## Supportive Care for Patients Living with Advanced Heart Failure (HF)

The Sabah Experience

Hospice &

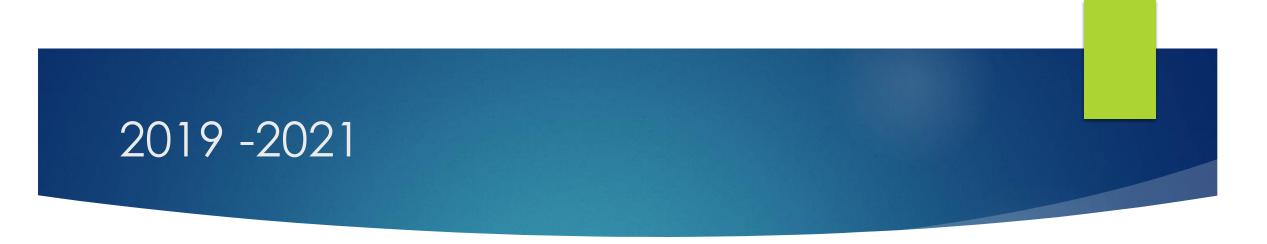
DR NG WANJUN

PALLIATIVE CARE PHYSICIAN

QUEEN ELIZABETH HOSPITAL, KOTA KINABALU, SABAH

## Mr L: 34 year-old IT store worker

- Underlying: tophaceous gouty arthritis, CKD, gastritis
- Non-ischemic dilated cardiomyopathy diagnosed 2012
  - First presented with failure symptoms to Sarawak Heart Centre. CMRI and CT Angiogram: normal coronary artery, severe dilated LV with EF 30%
  - 2014: moved to Sabah. ECHO in 2017: EF 20-35%, moderate to severe global hypokinesia
  - ▶ June 2018: ICD implanted
- Jan 2019: admitted for acute decompensation, referred palliative (inotropic dependence), but eventually discharged well



- Feb 2019 –Sept 2020: well during 3 clinic review, NYHA 1, then defaulted follow up
- Oct 2020 Apr 2021: 3 hospitalizations for acute decompensation

When to refer specialist palliative care?
What value can palliative care add to standard care?
How to integrate palliative care to standard care model?



## CONTENT

- Burden of heart failure
- Prognostication in heart failure
- When to initiate palliative care approach & refer specialist palliative care
- Integrating palliative care
- Case discussion
- Local collaborative work in Sabah

## Global burden of heart failure



#### **Journal of the American Heart Association**

Volume 12, Issue 6, 21 March 2023 https://doi.org/10.1161/JAHA.122.027852

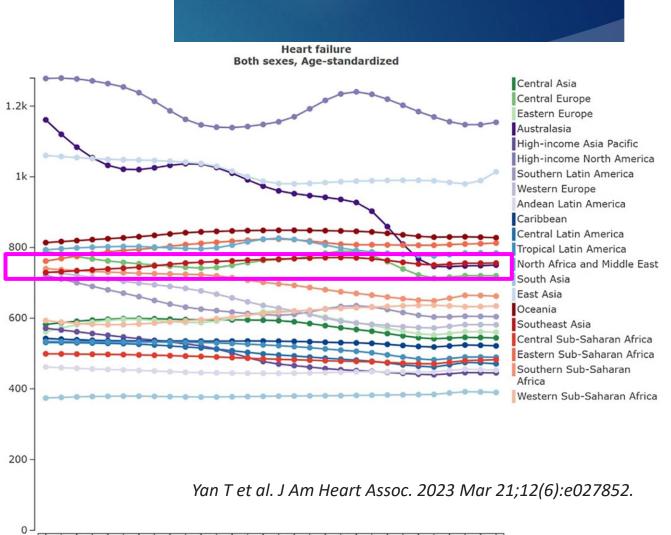
#### **ORIGINAL RESEARCH**

### Burden, Trends, and Inequalities of Failure Globally, 1990 to 2019: A Se Analysis Based on the Global Burde Disease 2019 Study

Tao Yan, MD (D<sup>\*</sup>; Shijie Zhu, MD<sup>\*</sup>; Xiujie Yin, MD<sup>\*</sup>; Changming Xie, MD; Miao Zhu, MD (D; Fan Weng, MD; Shichao Zhu, MD (D; Bitao Xiang, M) Gang Liu, MD; Yang Ming, MD; Kai Zhu, MD; Chunsheng Wang, MD (D; ; )

▶ 56.2 million

1-2% of adult population



1990 1992 1994 1996 1998 2000 2002 2004 2006 2008 2010 2012 2014 2016 2018

American

Heart Association

Prevalent

ESC European Society Cardiovascular Research (2022) 118, 3272–3287 https://doi.org/10.1093/cvr/cvac013

**INVITED REVIEW** 

#### Global burden of heart failure: a comprehensive and updated review of epidemiology

Gianluigi Savarese (1,2<sup>†</sup>, Peter Moritz Becher<sup>1,3<sup>†</sup></sup>, Lars H. Lund<sup>1,2</sup>, Petar Seferovic<sup>4,5</sup>, Giuseppe M.C. Rosano<sup>6</sup>, and Andrew J.S. Coats<sup>7</sup>\*

Prevalence	Incidence	Mortality	Costs	
Prevalence 1-3% in general adult population	Incidence 1-20 cases per 1,000 person-years or per 1,000 population	Mortality remains high 30-day Mortality ~2-3%	Annual health care costs up to €25,500 per year	Ae
Overall prevalence	Incidence stable/ declining	1-year Mortality ~15-30% 3-year Mortality ~30-50%	Increasing due to major demographic changes (>65 years)	•
Prevalence in HFrEF	Incidence in HFrEF	5-year Mortality ~50-75%	<u>Main cost drivers:</u> - Directs costs (~70%) - Non-CVD comorbidities - Invasive procedures	
Prevalence In HFpEF	Incidence in HFpEF	CVD HFreF HFpeF	- Medications/Diagnostics - Outpatient visits	



- IHD (40%, SEA 60%)
- Hypertension (15%)
- Rheumatic heart disease

## Prognostication in HF



## Classification of HF

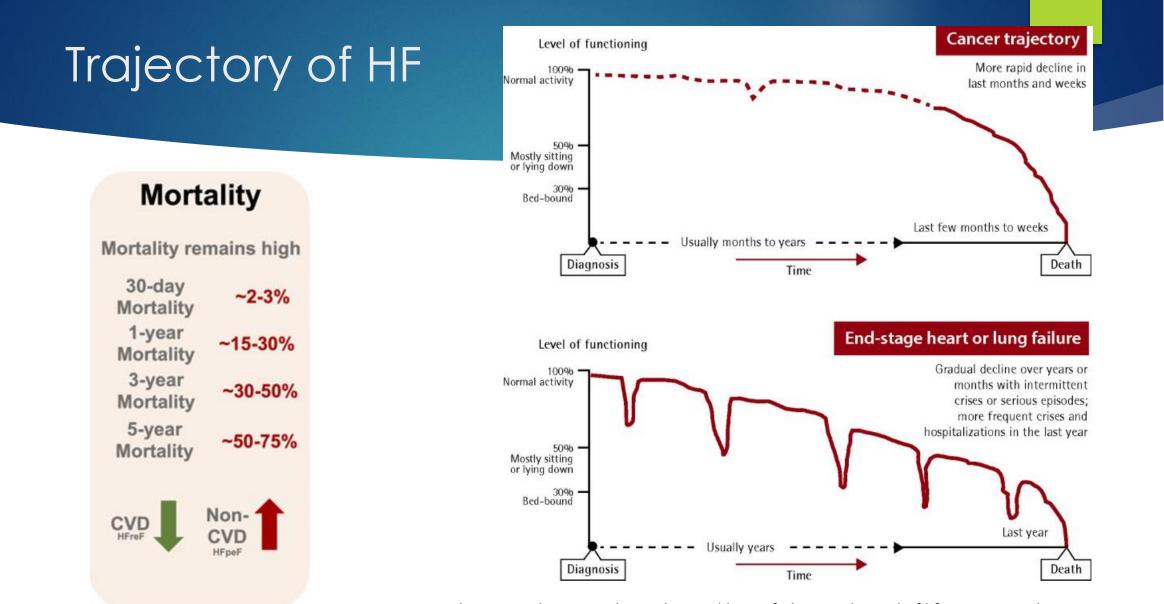
- Left ventricular ejection fraction
- Circulatory system: 🔶 vs 🔶



- Clinical Presentation:
  - Acute heart failure (Acute HF)
  - Chronic heart failure (Chronic HF)
- Functional: NYHA class, INTERMACS
- Stages of HF

Ejection Fraction Terminology	LVEF
Heart Failure with Reduced Ejection Fraction (HFrEF)	≤ 40%
Heart Failure with mildly reduced LVEF (HFmrEF)	41 - 49%
Heart Failure with Preserved Ejection Fraction (HFpEF)	≥ 50%
Heart Failure with Improved Ejection Fraction (HF <i>imp</i> EF)	HF with a baseline LVEF of ≤ 40%, a ≥10-point increase from baseline LVEF following treatment, and a second measurement of LVEF of > 40%.

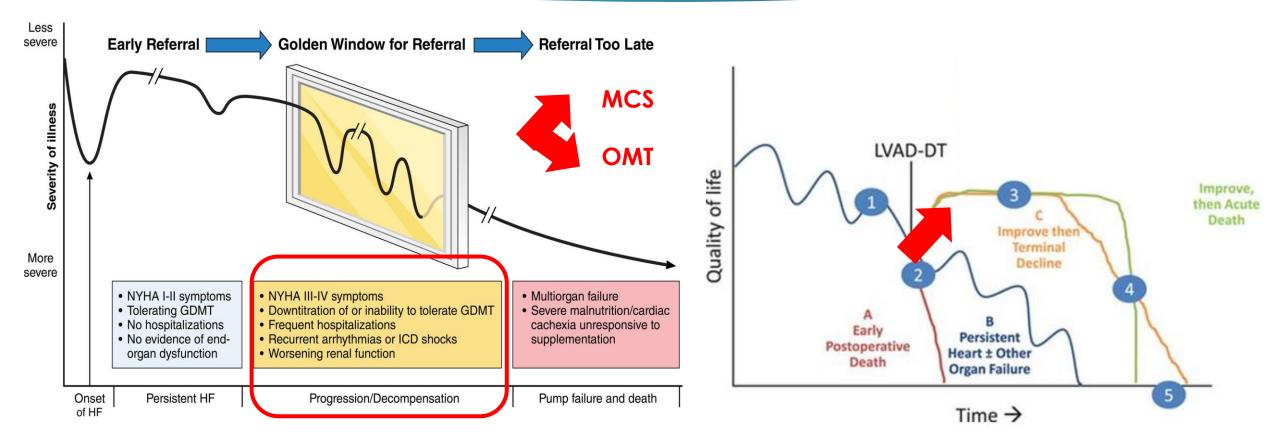
Stage A	Stage B	Stage C	Stage D
High-risk of heart failure, but 'normal' heart	Asymptomatic structural heart disease	Symptomatic structural heart disease	Refractory heart failure



Steinberg L et al. Approach to advanced heart failure at the end of life. Can Fam Physician 2017.



## Identifying patients with advanced HF for advanced therapies



MCS= mechanical circulatory support; OMT= optimal medical therapy

*Morris AA, et al. Circulation. 2021 Oct 12;144(15):e238-e250.* 

## Prognostic tools

#### Cardiac cachexia

- Anaemia
- Urea
- ► BNP
- Refractory symptoms

Seattle Heart Failure Model (SHFM)
Cardiovascular Medicine Heart Failure Index (CVM-HF)
Heart Failure Survival Score
Meta-Analysis Global Group in Chronic Heart Failure (MAGGIC)
EVEREST Risk Model
EFFECT
ADHERE
ESCAPE Discharge Score
PACE
SHOCKED
Palliative Performance Scale
Frailty Score

# When to initiate palliative care approach & refer specialist palliative care

## Identifying patients with palliative needs

Tool*	IPOS (version 1)	GSF-PIG (6th edition, 2016)	RADPAC (original)	SPICT (April 2019)	NAT:PD-HF (original)	NECPAL (version 3.1, 2017)
Patient identification		$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$
Needs identification	√				$\checkmark$	
Needs assessment/ decision aids		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Needs measurement	$\checkmark$					

\*This classification should not be considered rigid as there can be some overlap in these applications



#### Supportive and Palliative Care Indicators Tool (SPICT<sup>™</sup>)



The SPICT<sup>™</sup> is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

#### Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

#### Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

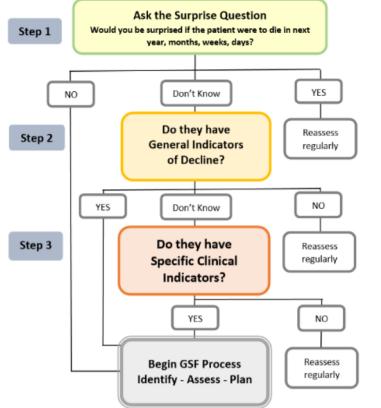
#### tegold standards framework

#### The Gold Standards Framework Proactive Identification Guidance (PIG)



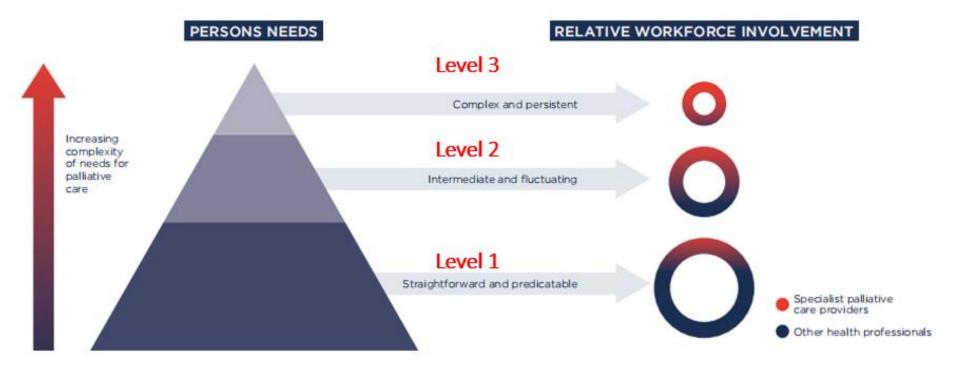
The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.

GSF PIG 7<sup>th</sup> Edition June 2022 Keri Thomas, Max Watson (HUK), Julie Armstrong Wilson and the GSF team



STEP 2: Gener	al indicators of decline and increasing needs
General phy	sical decline, increasing dependence and need for support
• Repeated ur	planned hospital admissions or acute crises at home
	sease - unstable. deteriorating. complex symptom burden
• Presence of	signi 2. <u>ORGAN FAILURE</u>
• Decreasing a	activi HEART DISEASE
Barthel or Ka	
in bed or cha	
daily living	exertion
• Decreasing r	
• Patient choi	
Progressive	
• Sentinel Eve	
to nursing h	
• Serum albur	
	<ul> <li>Unpredictability but other indicators include age, low EF, ischaemic</li> </ul>
	heart disease/arrythmias multi-morbidities including diabetes, obesity
	<ul> <li>depression, hyponatraemia, high BP, declining renal function, anaemia</li> </ul>

## Level of palliative care needs



Australian Palliative Care Service Development Guidelines, 2018

## Key domains of palliative care needs

- Advance care planning for goals & ceiling of care
- Crisis planning
- Device deactivation

- Emergency contact
- Telemedicine option
- ↓ hospital TCA burden
- Timing to engage hospice
- PPOC & PPOD



- GDMT & comorbid mx
- Refractory symptoms
- Justification for opioid
- Terminal symptoms

- Screening for anxiety & depression
- Request for hastened death/ futile Rx
- Caregiver capacity & coping

## Referral criteria to specialist palliative care

#### Prognosis-based criteria

- Surprise question
- Frequent hospitalization
- Functional decline
- Medical complications e.g. cardiorenal syndrome, frequent ICD shocks
- Intolerability of GDMT

#### Need-based criteria

- Complex and refractory symptoms despite optimal medical therapy
- Complex family dynamics and psycho-existential distress
- Decision support uncertainty, discordance
- Terminal care

Grądalski T. Pol Arch Intern Med. 2022 Mar 30;132(3):16223. Chang YK et al. Circ Heart Fail. 2020 Sep;13(9):e006881.

## Integrating palliative care to standard HF care

#### **Chronic Care**

**Crisis Care** 

#### **Terminal Care**

ACC/AHA (2022)	ESC (2021)	JCS/JHFS (2021)
For all patients with HF, palliative and supportive care should be provided to improve QOL and relieve suffering	Communication about the disease trajectory and anticipatory planning should start when a patient is diagnosed with advanced HF	process of dialogue about medical treatment
Best care includes high-quality communication, conveyance of prognosis, clarifying goals of care, shared decision- making, symptom management, and caregiver support	Proactive decisions and advanced planning with regard to palliative and end-of-life care discussions should be documented, regularly reviewed, and routinely communicated to all those involved in the patient's care.	
For patients with HF being considered for, or treated with, life-extending therapies, the option for discontinuation should be anticipated and discussed through the continuum of care, including at the time of initiation, and reassessed with changing medical conditions and shifting goals of care	enrolled in a multidisciplinary care management program to reduce the risk of HF hospitalization and mortality	Continue treatment for heart failure and complications and aim for palliation of coexisting symptoms

Abbreviations: ACC = American College of Cardiology Foundation; AHA = American Heart Association; COR = Class of recommendation; EOL = End of life; ESC = European Society of Cardiology; HFSA = Heart Failure Society of America; JCS = Japanese Circulation Society; JHFS = Japanese Heart Failure Society; LOE = Level of evidence; QOL = Quality of life.



## Sustainable integrated care model

- Need-based referral criteria to specialist palliative care preferred over prognosis-based criteria
- Shared-care model PC should be provided alongside guideline directed medical therapy (GDMT)
- SC Continuous interdisciplinary Collaboration/cross-training and Communication

Ponikowski P et al. Eur Heart J. 2016 Jul 14;37(27):2129-2200. Gaertner J et al. BMJ. 2017 Jul 4;357:j2925. Gelfman LP et al. J Palliat Med. 2017 Jun;20(6):592-603.

## Key interventions of palliative care



## Chronic care

#### Shared care with primary team

 Chronic phase: Outpatient Clinic

 Choice of models depends on disease trajectory, symptom burden, patient preference

 Regular HF clinic, palliative consult PRN
 Concurrent HF and palliative clinic
 Regular palliative clinic, cardiology consult PRN

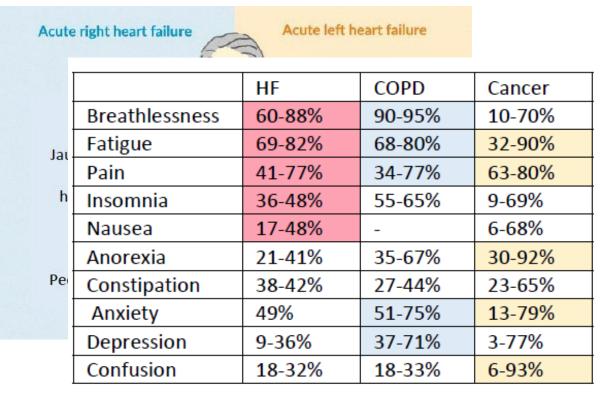
- Optimization of GDMT ACE-I/ ARNI, BB, MRA, SGLT2-I (regular blood taking)
- Screen for symptoms for decompensation: fluid status
- Monitor progression of disease: functional, nutritional
- Managing CVS risk factors and co-morbitiies

- ACP discussion & psychosocial support
- Care coordination

   hospice/
   domiciliary service



## Common symptoms



- Identify and treat reversible causes
- Role of opioid NOT 1<sup>st</sup> line medication
  - refractory dyspnoea/ angina
- Choice of palliative medication
  - Cardiotoxicity, renal impairment, pill burden

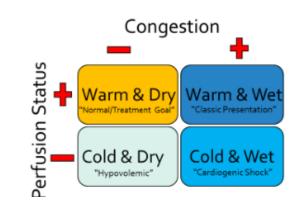
## Crisis care

- Reversibility of cause, refractoriness of symptoms
- Ceiling of care
- Disposition

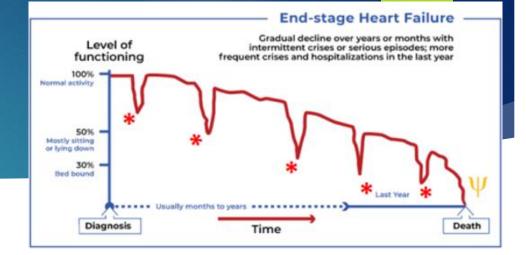
		ative walk-in clinic * g of care, bed availability, patie
Cardio rehabilitation	Medical ward	Palliative ward

Cardio	rehabilitation	
ward		

#### **End-stage Heart Failure** Gradual decline over years or months with Level of intermittent crises or serious episodes; more functioning frequent crises and hospitalizations in the last year 100% Normal activity 50% Mostly sitting or lying down 30% Bed bound ••••• Usually months to years Diagnosis Death Time



## Terminal care



Terminal symptoms

- Device deactivation, deprescribing
- Preferred place of care & dying feasibility

#### **W**Terminal phase (prognosis of hours to days):

Preferred place of dying depends on symptom burden, caregiver capacity, patient preference, hospice coverage area and capacity

Home (supported by community hospice care)

Hospital

Screen for risk of complicated grief

- Compassionate extubation
- Terminal discharge

## Roles of domiciliary/ hospice care

#### Challenges

- Medical complexity
- Intensity of care during crisis
- Greater unpredictability of disease trajectory

#### Roles

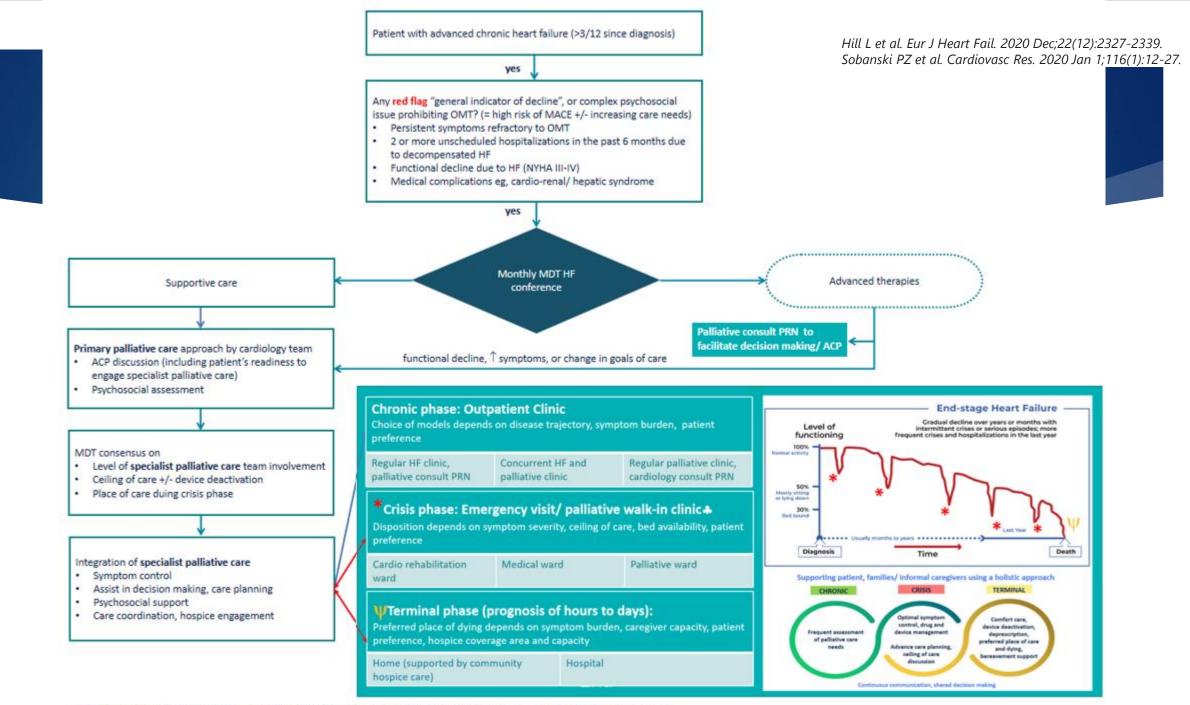
- Comprehensive screening for palliative care needs
- Review ACP
- Care coordination
- First liner during crisis advise for self titration of diuretics for mild symptoms











ACP=advance care planning; MACE=major adverse cardiovacular event; MDT=multidisciplinary team; OMT=optimal medical therapy

## Back to the case...

## Mr L: 34 year-old IT store worker

- Underlying: tophaceous gouty arthritis, CKD, gastritis
- HFrEF secondary to non-ischemic dilated cardiomyopathy diagnosed 2012, ICD implanted 2018
- First acute decompensation Jan 2019 (inotropic dependence)
- Oct 2020 Apr 2021: 3 hospitalizations for acute decompensation

## Referral criteria to specialist palliative care

#### Prognosis-based criteria

- Surprise question
- Frequent hospitalization
- Functional decline
- Medical complications e.g. cardiorenal syndrome, frequent ICD shocks
  - Intolerability of GDMT

#### Need-based criteria

 Complex and refractory symptoms despite optimal medical therapy



- Complex family dynamics and psycho-existential distress
- Decision support uncertainty, discordance
- Terminal care

Grądalski T. Pol Arch Intern Med. 2022 Mar 30;132(3):16223. Chang YK et al. Circ Heart Fail. 2020 Sep;13(9):e006881.

## Chronic care

#### Shared care with primary team

Chronic phase: Out Choice of models depend preference	t <b>patient Clinic</b> ds on disease trajectory, syr	nptom burden, patient
Regular HF clinic,	Concurrent HF and	Regular palliative clinic,
palliative consult PRN	palliative clinic	cardiology consult PRN

#### Optimization of GDMT – ACE-I/ ARNI, BB, MRA, SGLT2-I

- Screen for symptoms for decompensation & disease progression: fluid status, body weight
- Managing CVS risk factors and co-morbidities
- Psychosocial support & ACP discussion

## Chronic care - psychosocial history

- Divorcee with a young daughter of 4 years old who is now under custody of ex wife -> misses daughter but not allowed to visit her
- Has a partner who is working full time and lives with her parents emotionally very attached to partner -> support partner in understanding & anticipatory grief
- Problematic youth, estranged from family in Sarawak ambivalent relationship -> facilitate reconciliation
- Renting a house with another men, on PERKESO allowance RM 900/month
- Initially still works part time at IT store, but eventually stopped when housebound -> strong sense of demoralization & loneliness -> volunteer home visit, online support

## Chronic care - spiritual distress

- Converted to Muslim after first marriage but not practicing loss of identity
- In bargaining phase of grief asked for hastened death during bad days, but expressed hope to have more years with partner
- Grieving the loss of job, marriage, child custody, mobility and relationship - – felt that partner is "better off with another man" as there is no future in their relationship, but unable to let go

### Advance care planning

- Values dignity cannot accept himself requiring assistance for personal hygiene
- Wishes **not to become a burden** to his partner
- Ok with time limited trial of treatment for acute decompensation, not keen for painful shock from ICD
  - Agreed for elective ICD deactivation
- Understood futility of CPR

#### Advance Care Planning (ACP) Form

\*to be completed by certified ACP facilitators only

#### Patient Particulars

Name		
IC No.	What is ACP?	
Date of birth	ACP is a continuous, voluntary process by which patients make known their personal values, life goals, and preference	
Gender	regarding future medical care, to ensure they receive med	
Date of session	care that is consistent with their personhood and preferen	
Department/	in the event of mental incapacity.	
ward	(Adapted from EAPC Delphi Panel Consensus, 201	(7)

#### This plan is based on discussion with: (Please choose one)

- patient ONLY
- patient with next-of-kin/ proxy decision maker

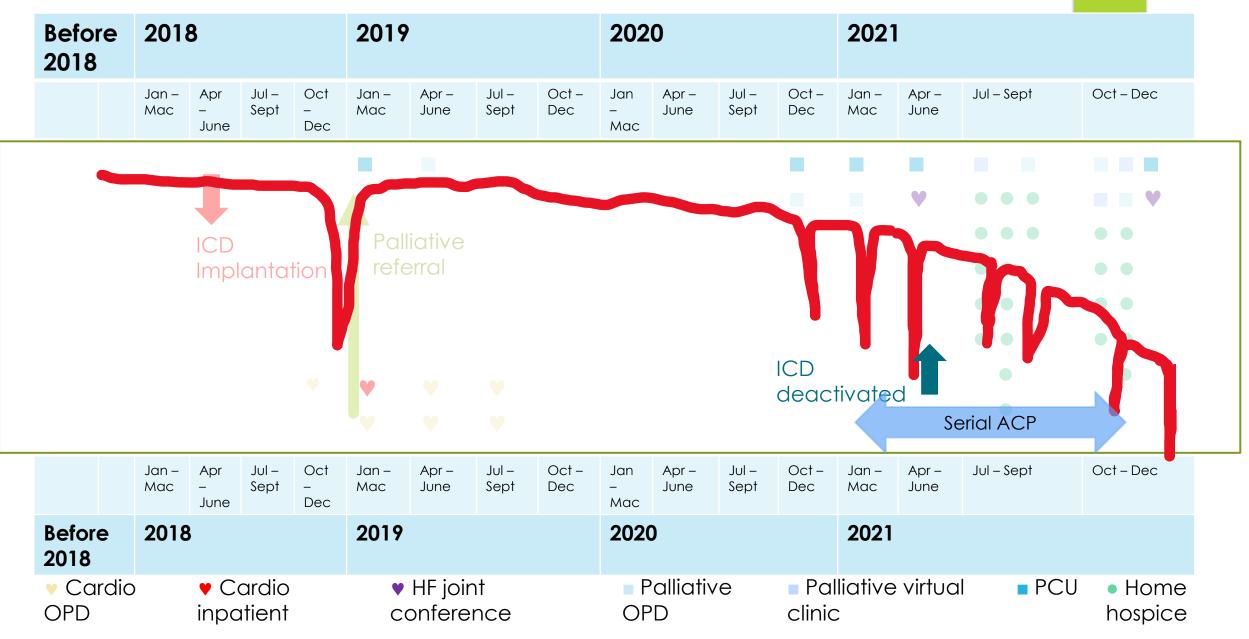
next-of-kin/ proxy decision maker ONLY because the patient lacks mental capacity to make his/her own healthcare decisions due to

(please state reason, e.g brain tumour, advanced dementia)

#### Section A: Statement of Values and Wishes (You may complete all or some of the sections)

Examples	A) What matters most in my life:
	(What does living well mean to me?)
Important persons/ activities/ roles/ values, what gives meaning to life	
	B) What I fear/ worry most about my future: (What does "suffering" mean to me?)
Distressing symptoms; loss of critical abilities (e.g. mobility, speech, swallowing, self care, cognition); loss of role/ connection; burden to family; death	
	C) What are my most important goals if my health situation worsens:
	(How I wish my medical team can help me?)
Life prolongation, physical comfort, independence, quality time with loved ones	
	D) I consider the following unacceptable outcomes of medical treatment
Loss of independence, not being able to recognize people or communicate, high level of care	(From personal or family experience of health care utilization)
	E) What/ who gives me strength during difficult times
Personal beliefs, community, religion, person	

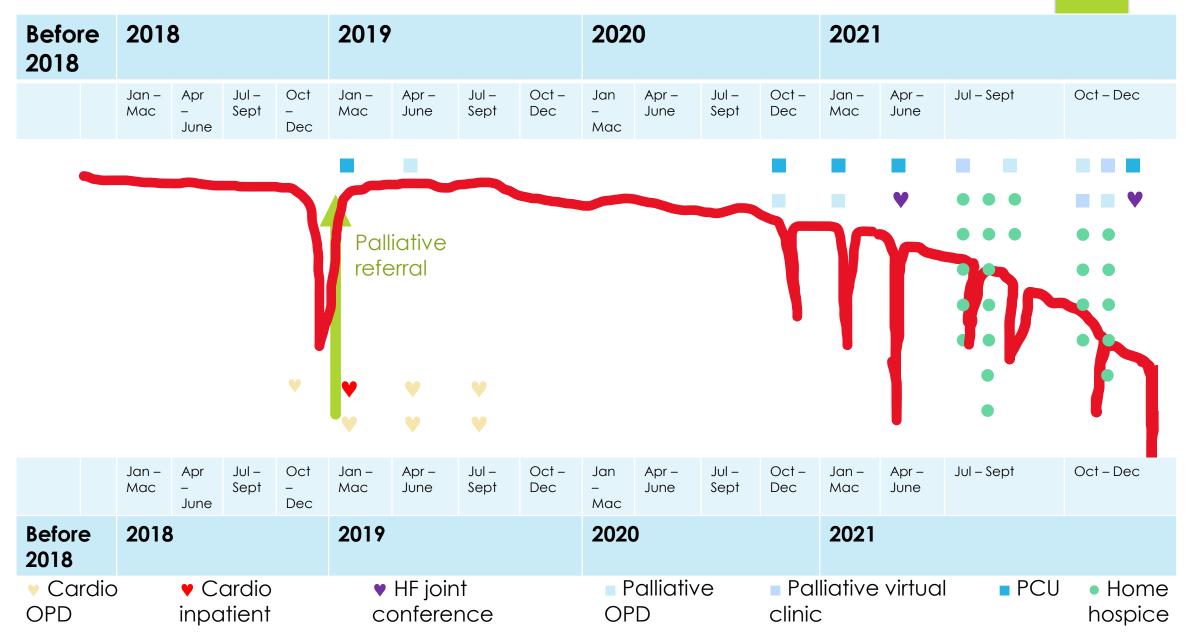
## Disease trajectory



## Crisis care

- Right sided failure symptoms, BW ↑ 8-10kg within 2-3 weeks – refractory to oral frusemide → CSCI frusemide 120-160mg/24h + T metolazone
- Gastritis symptoms, gouty flare
- ► Disposition: COVID era: home care → daily hospice nurse visit to titrate diuretics

## Acute decompensations

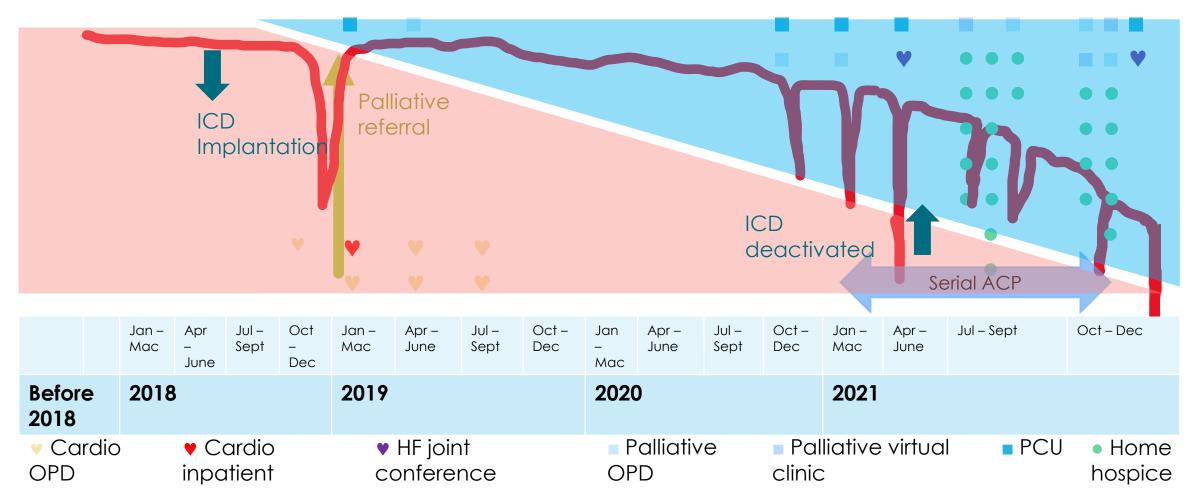


## Terminal care

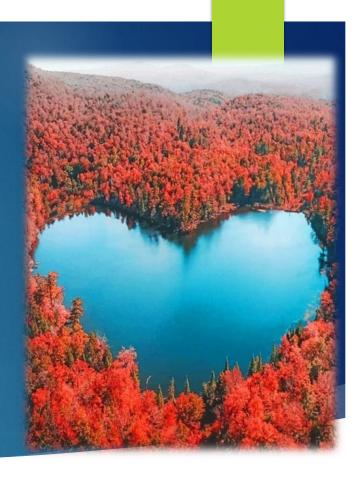
- Gradual functional decline & cardiac cachexia during last 3 months
- Preferred place of dying: hospital
- ► Terminal symptoms: mixed delirium → antipsychotic
- Father flew in from Kuching to visit him during final days

## Integrated model

Before 2018	2018		2019	2019			2020			2021					
	Mac -	or Jul- Sept ne		Jan – Mac	Apr – June	Jul – Sept	Oct – Dec	Jan - Mac	Apr – June	Jul – Sept	Oct – Dec	Jan – Mac	Apr – June	Jul – Sept	Oct – Dec



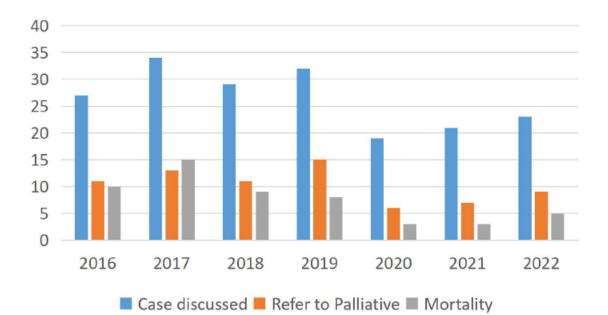
# Local HF palliative care collaboration





## Local collaborative work

- Collaboration started year 2015
- 2016 1<sup>st</sup> edition of local Guideline for Palliative Care of Advanced HF
- Monthly HF conference to discuss cases
- Whatsapp group chat to communicate/ update on cases under shared care





SABAH HEART CENTRE QUEEN ELIZABETH HOSPITAL II DEPARTMENT OF CARDIOLOGY





## Guidelines for Palliative Care of End- stage/ Advanced Heart Failure

Operational policy for symptom control Referral for multidisciplinary care: palliative care & primary care.

Prepared on April 2016

Reviewed on October 2016

Supported by

Consultant Cardiologist,	Honorary Consultant,	
Cardiologist Department, Hospital Queen	Palliative Care Unit,	
Elizabeth II	Hospital Queen Elizabeth	
Dr. Liew Houng Bang	Datuk Dr. Ranjit Mathew Oommen	



(please state i	or day.	s. it is a conaborative acc
Section A: Sta Examples	For ma	this document relevant ny, a good death is a dea ect for the patient's perso
Important pers activities/ roles what gives med	home, preferr	facilitation of meaningful 60-80% died in instituti ed place of death (PP ntion is deemed medical
Distressing sym loss of critical a mobility, speec swallowing, sel cognition); loss of role/cor	The pro home o III prep	al considerations for TD esence of a dedicated car death. <sup>2</sup> Clinical feasibility ared TD can be overwhel erations for TD include th
burden to famil	1	Can the symptoms be managed at home?
Life prolongatic comfort, indepe quality time with la	wad	

What to do when a death occurs at



#### Appendix 6.1

home?

#### Advance Care Planning (ACP) Form

\*to be completed by certified ACP facilitators only

#### Patient Particulars

Department/ ward

This plan is ba patient ON

patient with

next-of-kin

due to

Name	
IC No.	
Date of birth	
Gender	
Date of sessio	



TD HQE PCU Ed 1 (Sept 21)

#### Terminal discharge (TD) Protocol

Developed by Palliative Care Unit, Queen Elizabeth Hospital

#### What is terminal discharge (TD)?

A discharge home when patients are critically or terminally ill and likely to pass away within short hours or days. It is a collaborative decision between patient and/or family and the respective medical team.

ath at home. "A TD is seen as celebration of a patient's autonomy, a mark sonal, familial, cultural, religious values, social values, rituals and norms ul and private time with family".<sup>1</sup> Although many people prefer to die at tions. Thus it is a good practice to proactively discuss about patient's POD) to facilitate early planning and coordination (especially if an lly futile).

regiver and caregiver coping skills are important factors to enable a of TD also needs to be discussed during collaborative decision making. elming for both ward staff and families, leading to complex grief later.<sup>3</sup> he following:

	1	Can the symptoms be	TD may be challenging without community support if patient
		managed at home?	Has high symptom burden requiring continuous
			medication titration
			<ul> <li>Shows fluctuating clinical course</li> </ul>
loved	· • •		· · · · · ·



The Sabah Handbook of Supportive Care in Advanced Heart Failure 2<sup>nd</sup> Edition



#### Jointly developed by

Sabah Heart Centre, Queen Elizabeth Hospital II Palliative Care Unit, Queen Elizabeth Hospital Sabah, Malaysia (February 2024)

### Content

	Topics	Page
1	Introduction	1
2	Overview of guideline-directed medical therapy (GDMT) for heart failure	4
3	Integrating palliative care in advanced heart failure care	18
4	Symptoms management in advanced heart failure	32
5	Pharmacotherapy	42
6	Advance care planning	50
7	Decision making and ethics in advanced heart failure care	58
8	A guide for CIED in people at the end of life	62
9	Psycho-social spiritual care of patients living with advanced heart failure	64
10	Care during terminal phase of heart failure	71
11	Appendixes	76

## Key take home messages

- Need-based referral criteria to specialist palliative care preferred over prognosis-based criteria in small PC service
- Shared-care model PC should be provided alongside guideline directed medical therapy
- SC Continuous interdisciplinary Collaboration/cross-training and Communication

## THANK YOU

ngwanjun@moh.gov.my

