The role of specialist palliative medicine in advanced liver disease: lessons from an established service

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Outline

I keep six honest serving-men
(They taught me all I knew);
Their names are What and Why
and When
And How and Where and Who.

Rudyard Kipling

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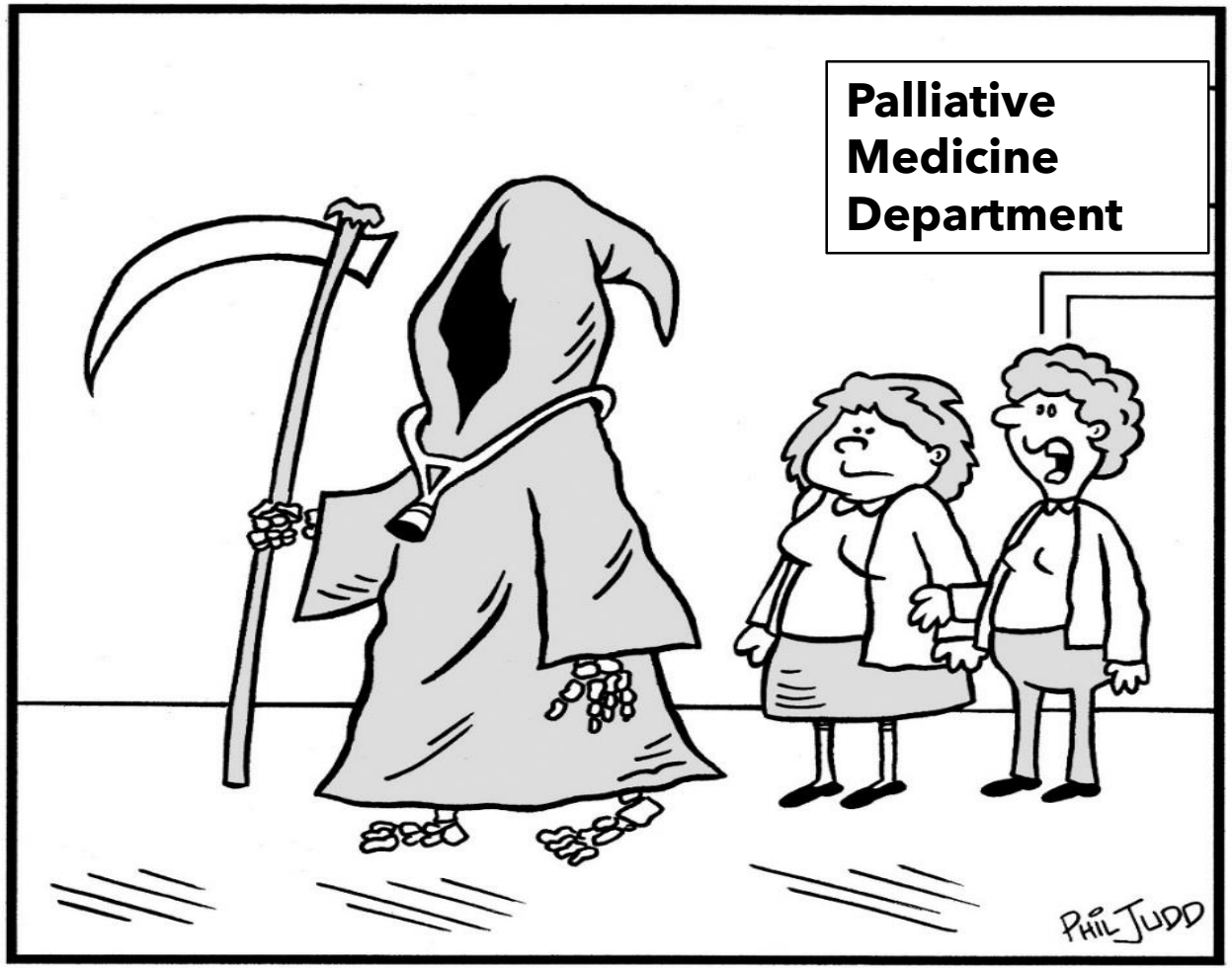
What is Supportive Care?

- A comprehensive, person-centred approach, focusing on the aspects of care most important to patients and significant others
- A team approach
- Is relevant throughout the continuum of the liver disease experience from diagnosis, through treatment(s), to post-transplant care and also encompasses survivorship as well as end-of-life care

It's how you sell it



Here's our new Palliative Medicine physician….

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Why?

Effectiveness

- Data showing positive impact of supportive care interventions in patients with advanced heart, lung, renal, and haematological diseases across multiple domains
  - Symptom control (e.g. fatigue, pain)
  - Psychological (e.g. depression, anxiety and mood)
  - Social
  - Spiritual
  - EoLC
  - ACP
  - Caregivers' quality of life
  - Cost-effectiveness of care

Author, year	Setting and population	Intervention	Comparator arm (study design)	Outcomes	Results	Palliative care domain addressed
Bajaj et al. 2017[61]	Outpatients with cirrhosis (n = 20) and depressive symptoms (Beck Depression Inventory >14) and their caregivers	Mindfulness-based stress reduction intervention with four weekly hour-long group sessions and audio-guided home practice	None (pre-/post-single-arm study)	Depressive symptoms, sleep, anxiety, encephalopathy, HRQoL, perceived caregiver burden, and caregiver depression, sleep quality	Significant reduction in depressive symptoms, improvement in sleep and overall HRQoL but not in anxiety or encephalopathy rates in patients; improved caregiver burden, depression, sleep	2, 3, CG
Ufere et al. 2021[86]	Transplant-ineligible inpatients and outpatients with advanced LD (n = 50)	Five-minute ACP video decision-support tool depicting three levels of goals of care: life-prolonging care (CPR and intubation); life-limiting care (hospitalization, no CPR/intubation); and comfort care	Control group listened to verbal narrative of the three levels of goals of care (RCT).	Feasibility; acceptability, knowledge of EoLC options, postintervention goals of care and CPR/intubation preferences	High enrollment rate; video highly acceptable to patients in video arm, who had higher EoLC knowledge scores and were less likely to prefer to receive CPR	1, 7

Note: Domain 1: Structures and Processes of Care. Domain 2: Physical Aspects of Care. Domain 3: Psychological and Psychiatric Aspects of Care. Domain 4: Social Aspects of Care. Domain 5: Spiritual, Religious, and Existential Aspects of Care. Domain 6: Cultural Aspects of Care. Domain 7: Care of the Patient Nearing the End of Life. Domain 8: Ethical and Legal Aspects of Care. CG: Caregiver Support (included under Clinical Implications in The National Consensus Project for Quality Palliative Care).

Abbreviations: APRN, advanced practice registered nurse; CPR, cardiopulmonary resuscitation; ICU, intensive care unit; PC, palliative care.

AASLD Practice Guidance: Palliative care and symptom-based management in decompensated cirrhosis

Shari S. Rogal[1,2] | Lissi Hansen[3] | Arpan Patel[4,5] | Nneka N. Ufere[6] | Manisha Verma[7] | Christopher D. Woodrell[8,9] | Fasiha Kanwal[10,11]

Author, year	Setting and population	Intervention	Comparator arm (study design)	Outcomes	Results	Palliative care domain addressed
Baumann et al. 2015[54]	Outpatients being evaluated for LT	One-time nurse practitioner and board-certified PC physician performing comprehensive physical and psychological symptom assessment; ACP	None (pre-/post-single-arm quality improvement study)	Physical and psychological symptom burden; ACP	Improved pruritus, fatigue, well-being, appetite; decreased depression; increased ACP	, 2, 3, 8
Kimbell et al. 2018[57]	Outpatients with DC	Nurse specialists assisted in care coordination, illness education, financial and psychosocial support, and ACP and provided a summary of this discussion to the patient's primary care physician and hepatologist	None (single-arm feasibility study)	HRQoL; perceived care coordination, coping, anticipatory planning (qualitative)	Improved HRQoL and secondary outcomes	, 4, 8
Lamba et al. 2012[55]	Surgical ICU admission for patients pre-LT and post-LT	Two-part communication-based intervention involving palliative care team (APRN, family support counseling, chaplain): initial physical and psychological symptom assessment with ACP, followed by interdisciplinary family meeting within 72 h	None (prestudy/poststudy design)	Length of stay in ICU, mortality, goals of care consensus (qualitative)	Decreased ICU length of stay, better consensus in goals of care, lower receipt of life-sustaining treatment, and earlier provision of comfort-focused care; no difference in mortality	, 8
Shinall et al. 2019[56]	Inpatients with DC	Board-certified PC physician or nurse practitioner, during which patients were provided with an informational packet containing education on LD and PC	Control group of inpatients with DC receiving usual care (RCT)	Time until first readmission; days alive outside the hospital, referral to hospice care, death, readmissions, patient quality of life, depression, anxiety, and quality of EoLC over 6 months	Increased time to readmission; no change in other outcomes; poor enrollment	, 3
Bailey et al. 2017[60]	Outpatient dyads of patients awaiting LT and their caregivers	Six-week telephonic intervention of a self-management intervention (n = 56 dyads) vs. LD education (n = 59 dyads); self-management intervention included coping skills and uncertainty management strategies.	Attention control group of patient-caregiver dyads receiving LD education alone (RCT)	Illness uncertainty, uncertainty management, depression, anxiety, self-efficacy, and quality of life at 10–12 weeks	No significant differences between groups and in most measures pre- to post-, though there was a numerical improvement in self-efficacy in both patients and caregivers.	, 4, CG

Costs

Palliative Care and Health Care Utilization for Patients With End-Stage Liver Disease at the End of Life

Patel et al. *Clin Gastroenterol Hepatol* 2017

"Palliative care consultation during terminal hospitalizations is associated **with lower costs and procedure burden**".

Early palliative care referral in patients with end stage liver disease is associated with **reduced resource utilisation**.

Barnes A, *J Gastroenterol Hepatol* 2019.

Cirrhosis with ascites in the last year of life: a nationwide analysis of factors shaping costs, health-care use, and place of death in England

Hudson et al. *Lancet Gastroenterol Hepatol* 2018

Day-case (vs unplanned care) large-volume paracentesis services in the last year of life assoc with

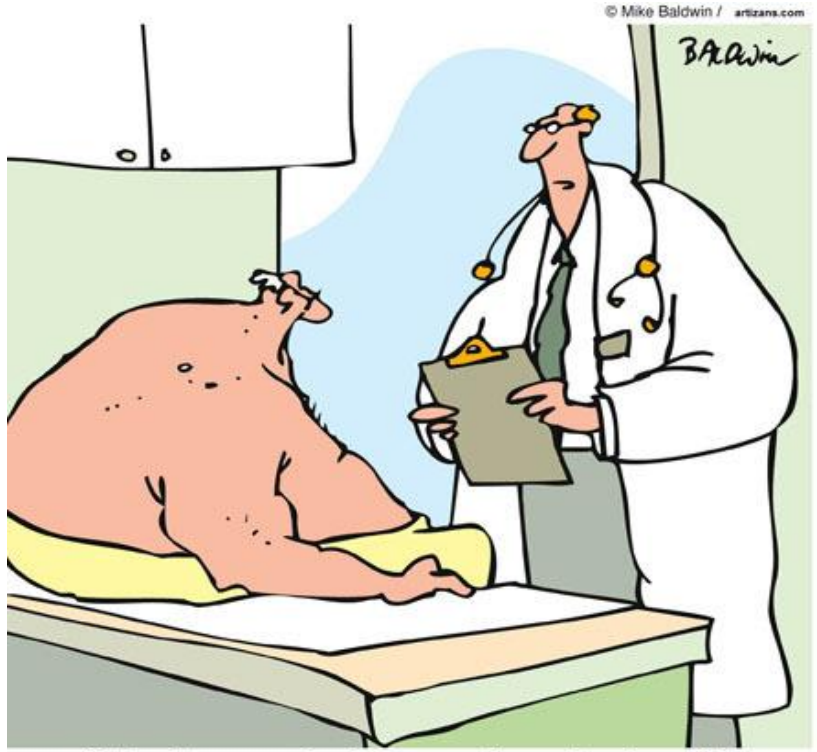
- **lower costs**
- **reduced pressure on acute hospital services**
- lower probability of dying in hospital
- partic HCC

Why?

-Improved patient/carer experience and QOL

-Decrease in healthcare costs

-Decrease use of aggressive interventions in last days/weeks of life



"You've got six months, but with aggressive treatment we can help make that seem much longer."

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When?

Use the following to identify patients with advanced liver disease who may benefit from supportive care.

The "surprise" question:

Would you be surprised if this person died in the next 12 months?

If the answer is 'no' then please consider how to use your knowledge of the patient's illness and prognosis to facilitate advance care planning and coordination of care.

Poor prognosis Bristol criteria[1]
Child Pugh Grade C
>2 liver related admissions last 6/12
Ongoing alcohol use (ARLD)
Unsuitable for transplant work up
WHO performance 3-4
TWO or more

Supportive and Palliative Care Indicators Tool (SPICT™)[2] for liver disease

Cirrhosis + ≥1 complications in the past year:

- Diuretic resistant ascites
- Hepatic encephalopathy
- Hepatorenal syndrome
- Bacterial peritonitis
- Recurrent variceal bleeds
- Liver transplant not possible

Gold Standards Framework Proactive Identification Guidance[3]

Hepatocellular carcinoma.
Liver transplant contra-indicated.
Advanced cirrhosis with complications including:

- Refractory ascites
- Encephalopathy
- Hepatorenal syndrome

Other adverse factors including malnutrition, severe comorbidities, bacterial infection, current bleeds, raised INR, hyponatraemia.

Liver transplant: patients that are listed for transplant and also those deemed not suitable for transplant may need support to address a symptom burden, to manage uncertainty or to talk about future care.

Social circumstances, including family/spousal relationships, social isolation & housing problems, will impact on a patient's well-being, their use of or access to healthcare and also prognosis.

Co-morbidities can have a negative impact on

- well-being
- resilience following an acute episode of decompensation or intercurrent illness
- prognosis

iPOS[4] – an holistic needs assessment may identify patient &/or family symptoms or concerns that need addressing.

If any of the following apply

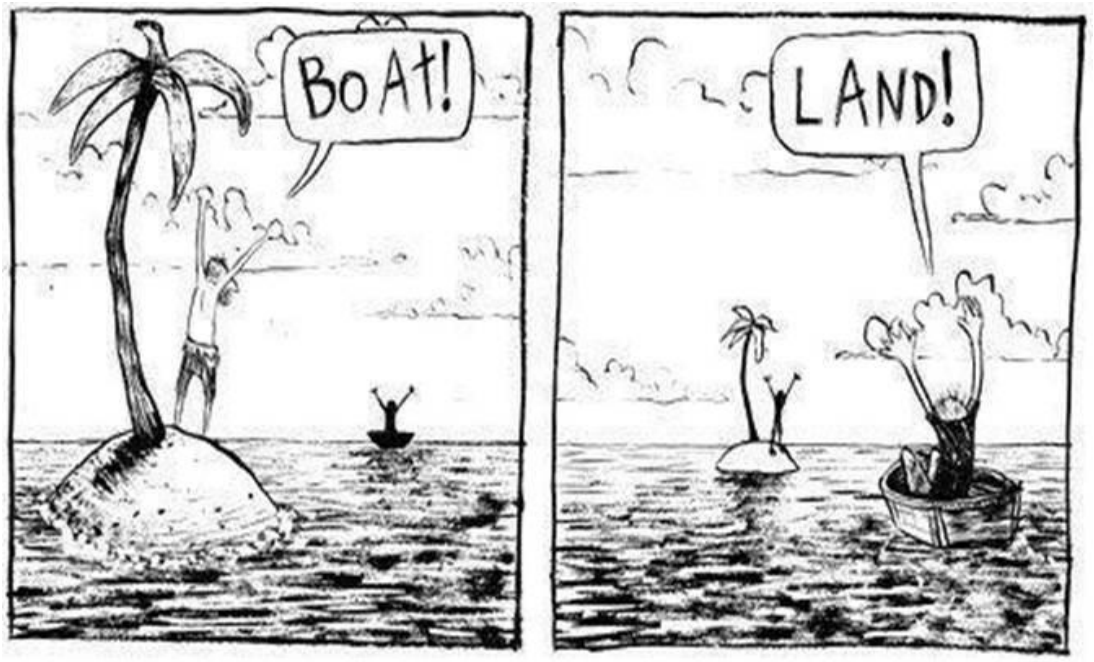
- **your answer to the surprise question is 'no'**
- **you recognise that a patient has a poor prognosis**
- **the patient has unmet symptom-control or planning needs**

then please follow the flow diagram for supportive and palliative care in advanced liver disease.

When?

Prognostication and referral criteria

Unmet needs



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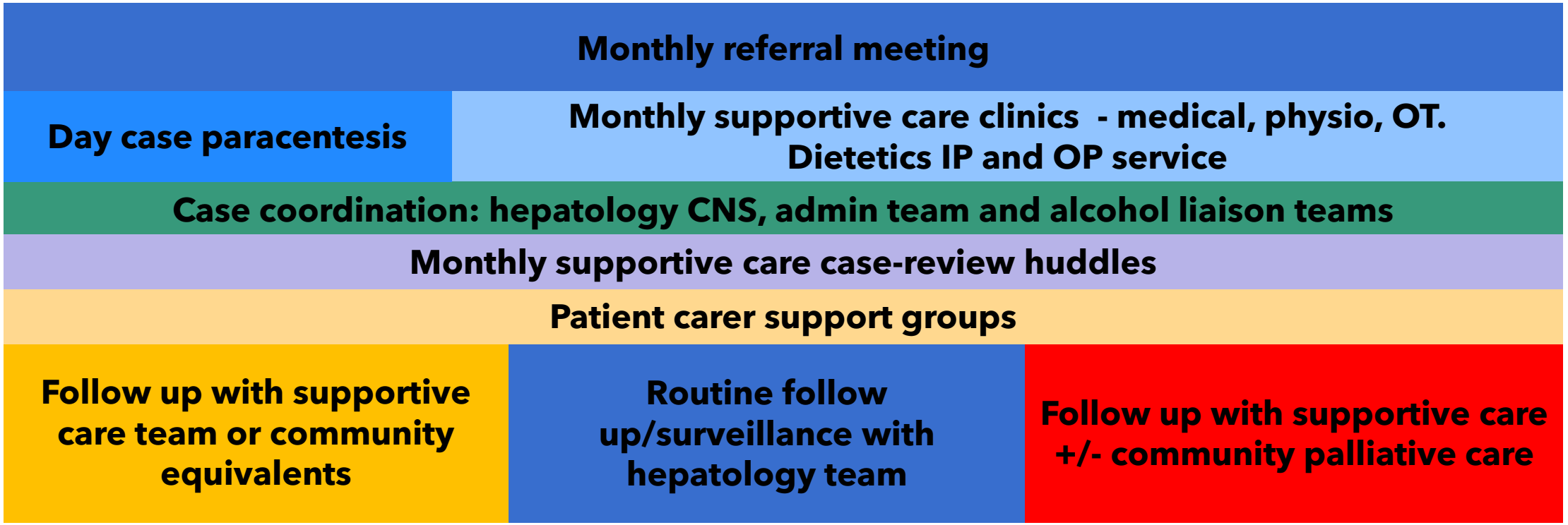
How?

Hepatologese....

Supportanglais....

Now…



if only…

- Inpatient/in-reach capacity
- More time for evaluation and education

How? ACP & contingency planning

Predictable emergencies

- Hepatic encephalopathy
- Infections/SBP
- GI bleeding
- Ascites

- Care planning for hospital and community

Ceilings of treatment

- Discussed at the referral MDT to reach consensus
- Discussed with patient and documented

- TEP/RESPECT etc

Sharing consensus

- Local system to ensure visibility, accessibility and version control and review of these plans

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Where?

Place.....

agility and flexibility of the service

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Who?

- Hepatology team
- Gastroenterology ward
- Admin
- Dietetics
- OT
- Physio
- Supportive care doctor
- Hospital and community palliative care HCPs
- Alcohol liaison
- Substance misuse and addiction services
- ITU
- A&E
- Homelessness/Roughsleeping services
- Patients/carers themselves
- Chaplaincy
- Day case unit
- GP, primary care teams

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Thank you