Palliative Care in the Emergency Department

DR SARAH DUNLOP MBCHB FRACP

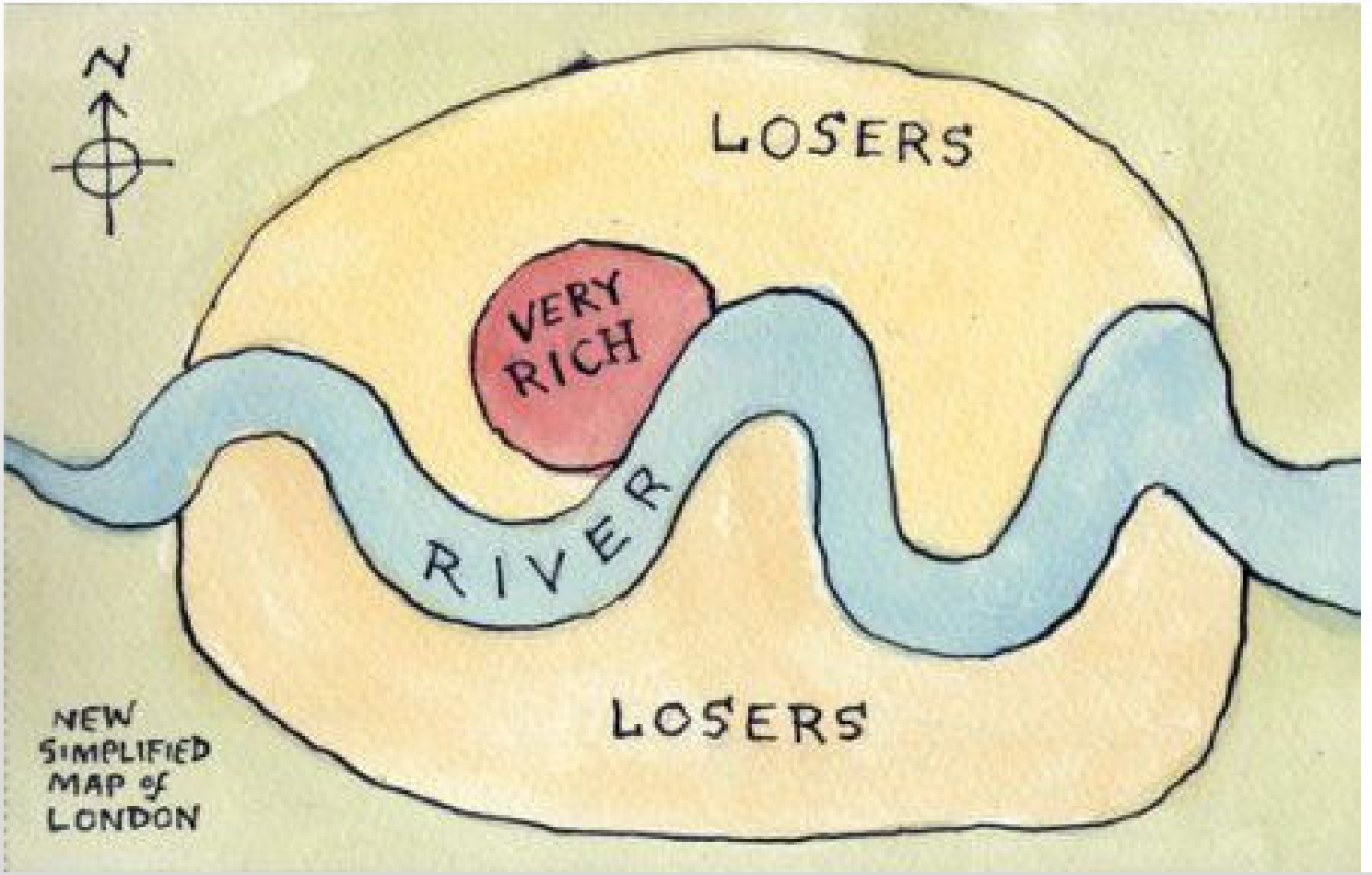
Additional funding- VAD

- $34m given by government to improve rural palliative care services over next 4 years
- 4 Pillars of improved care
- 1st pillar- improved rural access to palliative medicine specialists
- 2nd pillar- Increased equity of access to community based palliative care nursing via increased clinical nursing FTE, social work and aboriginal health workers, equipment, ACAT access and HACC services and development role for palliative care medical officers
- 3rd pillar- Innovation of access e.g. telehealth. Plans for a senior nurse lead telehealth clinic which is patient accessible. 1300 number continues for staff. Command centre approach
- 4th pillar- Improved governance. A Prof Kirsten Auret and palliative care nurse practitioner

Palliative Care Outreach

- Out of hours access to palliative care specialist for doctors:
  - 1300 558655

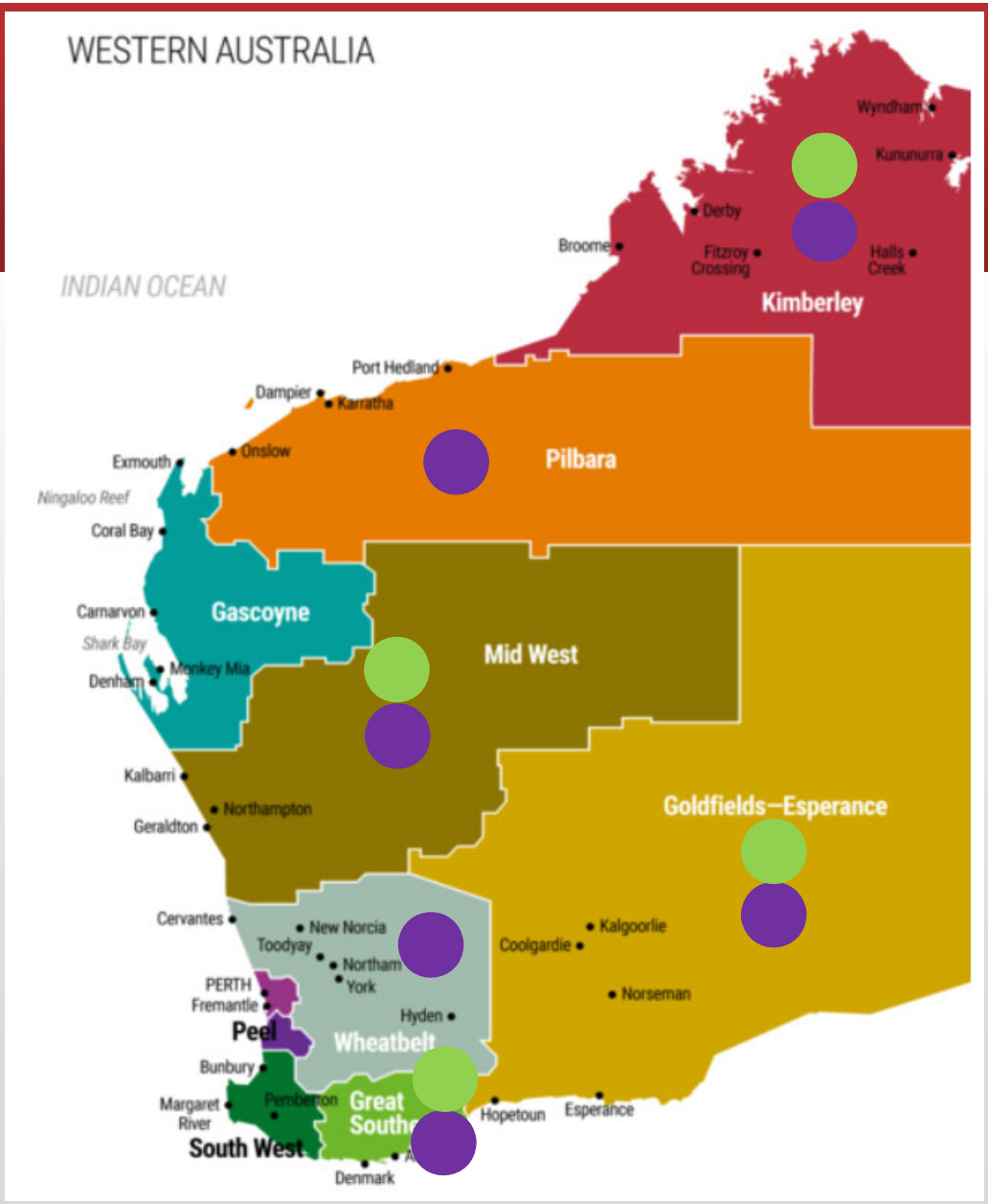
Current Model



New Model

- 0.2 FTE EOIs for palliative care specialists

- Established palliative care specialist clinics,
  Kimberly- Kevin Yuen
  Midwest- Ranbir Dhillon
  Goldfields- Anil Tandon
  Great Southern- Kirsten Auret



Medical officer positions planned for Broome and Kununurra,
Pilbara, Goldfields and Great Southern

Jan Stiberc regional palliative care co-ordinator in Kimberly for 6 months

Pilbara- Outreach service similar to MPaCS

Midwest- Community palliative care nurse team and nurse co-ordinator

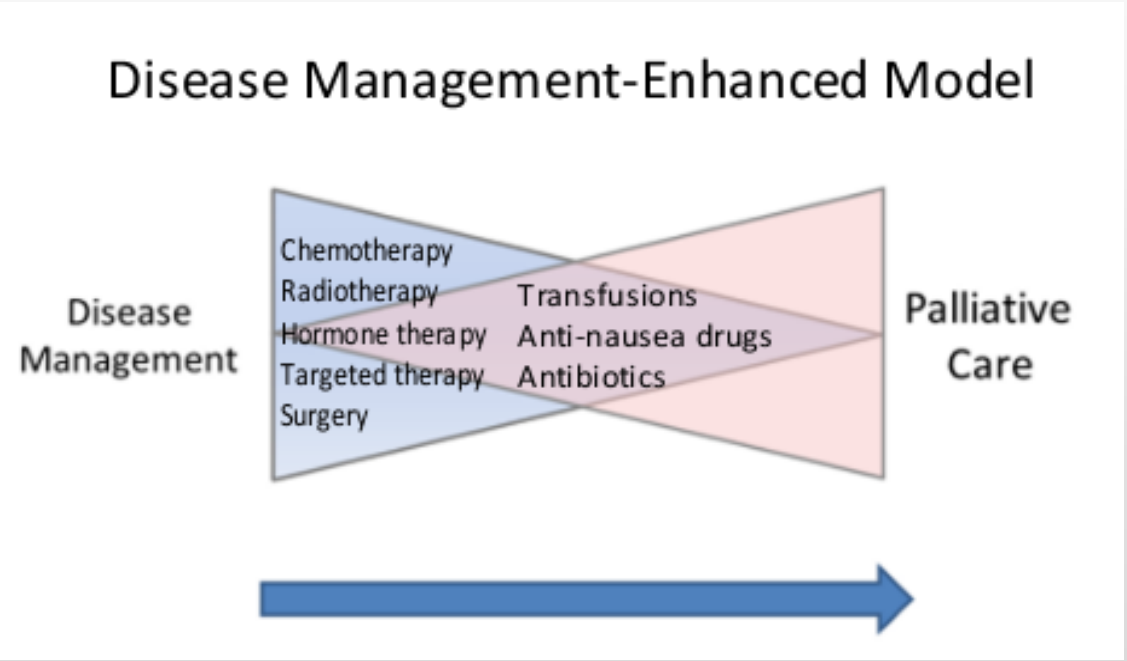
Goldfields- New regional nurse co-ordinator

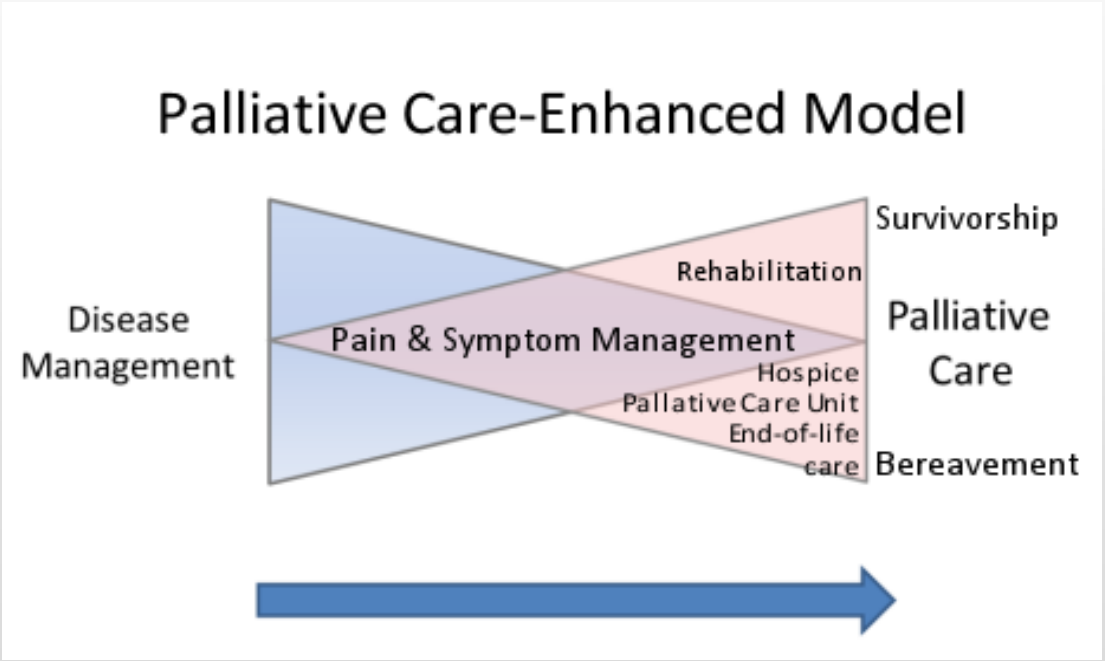
Great Southern- community palliative care nursing but only in Albany

WHO Definition

- “Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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. Palliative care:…
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

Bow-tie Model- Dr Pippa Hawley





Identifying patients with palliative care needs

- https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

the gold standards framework

4th Edition
October 2011

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

RCGP Royal College of General Practitioners

Why is it important to identify people nearing the end of life?

'Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care'

(GSF National Primary Care Snapshot Audit 2010)

About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-co-ordinated, high quality care.
This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such clarifying their particular needs, offering advance care planning discussions prevention of crises admissions and pro-active support to ensure they 'live well until they die'.

Predicting needs rather than exact prognostication. This is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

Definition of End of Life Care
General Medical Council, UK 2010

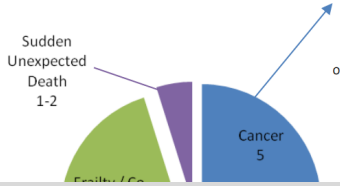
People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

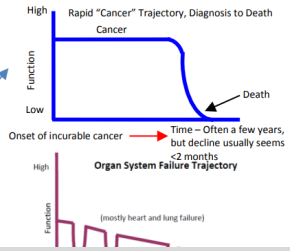
- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Three triggers that suggest that patients are nearing the end of life are:

1. **The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?**
2. **General indicators of decline - deterioration, increasing need or choice for no further active care.**
3. **Specific clinical indicators related to certain conditions.**

Average GP's workload – average 20 deaths/GP/year approx. proportions



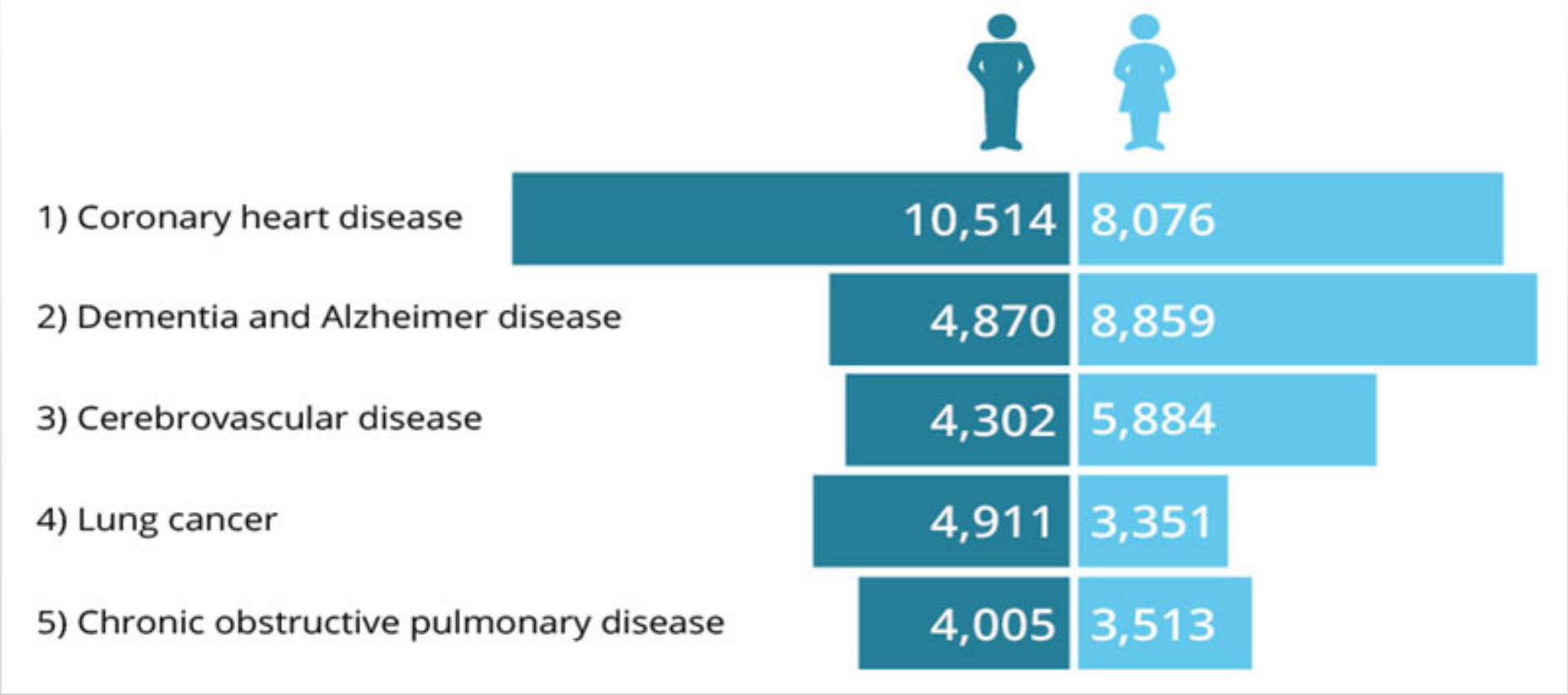


Typical Case Histories

1) Mrs A - A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline

2) Mr B – An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and

What do people die of?



Gold Standards Framework

- Barwon Health, Victoria used GSF framework to identify patients with life limiting conditions, 27.3% of their 626 in-patients reviewed met at least one GSF criteria.
- Limitations of treatment, finding this documented in just 30.5%.
- Patients meeting GSF criteria were also followed up for one, three- and five- years, showing 9.9% mortality at one year, 50.3% at three years and 70.2% at five years.
- Conclusion: GSF criteria assist in identifying patients with palliative care needs and a limited prognosis, however the rates of treatment limitation documentation suggested a large proportion of these patients are not recognised and, as such, may have unmet care needs.

GSF Framework

Dementia – no consistent meaningful conversation or needs assistance with ADL

General neurological diseases – progressive deterioration on max therapy; severe symptoms; Aspiration / sepsis / dyspnoea; Speech problems; Post CVA: minimal conscious state or dense hemiparesis

Congestive cardiac failure - NYHA stage III / IV or recent deterioration; on max therapy; >75yrs old

Renal failure - stage 5 CKD; long term dialysis or not for dialysis; eGFR <15mL/min; severe symptoms

Frailty – Clinical Frailty Score 6-9 (see below)

6 Moderately Frail People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail Completely dependent, approaching the end of life. Typically, they cannot recover even from a minor illness.

9 Terminally Ill Approaching the end of life. This category applies to people with a life expectancy < 6 months, who are not otherwise evidently frail.

COPD – on max therapy; disease severe (e.g. FEV1

Cancer – metastatic or not amenable to treatment; ECOG >2; persistent / severe symptoms

Advanced Care Planning

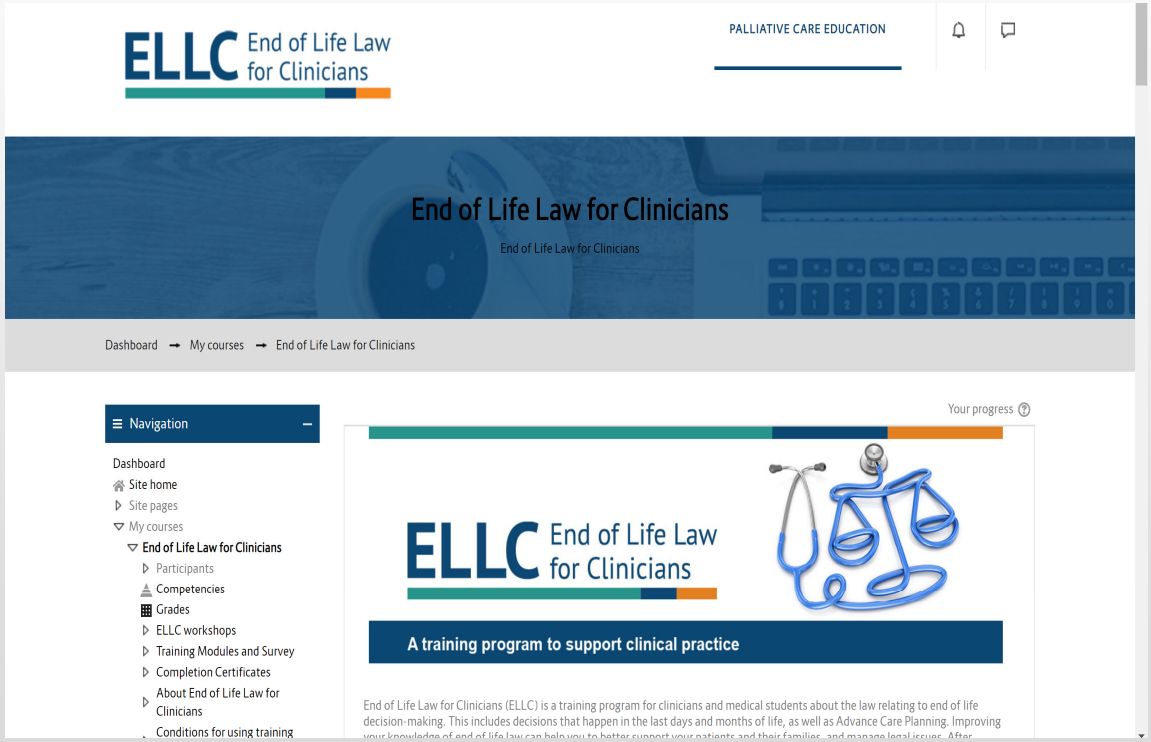
Type of ACP

- Advanced Care Plan
- Advanced Health Directive
- Enduring Power of Guardianship
- Enduring Power of Attorney
- Will

Resources

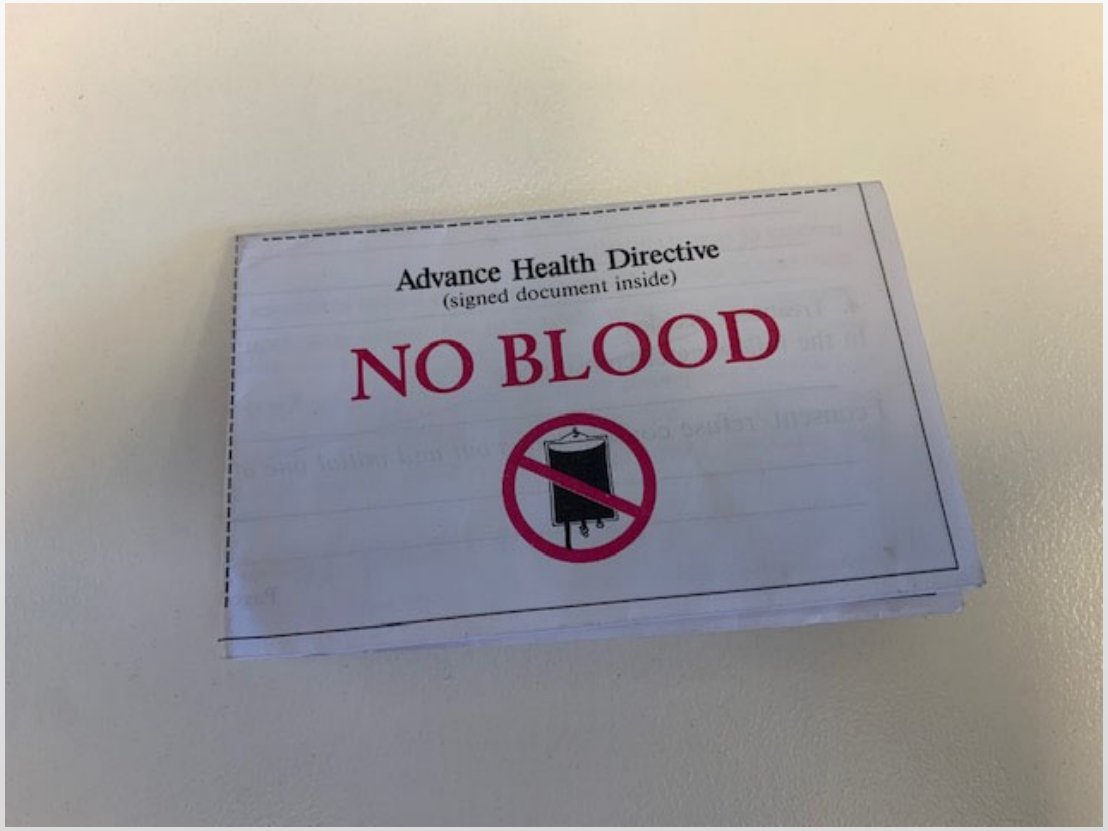
- http://www.health.wa.gov.au/docreg/education/population/HP11536_advance_health_directive_form.pdf
- https://www.publicadvocate.wa.gov.au/_files/epg_kit.pdf
- https://dyingtotalk.org.au/

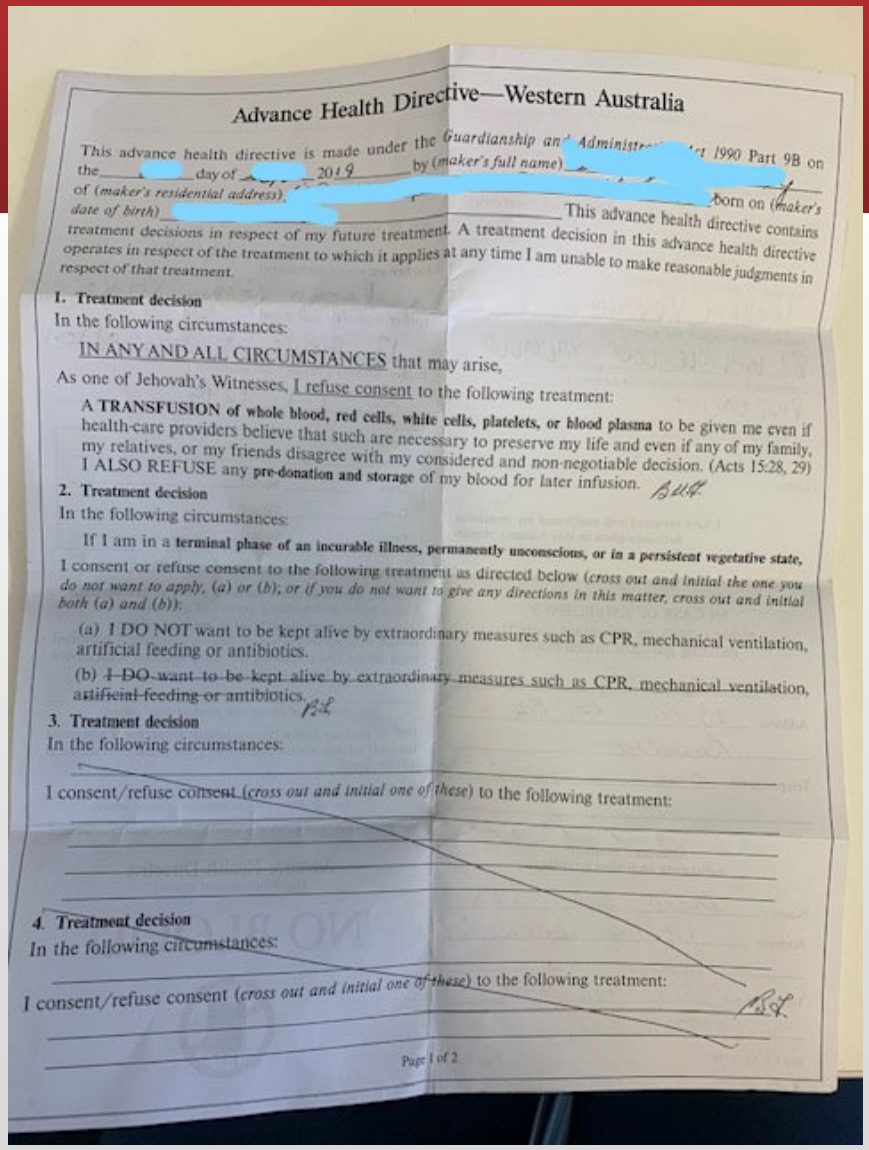
Resources



- https://palliativecareeducation.com.au/course/view.php?id=19

Common law AHD





Advance Health Directive—Western Australia

This advance health directive is made under the *Guardianship and Administration Act 1990* Part 9B on the [redacted] day of [redacted] 2019 by (*maker's full name*) [redacted] of (*maker's residential address*) [redacted] born on (*maker's date of birth*) [redacted]. This advance health directive contains treatment decisions in respect of my future treatment. A treatment decision in this advance health directive operates in respect of the treatment to which it applies at any time I am unable to make reasonable judgments in respect of that treatment.

1. Treatment decision

In the following circumstances:

IN ANY AND ALL CIRCUMSTANCES that may arise,

As one of Jehovah's Witnesses, I refuse consent to the following treatment:

A TRANSFUSION of whole blood, red cells, white cells, platelets, or blood plasma to be given me even if health-care providers believe that such are necessary to preserve my life and even if any of my family, my relatives, or my friends disagree with my considered and non-negotiable decision. (Acts 15:28, 29)
I ALSO REFUSE any **pre-donation and storage** of my blood for later infusion. BH

2. Treatment decision

In the following circumstances:

If I am in a **terminal phase of an incurable illness, permanently unconscious, or in a persistent vegetative state,**

I consent or refuse consent to the following treatment as directed below (*cross out and initial the one you do not want to apply, (a) or (b); or if you do not want to give any directions in this matter, cross out and initial both (a) and (b)*):

(a) I DO NOT want to be kept alive by extraordinary measures such as CPR, mechanical ventilation, artificial feeding or antibiotics.

(b) ~~I DO want to be kept alive by extraordinary measures such as CPR, mechanical ventilation, artificial feeding or antibiotics.~~ BH

3. Treatment decision

In the following circumstances:

I consent/refuse consent (*cross out and initial one of these*) to the following treatment:

4. Treatment decision

In the following circumstances:

I consent/refuse consent (*cross out and initial one of these*) to the following treatment: BH

Page 1 of 2

Why is it important? Concepts

- **Shared-decision making**, where doctor and patient mutually decide on a treatment plan, has grown out of the practice of informed consent and is increasingly becoming the standard of care in formation of health policy.
- **Patient-centred care**, a concept that aims to encompass patients' values, beliefs and autonomy as well as open communication. The phrase "nothing about me without me" typifies patient-centred care. A patient-centred approach to care is an expectation of the Australian Safety and Quality Framework for Health Care and underpins the National Safety and Quality Health Service Standard 2: Partnering with Consumers.
- **Paternalism** is the antithesis of patient-centred care, where "doctor knows best". Paternalism has been criticised for failing to address patient autonomy and respect the right to self-determination.
- **Futility** is defined as a treatment where physician experience and reasoning suggest that success is improbable.
  - The survival to discharge rate in hospital patients undergoing CPR is in the region of 15-18%, however, this falls to 6-8% in patients with hepatic insufficiency, haematological malignancy, metastatic cancer or sepsis and 2.3% in patients with advanced cancer and poor functional capacity.
  - What constitutes a futile treatment is subjective. Studies have sought to address this subjectivity by using qualitative outcome data to determine futility, though have been criticised for lack of statistical confidence due to small study sizes and lack of explicit criteria of futility.
  - Additionally, there is no legally agreed definition of futility and so withholding a treatment or procedure, on the grounds that it is considered futile, is open to legal contest. Consequently, there are no validated tools available for determining futility of CPR.

Why is it important

- ‘Early discussions about goals-of-care are associated with better quality of life, reduced use of nonbeneficial medical care near death, enhanced goal-consistent care, positive family outcomes, and reduced costs’
  - *Bernacki RE, Block SD, American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med 2014; 174: 1994–2003.*

Goals of Patient Care

- Influenced by the POLST, Goals of Patient Care (GOPC) was devised in Australia to address limitations of DNAR forms and improve patient centred care.
- Can be considered in two parts, first a goal setting conversation between medical professional and patient and or their 'person responsible', usually a family member or friend, and second, documentation of the decision making on a specially designed form. GOPC has been endorsed by the Department of Health Western Australia and is currently being implemented in urban and rural, public and private hospitals throughout the state.

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Murdoch Hospital

GOALS OF PATIENT CARE

U.R. Number .....
Surname .....
Given Names .....
Date of Birth ..../..../.... Sex .....
Use Label If Available or BLOCK LETTERS

MUH003

THIS SECTION TO BE COMPLETED BY A CLINICIAN

SECTION 1 BASELINE INFORMATION

Primary illness: _____
Significant co-morbidities: _____
In the event that the patient is unable to speak for themselves, who would they wish to speak for them? This is known as the **'Person responsible'**
Name: _____ Relationship: _____

* Advance Health Directive (AHD) ☐ Yes ☐ No
* Advance Care Plan (ACP) ☐ Yes ☐ No
* Enduring Power of Guardianship (EPG) ☐ Yes ☐ No
  EPG contact name: _____ Phone: _____
* Instructions to donate tissues/organs ☐ Not applicable ☐ Yes ☐ No

Clinician's Name
(please print): _____ Designation: _____
Date: ____/____/____ Time: _____ Signature: _____

THIS SECTION TO BE COMPLETED BY A REGISTRAR OR CONSULTANT

SECTION 2 GOAL OF CARE

Please tick one only and complete section 3 over the page to be valid. In discussion with the clinician, patient, person responsible and/or family/carer(s), please select the most medically appropriate agreed goal of patient care that will apply in the event of clinical deterioration.

☐ **All life sustaining treatment**

* For Rapid Response (MER/MET Calls)
* For CPR
* For ICU

☐ **Life extending intensive treatment – with treatment ceiling**

* Not for CPR

* For Rapid Response ☐ Yes ☐ No
* For ventilatory support, including intubation ☐ Yes ☐ No
* Specify maximum level of support .....
* For ICU/HDU admission
* *Additional comments (e.g. use of inotropes, NIV, dialysis)* .....

☐ **Active ward based treatment – with symptom and comfort care**

* Not for CPR
* Not for ICU
* Not for intubation

* For Rapid Response ☐ Yes ☐ No
* For ventilatory support (intent is symptom control) ☐ Yes ☐ No
* Specify maximum level of support .....
* *Additional comments (e.g. use of antibiotics, IV fluids)* .....

☐ **Optimal comfort treatment – including care of the dying person**

* Not for Rapid Response
* Not for CPR
* Not for intubation
* Not for ICU

* For ongoing review to identify transition to the terminal phase
* Ensure timely commencement of the *Care Plan for the Dying Person*

All patients can have Rapid Response based on 'Worried Criteria' or to 'Summon Clinical Review'.

NO WRITING IN MARGINS

GOALS OF PATIENT CARE

HR H003

SCHMHFMRH003 04/17

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GOALS OF PATIENT CARE

U.R. Number .....
Surname .....
Given Names .....
Date of Birth ..../..../.... Sex .....
Use Label If Available or BLOCK LETTERS

THIS SECTION TO BE COMPLETED BY A REGISTRAR OR CONSULTANT

SECTION 3 SUMMARY OF DISCUSSION(S)

Goals of Patient Care has been discussed with: Date: ____/____/____ Time: _____
Patient ☐ Yes ☐ No Person Responsible ☐ Yes ☐ No Family/carer(s) ☐ Yes ☐ No
Name(s) of those present at this discussion: _____

Is the patient able to fully participate in this discussion? ☐ Yes ☐ No
Comments: _____

What is the patient's likely response to CPR and critical intervention? _____

Patient preferences (needs, values and wishes): _____

Decision rationale for agreed **Goals of Patient Care** (please tick one only):
☐ Medically-driven decision ☐ Patient wishes ☐ Shared decision-making
Other information:

Doctor's name (please print): _____ Designation: _____
Signature: _____ Date: ____/____/____ Time: _____
Consultant review completed: Name (please print): _____
Signature: _____ Date: ____/____/____ Time: _____

ENDORSEMENT BY A CONSULTANT

SECTION 4 EXTENDED USE

Consultant endorsement for extended use beyond this admission for 12 months until
This includes patient transportation to another facility or home following the current admission.
Consultant's comments: _____

Consultant's name (please print): _____ Signature: _____
Specialty: _____ Date: ____/____/____ Time: _____

IMPORTANT: Please ensure this form is filed in the alert section of the patient's current medical record.

NO WRITING IN MARGINS

Murdoch study

- 44 patients of 344 discharged from TF during the audit period, (13%) had a GOPC form completed. Optimal comfort care was chosen as the goal of care in the majority of cases (30/44, 68%). The summary of discussion section was complete in 22 (50%) and partially complete in 21 (48%).
- 34 (77%) patients with GOPC forms met futility criteria for CPR, predominantly due to advanced malignancy refractory to treatment. All 44 patients had documented goals consistent with a not for CPR decision.

Subiaco study

- GOC patients had a higher uptake of ACP documentation (346 vs 150 ACP forms per 1000 admissions) and a higher proportion of ACP forms completed within the first 48 h of admission (58 vs 39%) but a higher incidence of altering the initial ACP level of care.
- GOC documentation was often incomplete, with most subsections left blank between 74 and 87% of occasions.
- Conclusion: Despite an increased uptake of the GOC form, overall use remained low, written completion was poor, and most quantitative outcomes remained statistically unchanged. Further research is required before a wider GOC implementation can be supported in Australia's healthcare systems.

Talking about Death and Dying

Barriers to talking about death and dying

- Still taboo
- Facing our own mortality as well as that of loved ones
- A sense that we are not just another animal
- Aging population and more death and dying in hospital (70% Australia wide)
- Death less visible
- Euphemistic language
- Communication techniques
  - Ask-tell-ask
  - NURSE

Responding to emotional cues

N: Name it: "...it sounds like you've been worried about what's going on..."

U: Understand the core message: "...if I understand you correctly, you are worried about what to say to your family and how they will react..."

R: Respect /Reassurance at the right time: "...I'm really impressed that you've continued to be independent ...".

S: Support: "... would you like me to talk to your family about this..."

E: Explore: "... I notice that you're upset, can you tell me what you're thinking?"

❖Back, Arnold, Tulsky – Mastering Communication with Seriously Ill Patients

Video

Limitations/Discussion points for Emergency

- Assumption that every patient attending hospital wants to discuss treatment goals/advanced care planning
- Is it even useful to have the discussion in ED
- Do we make it mandatory for all patients or only for those with life limiting diagnoses
- Takes more time to have these discussions than NFR tick box forms
- Should there be a difference in approach in public and private hospitals
- Assuming these forms are useful, how can we improve uptake

Summary

- Palliative care is for life threatening illnesses and not restricted to dying/last few days or weeks of life
- Bow-tie model incorporates transition between life prolonging interventions as well as improving quality of life
- We can identify patients with a palliative care need by using the Gold Standards Framework
- Advanced care planning options
- Goals of patient care importance, evidence and how to conduct GOPC discussion