

# Rethinking Palliative Care in Non-Malignant Disease: Time for new models of care

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# Advanced COPD research survey

To explore physicians' attitudes to:

- prescribing medications for breathlessness
- Use of oxygen,
- Advance care planning
- Role of specialist palliative care services

Palliative Medicine specialists and registrars

<https://www.surveymonkey.com/r/copdmanagement>

Paper copies of the survey are available from and can be returned to boxes at the **auditorium exits** or to the **“Centre for Palliative Care” booth** in the trade foyer

With a lolly for every participant – THANK YOU!

# 2012 - 147,098 deaths in Australia

- **2 in 3** deaths occurred among people aged 75 or over.
- **3 in 10** deaths were due to cardiovascular disease
- **4 in 5** deaths involved more than one disease.

# What will it be like for us?

- Chronic illness
- Period of disability / care
- Multiple diagnoses
- Commonly isolated.
- Likely die in hospital



# Different ways of dying



# What do we think is important at End of Life?

- Pain & symptom management
- Preparation for death
- Sense of completion
- Decisions about treatment preferences
- Being treated as a whole person



*Steinhauser 2000*

# Palliative care for people with non-malignant disease

- The case for PC
- Engagement with palliative care
- Challenges
- Characteristics of successful approaches
- New models of care

**Palliative Care**  
*everyone's business*

# The case: palliative care in severe Non-Malignant Disease (NMD)

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## The example of COPD





# The case: 'severe' COPD associated with poor prognosis

- 304 patients with 3+ exacerbations survival 30% at 5 yrs, cf 80% those without exacerbation
- Those requiring readmission, 20% survival at 5 years
- In-hospital mortality varies between <10% and 60%

*SolerCataluña 2005, Johnston 2008*

# The case: Severe COPD patients have high symptom burden

- Symptoms:
  - SOB (75-98%) – painful, hard work, a constant struggle, continuous fight & exhausting.
  - Reduced activities (54%)
  - Poor sleep (52%)
  - Pain (70%)
  - Fatigue (96%)

*Miravittles 2007, Gysels 2007*

- Psychological symptoms:
- Depression (41-72%)
  - Low mood (77%)
  - Anxiety (28%)
  - Social isolation
  - Guilt about smoking
  - Concern with effect of illness on family
  - Loss of personal freedom / dignity and a future

*Hill 2008, Shackell 2007, Seamark 2004, Robinson 2005*

# COPD vs lung cancer

## ➤ Patients with COPD

- Worse ADLs
- Poorer physical, social and emotional functioning on QOL scales
- Anxiety or depression 90% vs 52% lung cancer

*Gore et al 2000*

# The case: Policy support for Palliative Care in COPD

- ‘Patients with chronically progressive COPD...frequently develop disabling symptoms of cough, dyspnoea, anxiety and depression. Such patients require clinicians with expertise in palliative care...’ American Thoracic Society 2015

# The case: Established Benefit of Palliative Care

- Improved symptom relief
- Improved psychological status
- Improved carer psychological status
- Reduced hospitalisation, ED presentations, LOS and death in acute hospital system
- Improved survival
- Improved well being and survival of spouses.

*Higginson 2009, Temel 2010, Hudson 2011, Christakis 1998,  
Philip 2013, Temel 2013, Rosenwax 2006*



# So case for PC is strong, yet.....?

- all patients satisfied with medical care  
but 30% lung cancer had PC support vs. none with COPD.

*Edmonds 2001*

- Relatives of deceased COPD patients:
  - Died in hospital
  - Lacked surveillance
  - Inadequate support from both 1<sup>o</sup> & 2<sup>o</sup>ary HC services

*Elkington 2004*

- Western Australia:
- 2/3 (68%) of people who died of cancer received SPC
- < 1/10 (8%) non-cancer.

*Rosenwax 2006*

# Perhaps receiving a palliative approach rather than SPC?

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# Awareness & Communication?

- 1/3 O2 depdt pts discuss EOL issues with Dr.
- 82% UK GPs feel should discuss prognosis, but occurs 41%.
- Despite family members feeling discussion of prognosis and ACP important, none had done so until death admission

*Curtis 2005, Jones 2004, Elkington 2001, Philip 2014*

# What about pain and symptom relief?

- 1016 patients COPD
- 116 died enrolment hospitalisation, further 300 next 12 months
- Symptoms?
  - 25% serious pain throughout last 6 months
  - 2/3 serious dyspnoea

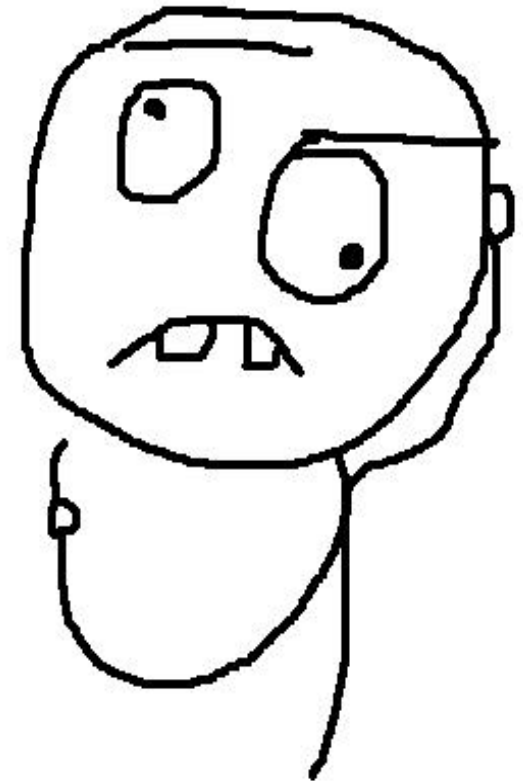


*Claessens MT, 2000*

# Substantial ramifications (SUPPORT study)

- Dr. understood preferences:
  - 86% who wanted CPR
  - 46% who did not want CPR
- Of those did not tell Dr CPR wishes during admission
  - 50% of those who wished no CPR did not tell Dr.
  - Declining QOL was not a prompt for discussion.

*Claessens MT, 2000*



# Current practice of palliative care in advanced COPD

- Despite prognosis, needs and policy, patients with COPD not referred to palliative care
- Palliative approach: difficult to gauge but surrogates suggest limited.

# The challenges: Why not referred to Palliative Care?

- Patient factors
- HCP factors
- Service factors



k1610349 www.fotosearch.com

# Patients factors....don't or perceived as not wanting palliative care

- Patients do not see palliative care as relevant
  - PC = end of life care
  - Palliative care is cancer
  - Palliative care is NH care
  
- Not terminal just chronic

*Philip 2014*

# Health Care professional factors

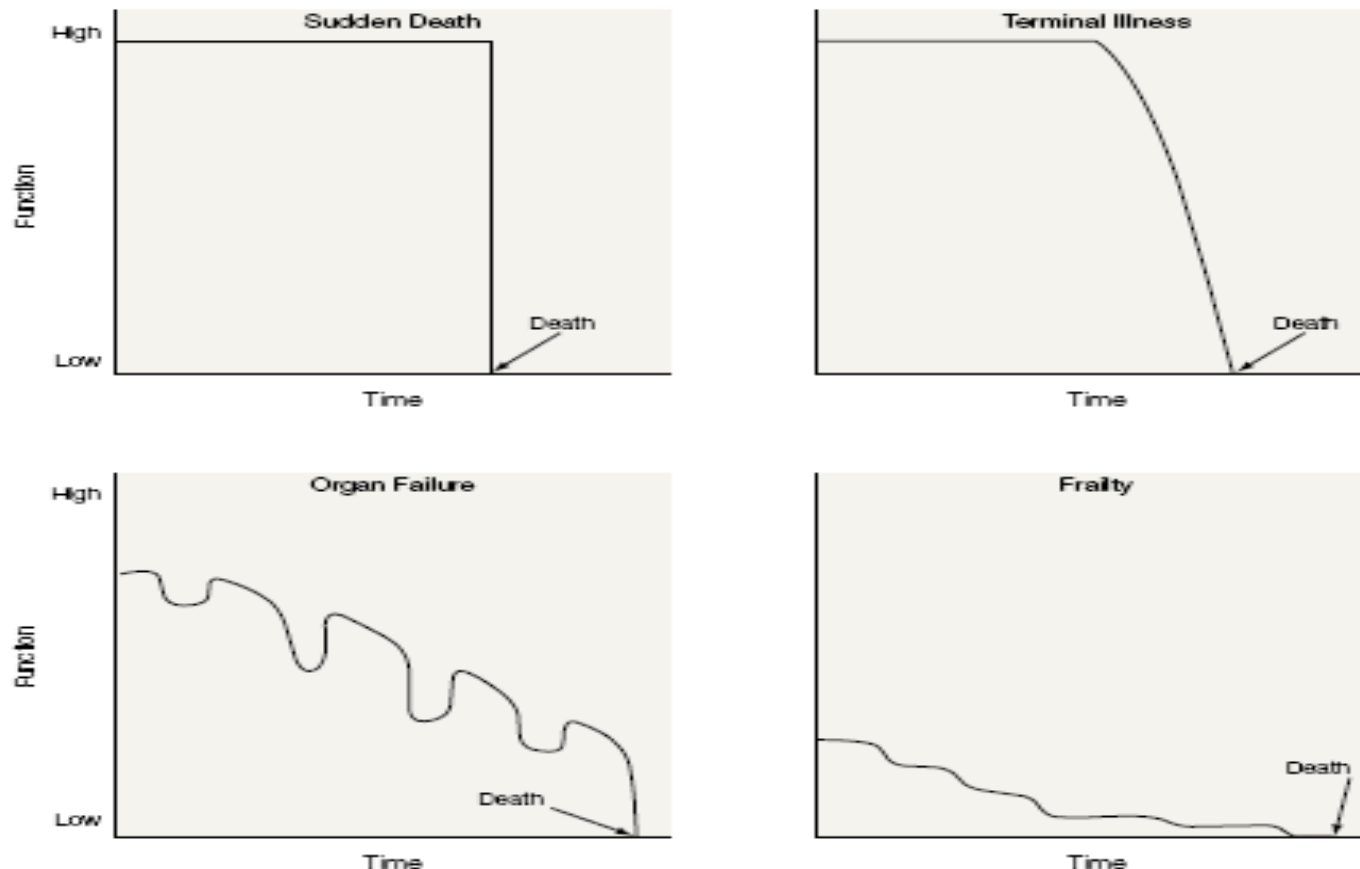
- Not part of respiratory culture
- Do not think of COPD as a terminal illness
- Focus on the immediate
- Not my responsibility
- Difficulty prognosticating, when is the 'right' time?

*Le 2013, Murray SA 2005, Murray SA 2006, Philip 2014*

# Health care professional and illness factors

Lynn 2008

**Figure 1.** Theoretical Trajectories of Dying





## Those dying of organ failure

- fluctuating pattern: decline /episodic exacerbations
- Each exacerbation
  - successfully treated + return to usual function
  - successfully treated but at lesser level of function
  - death.
- overall prognosis poor, but difficult to predict outcome of each particular exacerbation.

*Murray SA 2005, Murray SA 2006*

# Health care professional factors

## Communication issues:

- Takes too much time to raise the issues
- Fear of destroying hope / upsetting patients

Not confident that service will 'accept' the referral

*Philip 2014*

# Palliative Care service factors

- Time based
- Based on cancer trajectory - Assumed predictability in progression, prognostication, likely scenarios to death
- BUT: Assumptions on predictability don't apply
- Service organisation : patients admitted (IP and Community)
- Education focus in training based on cancer care model
- Can we simply apply this cancer model to non-cancer populations?

*Ferris FD, Bruera E, Cherny N, et al. JCO 2009*

# Palliative Care service -limitations

- Best palliation may be disease directed therapies which may be best delivered in an acute hospital
  - Eg. IV diuretic infusions in decompensated CCF
- Community-based care providers can feel disempowered
  - Lack of clear role / task for service
  - Links with acute services continue.

*Philip 2013*

# Palliative Care service - limitations

- Long term high levels of morbidity of non-malignant disease
  - Length and intensity of involvement stretches resource capabilities

# Resourcing implications of NMD palliative care

- Secondary analysis data from the Regional Study of the Care of the Dying (UK)
- 1/3 (243/720) of cancer patients referred to specialist palliative care scored > median on 3 symptom measures
  - Suggesting severe problems with significant needs

*Addington-Hall 2008*

# Resourcing implications of NMD palliative care

- 269/1605 non-cancer patients (16.8%) fulfilled these criteria.
- Therefore: estimated that 71, 744 people dying from non malignant disease in England and Wales each year may require specialist palliative care
  - A 79% increase in caseload
  - Conservative given matched to 1/3<sup>rd</sup> of cancer referrals

*Addington-Hall 2008*

“Population with bad symptoms, bad problems, can live for a long time with very significant needs and significant resource requirements and they die but it is hard to know when”



# A new model of thinking required...

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# What do patients want?

- Want care to include possibilities of survival while exploring plans for end of life
- Hold concurrently losses with optimism.
- Want treatment but not at all costs
- Confident doctors will make right decision

*Philip 2014*

*Being the supreme optimist I think that if I stop smoking now and I start taking care of myself by exercising a bit, by eating properly...I think I'll live...I don't think he's ready to take me yet.*



# What do patients want?

- Embrace symptom management measures:
  - Most would weigh benefits vs AEs and decide accordingly

*One way or the other my life's getting shorter isn't it? Whether I have something that will help me now (morphine) or let it go and I go anyway...quality of life is the main thing while you can have it.*

*Philip 2014*

# What do patients want?

- Information of illness course
- Want doctors to hold EOL discussions
  - In context of a good Dr-pt relationship
  - Matter of routine
  - Hard, therefore won't occur spontaneously
  - Ongoing care with respiratory doctors

*I think the more a person can know about the end or possible scenarios the better you are to make an informed decision.*

*the main person I look to for information is here, at this clinic*

*Philip 2014*

# What do patients want?

- Want practices of palliative care, do not think the 'service' is relevant
- Esp. want family support
- When receiving palliative care find highly acceptable.

*Philip 2014, Brown 2012*



# So.... according to patients, a PC service for COPD should include:

- Access to PC practices rather than name
- Specific symptom control measures
- Want communication opportunities: information and decision making
- Routine incorporation of planning discussions
- Support for families
- Want to maintain respiratory / usual care relationships

# HCPs: Additional elements of a PC service for COPD must consider...

- Identification of patients
- Approach
  - Relevant to patient, disease parameters, culture of usual care
  - Able to be resourced

*Philip 2014*

# How to identify those who may benefit?



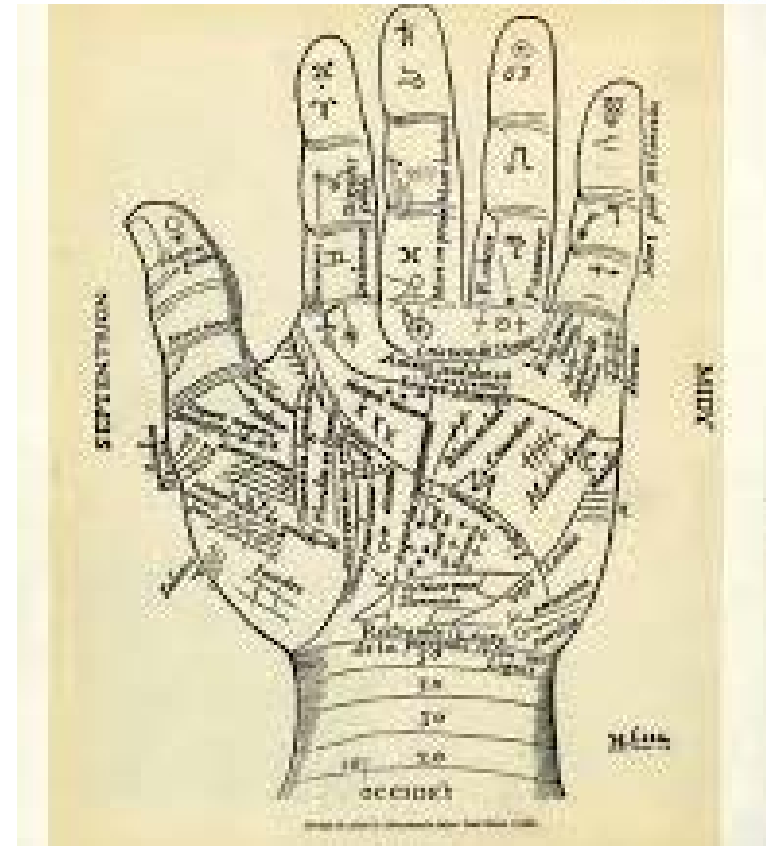
- Identify patients according to perceived prognosis
- Identify according to ‘surprise’ question.
- Identify patients according to need/symptomatology



# Identification based upon prognostication

- Disease specific prognostic models
  - Eg. BODE score
- Palliative Care Tools
  - Eg. SPICT tool
- Hospital administration datasets

*Lynn, Harrell 1997, Fox 1999, Christakis 2008  
Philip 2010, Hight 2014*



# Hospital datasets

- Increased risk of death in next 6 months if:
  - older, widowed,
  - Live in supported accommodation
  - LOS >5 days
  - Presence of comorbidities esp CV, Ca, renal,
  - Any previous admissions last 6 months and LOS of these
- Model based on variables admission history to highlight those at increased risk.
  - Calibrate the risk level eg. 30% chance of dying in 6 months
  - Physician automatic prompt

# But ..... limits to utility of prognostication

- Heart failure patient had a 50-50 chance to live (acc. to dr and prognostic models) on day that turned out to be their last
- Physician discomfort around prognostication

*Lynn, Harrell 1997,*

# Approaches based upon expectations

- “Would you be surprised if this patient died in the next (6 – 12) months?”
- "safer space"
- If answer is no,
  - what things would you have in place for them?
  - what things might be important to consider?

*Lynn, Johnson 2002*



Gold Standards Framework – surprise in conjunction with other COPD parameters - mobilisation of a system of care for those identified

- Approach to optimise care for patients nearing the end of life delivered by generalist providers.
  - More advance care planning discussions
  - More dying in preferred place – home
  - ↓ hospital bed days

<http://www.goldstandardsframework.org.uk/>

But 71% of all UK admitted patients identified *Highett 2015*

# Identification based upon needs

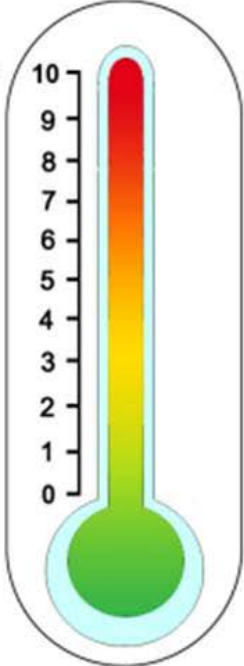
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# Identification based upon needs

## The Distress Thermometer

<p>First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.</p>	<p>Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.</p>																																																																																																																					
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# Identification based upon needs

## ➤ PC-NAT

1. Fast track review: available caregiver?  
Requested? HCP needs assistance
2. Patient well being: physical, psychological,  
functional, information, spiritual, sociocultural,  
legal
3. Ability of caregiver to care?
4. Caregiver well being
5. HCP thinks is necessary

*Girgis 2008*



# But.....

- Require consideration and engagement with task
- Step outside usual practice approaches in medicine especially respiratory clinic



# Identification based upon making a diagnosis

## Exemplar of COPD and refractory breathlessness

‘Refractory breathlessness’ is .....

‘chronic breathlessness at rest or on minimal exertion, which persists despite the maximal therapy of any underlying conditions that might cause or worsen the symptom’

*Wiseman, 2013*

- Positive diagnosis of ‘refractory’
- Diagnostic task --- culturally aligned
- Opportunity:
  - symptom relief through direct prescribing for the subjective experience of the symptom itself.
  - Also a prompt to consider other things that might be important.

# Having identified who may benefit

## ➤ Identification of patients

## ➤ Approach

- Relevant to patient, disease parameters, culture of usual care
- Able to be resourced

# Approaches detailed in the literature

- Breathlessness Intervention Service, Addenbrook, Cambridge University Hospital
- COPD care coordinator, SA
- Canadian customised community care model for COPD (COPD-IMPACT Study)
- GP case conferencing with PC service, Qld
- HOPE: Helping Older Patients with End-stage kidney disease - Renal Supportive Care Clinic, St George's Hospital Sydney

*Brown 2013, Horton 2013, Burgess 2013, Mitchell 2008, Higginson 2014*

# Comprehensive anticipatory care (PC) for patients with severe chronic NMD

➤ Palliative care fellow/physician attends non-malignant clinics:

- Renal
- Respiratory
- Cardiology

For identified patients:

- Optimise disease specific therapies.
- Screen for
  - Symptoms & Psychological concerns.
  - Community support.
- Discussions re. future care:
  - patient's goals,
  - Frame medical care to match these goals.
- Link to PC services as necessary

# Comprehensive Anticipatory Care Clinic enables

- Equitable access to PC
- Ongoing acute care links including emergency care
- Honours long standing relationships
- Overcomes wariness of admission to PC services
- Allows 'holding' and triage to usual PC services – without surprises
- Sustainable



# Identification for Comprehensive Anticipatory Care Clinic?



1. “Would you be surprised if this patient died in the next .....?”
2. Hospitalisation history
3. Diagnosis of ‘refractory’ symptoms.



# Benefits of Comprehensive Anticipatory Care

- Patient benefits
  - Value discussions
  - Attention to symptoms and psychological symptoms
  - Enhanced support
- Family caregiver benefits
  - Enhanced support and reduced unmet information needs
- Health care professional benefits
  - facilitates response upon acute hospital admission
  - Mutual learnings between disciplines
- System benefits
  - Direct admission to PCU for selected patients
  - Reduced resource load for community palliative care services



- Bill, 78 yo man
  - Long term smoker, now ceased
  - Lives with wife, adult children nearby
- Long standing COPD
    - First hospitalised when 69 – ICU admission
    - Subsequent multiple hospitalisations , required NIV at least once.
    - Maximised COPD medications
    - Some LOW, able to walk around house, slowly go to local shop.
    - No oxygen

- During previous admissions discussions held about resuscitation, Bill had voiced “I want everything done”.
- Underwent pulmonary rehabilitation
- Seeing respiratory OP team 6/12ly
- Referred to Comprehensive Anticipatory Care Clinic doctor.

# 1<sup>st</sup> appointment

- Very dyspnoeic minimal exertion
- A little suspicious – ‘what’s this all about? Don’t they want to see me any more?’
- Symptoms: overwhelming dyspnoea, poor sleep, low energy, and probably underlying depression
- Brief discussion of past treatments and thoughts – Bill curtailed.
- Agreed to trial low dose morphine for dyspnoea

# 2<sup>nd</sup> appointment

- Significant reassurance re morphine (LMO & pharmacist)
- Good response to opioids
- a bit more engaged
- More discussion: perception of illness/ treatment, what is important to him.
- Initial ‘just want to get better’, ‘want everything done’ but probed what means by this.
- Good understanding of illness
  - likelihood of eventually being fatal,
  - wants treatment if helps, but clear about what life/disability was unacceptable.

# Subsequent appointments

- Important conversation
- Revisited in 2/52: wife & children present.
- More in depth discussion:
  - development of goals
  - remain home as long as possible and medical treatment to attempt to prolong life – ‘trial of treatment’.
  - Parallel discussion: if not possible would have all comfort measures.
- Next 6 months: seen approx 6/52ly,
  - started antidepressant
  - revisited his goals from time to time

- About 7 months after discussion: admitted with exacerbation – NIV for 24 hours
- Improved but described very difficult, did not want again
- Discharged after 4 days
- Readmitted 5 days later further/ongoing exacerbation – very dyspnoeic, some distress
- Admitted to palliative care unit
- Began morphine SC and low dose midazolam – calm
- Family supportive
- Died following day

# For Bill.....

- Relationship and trust established around symptom control
- Not about stopping treatment, but tailoring and setting up the parameters and limits
- Establishing goals and matching medical care to those goals was substantial communication task
  - Took persistence, skills
  - More than 1 encounter
- Family involvement important



# Summary: A model of PC in NMD

## involves:

- Identification & recognition
- ‘Engagement’ with tasks of palliative care, including
  - Maximizing treatment options
  - Symptom & needs assessment, management & planning
  - Information, Advanced care planning
  - Psychosocial & carers
  - Bereavement
- Be relevant, responsive and able to be resourced
- Models require comprehensive evaluation:
  - Patient, family & HCP views,
  - health service use, health economics &
  - survival

# Equity in Palliative Care.



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