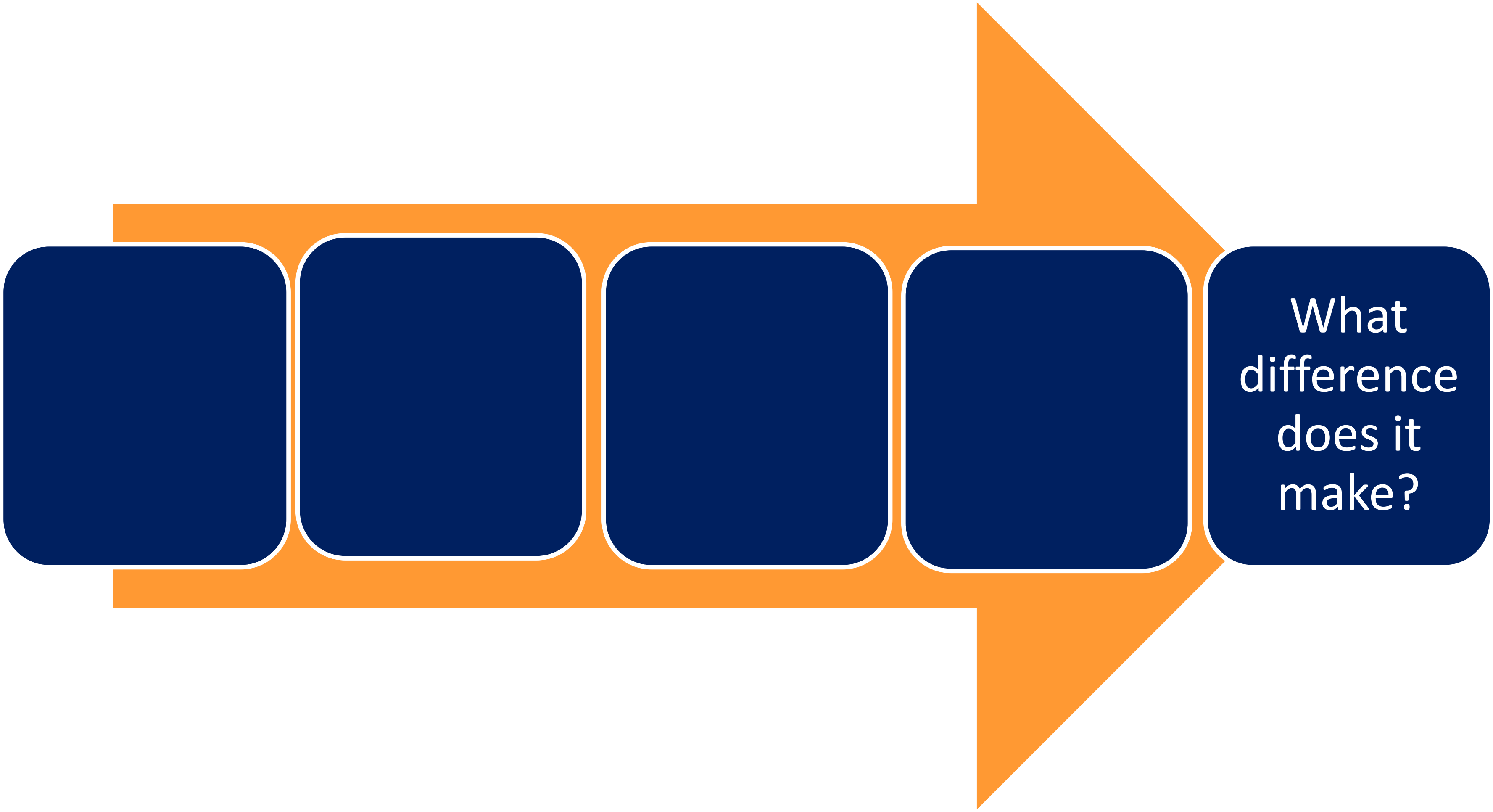
How?

NICE Quality Standards

- …offered personalised information, education, support and opportunities for discussion throughout their care to help them understand their condition and be involved in its management, if they wish.
- …cared for by a multidisciplinary heart failure team led by a specialist and consisting of professionals with appropriate competencies from primary and secondary care, and are given a single point of contact for the team.
- …[following HF admission]have a personalised management plan that is shared with them, their carer(s) and their GP.
- …people with moderate to severe chronic heart failure, and their carer(s), have access to a specialist in heart failure and a palliative care service.

How?

- Integrated teams will:
  - allow patients to access expertise as needed
  - upskill cardiology and primary care teams in palliative care
  - upskill palliative care teams in cardiology
- Prevents:
  - either/or
  - “are we there yet?”
- Focus on the problem rather than the prognosis



What difference does it make?

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- Access to services:
  - Symptom control/respite and support for carers/psycho-socio-spiritual support
- Development of:
  - symptom guidelines
  - ICD deactivation protocols/communication training
  - DNACPR documentation agreement/communication training
- Support for preferred place of care
- Care of the dying

End of life care? – a flexible service

- 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

Dennis

- 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 (pain and breathlessness)
- Sleeping better (helped coping)
- Rediscovered role in family (story writing!)
- Children less distressed
- Psychologically improved (and wife happier too)
- Tolerating up-titration of ACE-I, now on target dose
- Discharged from SPC service now NYHA class II

- End of life care? It might have been….

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.”