

Understanding palliative & EoL care: How does this help us identify and manage patients at this stage?

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What do we think of when we think about palliative care?

Cardiology perspective:

- Only appropriate for patients
 - Cancer
 - Facing imminent death where the time lines are clear
 - We have to know when patients are going to die
- Impact on HF treatments
 - De-escalation of medical Rx
 - Deactivation of device therapy
 - Not for any further escalation of Rx
- Focus is very much about death



What happens when we don't understand what palliative care means:

“intervention is left too late”

- **YC (68yr old female)**
 - Ischaemic cardiomyopathy with severe LVSD
 - Late presentation MI complicated by VF arrest aged 50
 - Multiple comorbidities
 - Poorly controlled Type 1 DM
 - Hypertension
 - Mild renal impairment
 - COPD (Smoked 40-60 cigarettes per day)
 - Management
 - Shared care local cardiology team, Tx team, HFLN & 1⁰ care team
 - Optimal doses of evidence based medical therapy
 - CRT-D
 - Not for cardiac Tx

What happens when we don't understand what palliative care means:

“intervention is left too late”

- 8yrs after index event before she had 1st HF admission
- Over the next 3 years
 - 12 admissions with HF (300 bed days)
 - 4 admissions with shocks from device
 - Single shocks deteriorated to multiple shocks
 - Worsening symptoms
 - Struggling with ADL
 - Housebound unkempt and depressed
 - Leg ulcers with recurrent cellulitis
 - Cachectic
 - Symptomatic hypotension & renal impairment
 - Medical therapy reduced
- CP had raised concern about her active device and no management plan but her concerns were not shared by the medical team

What happens when we don't understand what palliative care means:

"intervention is left too late"

- **Final admission**

- Pulmonary oedema and shocks from CRT-D
- Multiple attempts at central line access
- IV Frusemide & IV Amiodarone
- 21 shocks from CRT-D & external defib prior to death
- Failed attempts at overdrive pacing
- Anaesthetist was called to discuss admission to ITU
- Family were not present
- Died in CCU in the procedures room

- **Discussion with the family**

- “shocked” – didn’t realise how unwell she was
- “hospital admissions & shocks from device were signs that this would happen so soon?”
- “were the shocks prior to death painful?”

What happens when we don't understand what palliative care means:

“intervention is left too late”

- Despite technically good “cardiology” care
 - Poor QoL
 - No early identification and planning despite being at a ceiling of treatment
 - Uncoordinated care including EoL care
 - Uncomfortable & undignified death in hospital
 - Discharges from device hours prior to death
 - Family viewed her predictable death as a “sudden death”
 - Unsupported
 - Many unresolved issues mainly related to
 - » Poor planning & communication

**What happens when we don't understand what
palliative care means:
*“Increased risk of inappropriate actions/decisions”***

- 78yr old lady
 - Chronic HF with severe LVSD
 - Severe COPD
 - Recurrent admissions with infective exacerbations
 - Secondary prevention ICD
 - Appropriate shocks for VT since implant 4 years previously
 - AF
 - DM, IHD, HBP, OA
- Lived independently at home
 - Carer for her husband with dementia
 - Good family and friends support

What happens when we don't understand what palliative care means:

“Increased risk of inappropriate actions/decisions”

- **Admitted with SOB**
 - ? HF ? Infective exac COPD
 - 3 shocks from ICD in close succession
 - Confused
- **Management from the medical team**
 - IV diuretics
 - IV antibiotics, nebulisers & oxygen
 - Deactivation of ICD
- **Physiologist who knew the patient well asked cardiology team to review**
 - CXR: Consolidation Left base
 - CRP 305, WCC 17, Temp 38.5
 - Dehydrated with mild renal impairment

What happens when we don't understand what palliative care means: *“Increased risk of inappropriate actions/decisions”*

- **Device interrogated**
 - Inappropriate shocks for AF
- **MDT discussion**
 - Clinical situation was potentially reversible
 - Secondary prevention ICD with previous appropriate shocks since implant
- **Outcome**
 - Device should remain active
 - Reprogrammed to minimise shocks
 - 2 years later
 - Patient alive, reasonably well and living independently
 - HF stable and no further shocks from her device
 - Continues to have admissions with infective exac COPD
 - Medical ACP with active device and device deactivation plan
 - HF&SC service
 - Managed actively
 - Active device

**What happens when we don't understand what
palliative care means:**

“Poor communication/management of expectations”

- **81yr old female**
 - Moderate–severe LVSD
 - Secondary prevention CRT-D
 - Severe mitral regurgitation
 - Moderate COPD
 - DM, IHD, AF, anaemia, CKD III, arthritis
 - Limited mobility & housebound
 - 12 admissions over past 18 months with HF
 - including 2 with discharges from her device

**What happens when we don't understand what
palliative care means:
*“Poor communication/management of expectations”***

- **Final admission**

- Heart failure

- Slow progress with fairly aggressive medical Rx
 - 1 further shock from her device

- Complicated

- LRTI and subsequent acute on chronic kidney injury
 - CVA with left hemiparesis

- Progressively declined

- Worsening renal function
 - Spending increasing time asleep

What happens when we don't understand what palliative care means:

“Poor communication/management of expectations”

- **Clinical plan**

- Ward doctor spoke with family
 - Patient was dying and would be for symptom Mx
 - Aim now was to keep her comfortable
- Patient's defibrillator was deactivated
- DNACPR form completed
- Daily ward rounds by ward team
 - 2x weekly consultant ward rounds

- Patient remained comfortable and died peacefully overnight

What happens when we don't understand what palliative care means:

“Poor communication/management of expectations”

- **Outcome**

- Patient died 21 days later in hospital
- Family placed a formal complaint
 - They felt traumatised “we were told that our mother was dying but they were wrong she lived for weeks”
 - “Once we were told she was dying nobody spoke to us and nobody did anything”
 - Somebody we do not know, who did not even introduce herself came and turned off my mother's defibrillator and walked out without speaking to us”
 - “I don't think the doctors even saw her anymore, just the nurses”
 - “We were avoided, nobody came near us, we had to approach the nurses for information”

What happens when we don't understand what palliative care means:

“Poor communication/management of expectations”

- **Why was the outcome so bad despite good technical care?**
 - No early identification
 - No anticipatory care planning
 - No management of the family's expectations
 - Perceived poor communication
 - Especially related to defibrillator deactivation
 - No mechanism for assessing the patient and family's understanding
 - Poor management of the prolonged dying situation
 - Junior member of staff was left to manage/discuss what is often a complex clinical and emotional situation
 - No mechanism for ward level “information rounds”

**What happens when we don't understand what
palliative care means:**

***“Miss the significant detrimental change in another
clinical condition”***

- **74yr old male**
 - Secondary prevention ICD following OOHVF arrest
 - Severe LVSD
 - EF 19%, NYHA III, QRSd 104ms
 - Ischaemic aetiology
 - No discharges from device since implant 4 years ago
 - Tolerated good medical therapy
 - Reasonable QoL restricted only by SOB on exertion
 - Good family support
 - Co-morbidities including COPD, DM, RA

**What happens when we don't understand what
palliative care means:**

***“Miss the significant detrimental change in another
clinical condition”***

- **Dx with pancreatic carcinoma**
 - 2 month history of back pain
 - Surgeons – not for intervention
 - Oncology – palliative Rx
 - During his Rx he developed persistent diarrhoea
 - Found attendance at clinic appts impossible
 - 3 DNAs HFLN service: Subsequently discharged from FU
 - DNA 2x device FU – reappointed
 - Routine cardiology clinic - junior member of staff
 - Bloods done from oncology – relative hypokalaemia (2.8-3.3)
 - Anorexic and lost weight quickly - cachectic

**What happens when we don't understand what
palliative care means:**

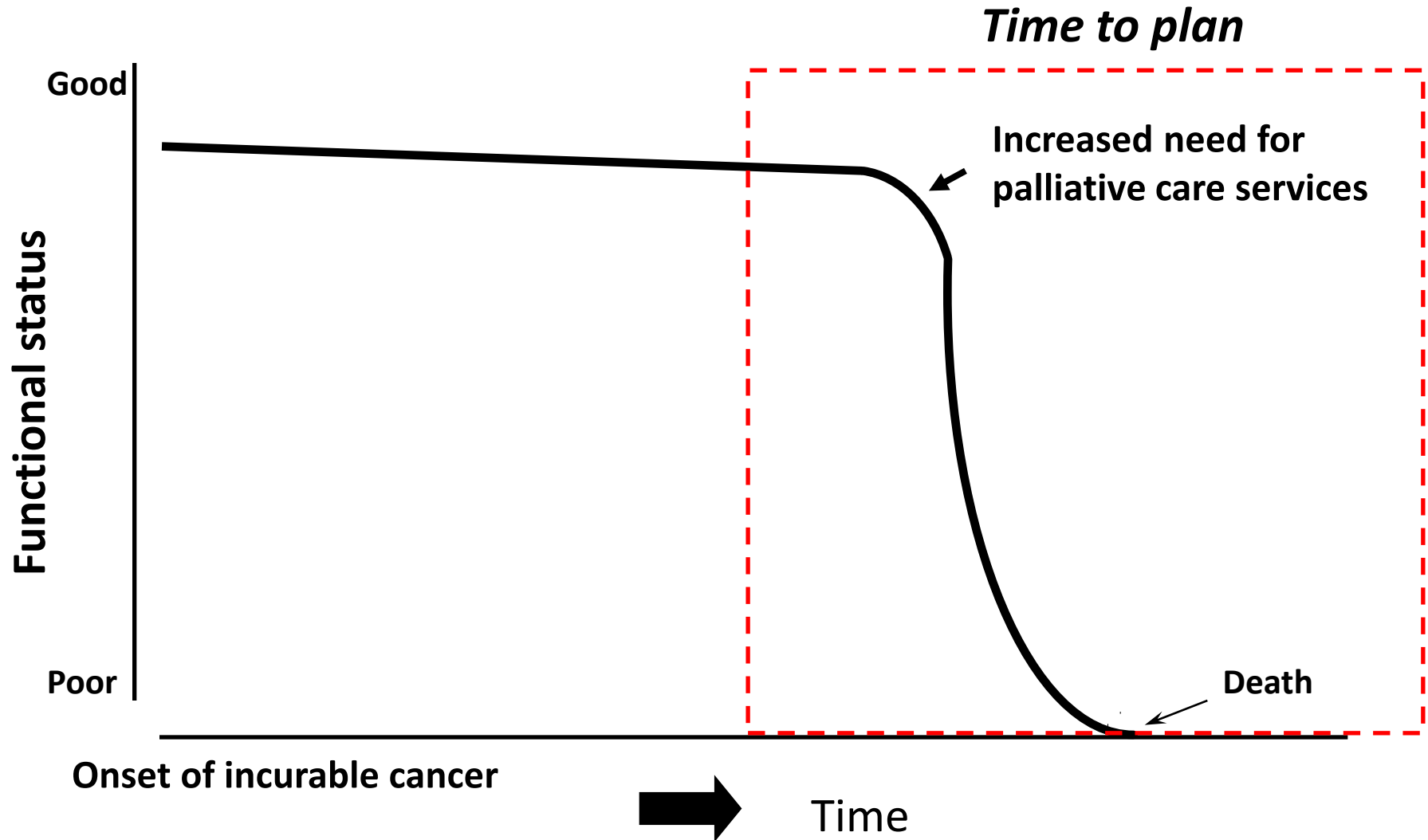
***“Miss the significant detrimental change in another
clinical condition”***

- Family called ambulance on the day he died
 - “recurrent fits” which he had been having for the past few days
 - Discharges from his device
 - Died within a few hours of hospital admission in A&E
 - Device was deactivated 7 mins prior to death
 - Last shock was 12 mins prior to death

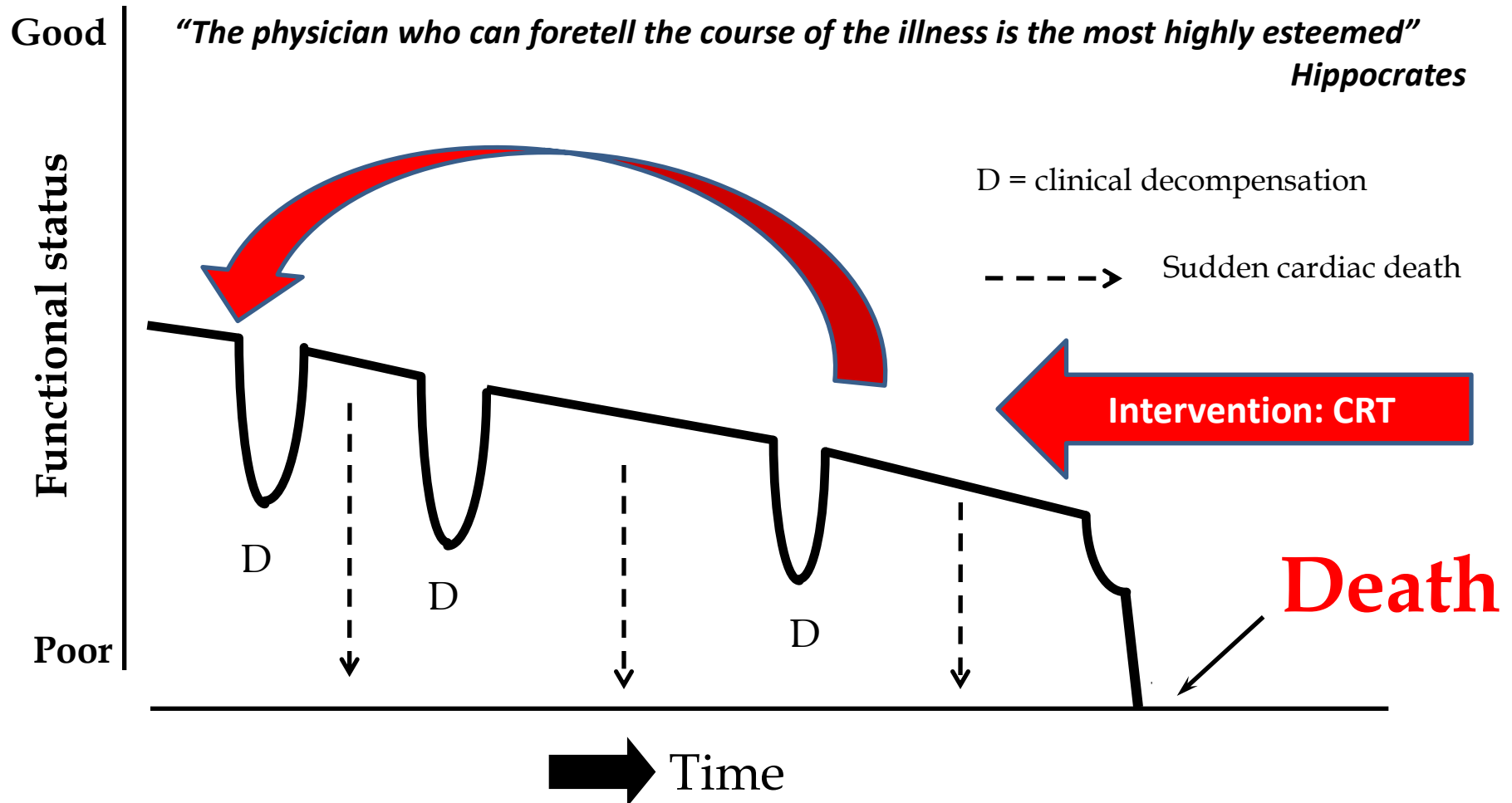
What is lacking?

- **Understanding of palliative & end of life care**
 - Changing the focus from being centered around death
- **Impact**
 - Failure to identify early patients with
 - Palliative care needs
 - Changing clinical circumstances
 - No anticipatory care planning
 - No planned device management for EoL care
 - Device plans
 - Deactivation pathways for care at home, NH, hospital and hospice
 - No pathways of care for managing inevitable decline

Why does identification of patients with palliative care needs seem so hard?



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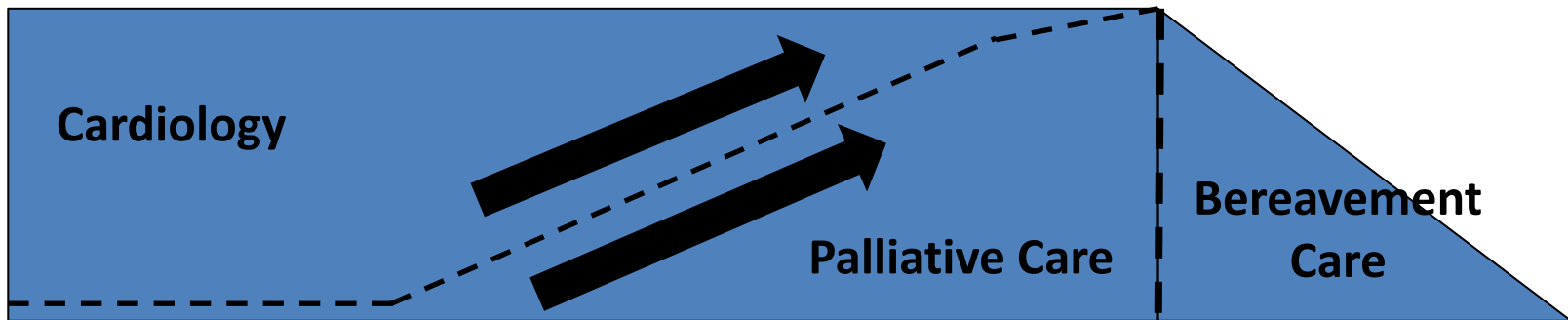
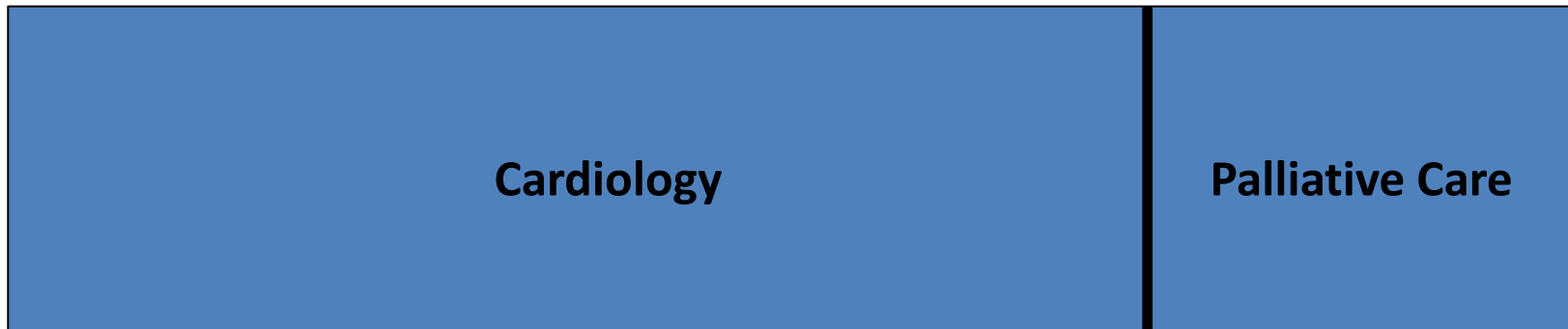


Understanding palliative care: How does that help?

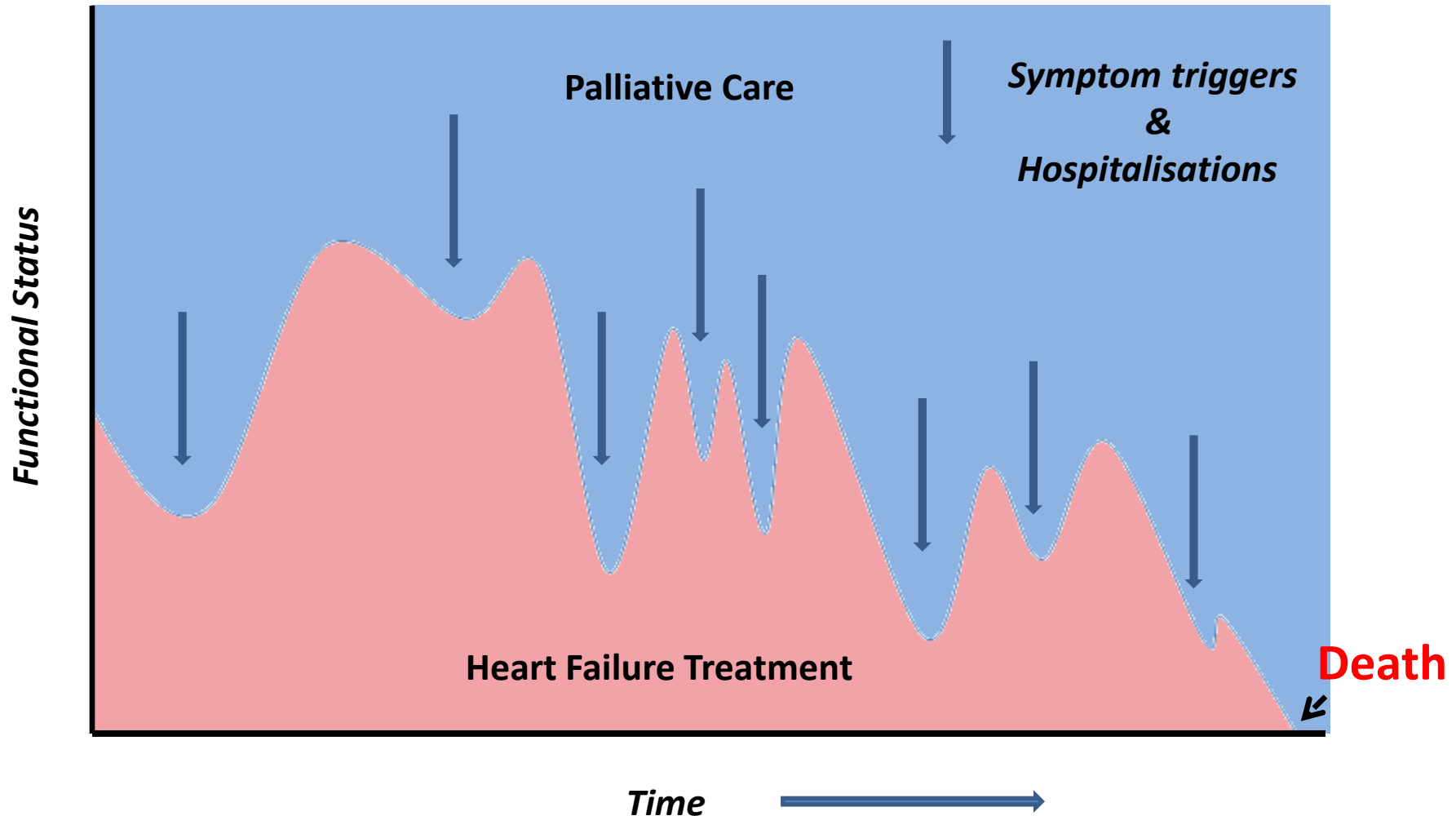
WHO Definition of Palliative Care

- Palliative care is an **approach**
 - **improves the quality of life of patients and their families** facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of **early identification** and impeccable **assessment and treatment of pain and other problems, physical, psychosocial and spiritual**
- provides relief from pain and other distressing symptoms
- intends neither to hasten or postpone death
- offers a **support system to help patients live as actively as possible until death**
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a **team approach to address the needs of patients and their families**, including bereavement counselling, if indicated
- will **enhance quality of life**, and may also positively influence the course of illness
- is **applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life**, and includes those investigations needed to better understand and manage distressing clinical complications.

Understanding palliative care: How does that help?



Identification of patients with palliative needs



Who should we identify with palliative care needs?

- Patients with advanced progressive disease
- Optimal or near optimal medical Rx
- No real intervention to modify the underlying disease process
- Ongoing symptoms and/or hospitalisations
- Significant changes in other unrelated conditions

Could the patients have been identified sooner?

	Patient 1	Patient 2	Patient 3	Patient 4
Optimal Rx	Yes	Yes	Yes	Yes
Ongoing symptoms	Yes	Yes	Yes	No
Hospital admission	Yes	Yes	Yes	No
Detrimental change in another condition	No	No	Yes	Yes
Focus	Technical cardiology care	Technical cardiology care	Technical cardiology care	Technical cardiology care

	Patient 1	Patient 2	Patient 3	Patient 4
Early identification	No	No	No	No
Collaborative cardiology and palliative care approach	No	No	No	No
ACP & device plans	No	No	No	No
Shocks from device in days/hrs prior to death	Yes	Yes	Yes	Yes
Inappropriate deactivation	No	Nearly	No	No
Appropriate communication	No	No	No	No
Complaint from family	Yes	Yes	Yes	Yes
Unnecessary hospital admission or death in hospital	Yes	Yes	Yes	Yes

Summary: Palliative care

- **Management of patients with**
 - Progressive and debilitating illnesses
 - Regardless of their time to death or the diagnosis
 - Not solely about the management of patients who have cancer or who are imminently dying
 - Does not hasten death by any means
- **Understanding palliative care allows us to:**
 - Identify patients with palliative care needs early
 - Provide a collaborative cardiology and PC approach
 - Focus good technical care, QoL, carer support
 - Plan for the predictable within an unpredictable trajectory
 - Including device management plans for EoL care

Summary: Palliative care

- **Providing a collaborative approach to care**
 - Increases the likelihood of patients being cared for in their preferred place of care (which is often at home)
 - Reduces unnecessary hospital admissions including patients with active devices
 - Potentially reduces
 - Complaints associated with EoL care
 - Health care utilisation costs

