

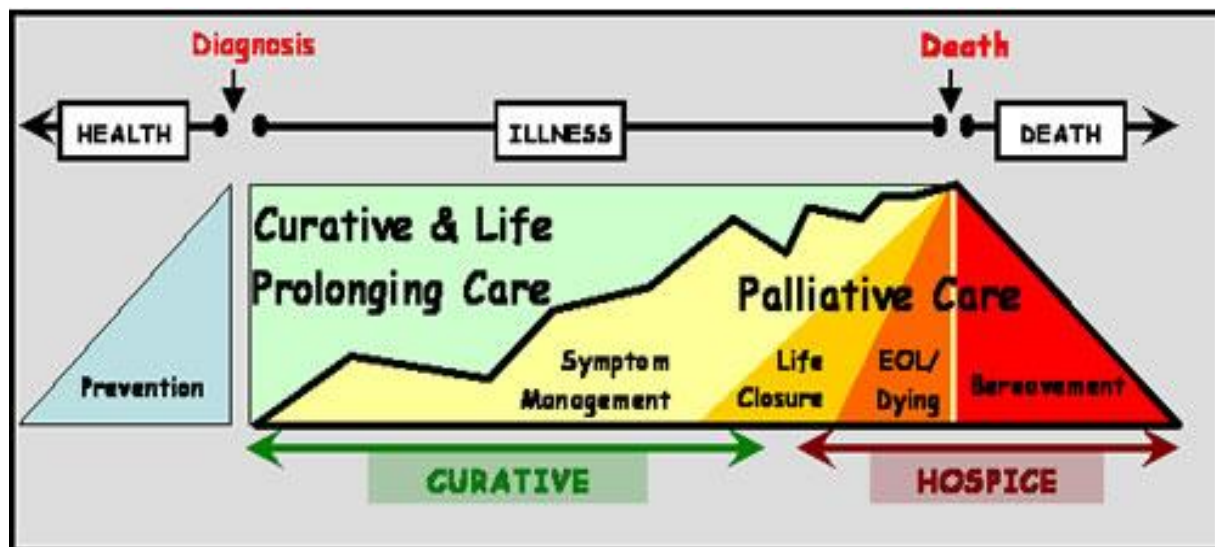


# Úvod

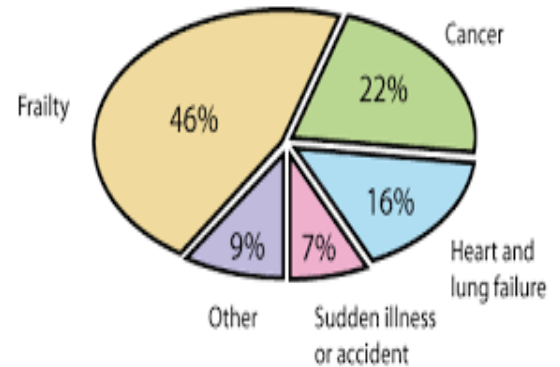
- kultúrne a psychologické **popieranie smrti** – fenomén dneška
- medicínsky pokrok z 2.pol. 20. str. - predĺženie života a „oklamanie“ smrti
- nevyhnutný následok v podobe predlžovania umierania a utrpenia
- **smrť** – výsledok zlyhania medicínskych postupov a vlastný neúspech, nie prirodzená súčasť života
- nevedomosť príznakov smrti
- zomieranie v nemocnici je čisto technického rázu, nedostatok personálnych kapacít znamená stratu dôstojnosti terminálnej fázy

# Paliatívna medicína

- pacienti s chronických ochorením, resp. funkčne limitujúcim procesom
- cieľ: čo najlepšia kvalita života vzhľadom na limity
- bez invazívnych výkonov a liečby
- terminálna starostlivosť – EOL – starostlivosť o zomierajúceho pacienta
- hospicová medicína



# PM vs. UM



- opakované zásahy a ošetrenia ZZS a na UP
- 75% pacientov starších ako 65 rokov je ošetrovaných min. 2x v posledných šiestich mesiacoch života, 51% pacientov v posledný týždeň života
- vysoká frekvencia ošetrovaní – indikátor nízkej až zlyhávajúcej kvality PS
- 50-80% zomierajúcich pacientov potrebuje všeobecnú PS, 20% nádorových a 5% nenádorových pacientov potrebuje špecializovanú PS

# Kritériá zaradenia pacienta do PS

- chronické, život ohrozujúce ochorenie
- vysoká pravdepodobnosť úmrtia do 12 mesiacov (u detí nedosiahnutie dospelosti)
- viac ako 1 ošetrovanie na UP za posledné 2 mesiace
- stav vyžaduje komplexnú starostlivosť (sociálna, medicínska, psychologická a i.)
- sekundárne kritériá: domáca oxygenoterapia, nízky nutričný status, zlyhávanie funkcie orgánov...
- pôvodne len onkodg., teraz KAR, PNEU, NEU, REN...

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assessment of unmet supportive and palliative care needs may be appropriate.

## Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

## Look for any clinical indicators of advanced conditions

### Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

### Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

### Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

### Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

### Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

### Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

### Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

## Supportive and palliative care planning

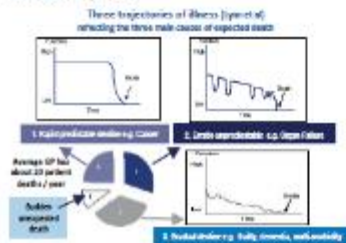
- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

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 6th Edition Dec 2016 K Thomas, Julie Armstrong Wilson and GSF Team, National Gold Standards Framework Centre in End of Life Care <http://www.goldstandardsframework.org.uk> for more details see GSF PIG

Proactive Identification Guidance – proactively identifying patients earlier.

This updated 6th edition of the GSF PIG, renamed as Proactive Identification Guidance and formally known as Prognostic Indicator Guidance, aims to enable the earlier identification of people nearing the end of their life who may need additional supportive care. This includes people who are nearing the end of their life following the three main trajectories of illness for expected deaths – rapid predictable decline e.g. cancer, acute decline e.g. organ failure and gradual decline e.g. frailty and dementia. Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.



Why is it important to identify patients early?

Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care. About 1% of the population die each year, with about 30% hospital patients and 80% of care homes residents in their last year of life. Most deaths can be anticipated through a minority are unexpected (estimated about 10%). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and care tailored to people's wishes. This in turn results in better outcomes with more people living and dying in the place and manner of their choice. Once identified, people are included on a register and where available the locality/electronic register, triggering specific active supportive care, as used in all GSF programmes and in GSF cross boundary care sites.



PIG and GSF – Early proactive identification of patients is the crucial first step of GSF, used by many thousands of doctors and nurses in the community and hospitals. For more information on GSF how it is used in practice to help identify patients early, assess needs and wishes through advance care planning discussions and plan care tailored to patient choices, see the GSF website.

National Policy support for earlier identification.

General Medical Council – 2010 [www.gmc-uk.org/website/documents/content/End\\_of\\_life.pdf](http://www.gmc-uk.org/website/documents/content/End_of_life.pdf)

The GMC definition of End of Life Care: '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.'

NICE Guidance in End of life care 2011 Quality statement 1

- Identification – People approaching the end of life are identified in a timely way.
- Systems – Evidence of local systems in place to document identification of people approaching the end of life.'

Proactive Identification Guidance – GSF PIG Flow-chart



The GSF PIG 2016 – Proactive Identification Guidance

Step 1 The Surprise Question

For patients with advanced disease or progressive life limiting conditions, would you be surprised if the patient were to die in the next year, months, weeks, days? The answer to this question should be an intuitive one, putting together a range of clinical, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

Step 2 General indicators of decline and increasing needs?

- General physical decline, increasing dependence and need for support.
- Repeated unplanned hospital admissions.
- Advanced disease – unstable, deteriorating, complex symptom burden.
- Presence of significant multi-morbidity.
- Decreasing activity – functional performance status declining (e.g. Barthel score linked self-care, is end of chair 60% of day and increasing dependence in most activities of daily living).
- Decreasing response to treatments, decreasing reversibility.
- Patient choice for no further active treatment and focus on quality of life.
- Progressive weight loss (>10%) in past six months.
- Serious event e.g. serious fall, non-verbal, transfer to nursing home.
- Serum albumin <25g/l.
- Continued ongoing for cost/100 payment.

Step 3 Specific clinical indicators related to 3 trajectories

**1. Cancer**

- Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not amenable to treatment – If spending more than 50% of time in bed/dying down, prognosis estimated in months.
- Persistent symptoms despite optimal palliative oncology. More specific prognostic predictors for cancer are available, e.g. PSA.

**2. Organ Failure**

**Heart Disease**

At least two of the indicators below:

- Patient for whom the surprise question is applicable.
- CHF NYHA Stage 3 or 4 with ongoing symptoms despite optimal HF therapy – shortness of breath at rest or minimal exertion.
- Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1yr mortality).
- Difficult ongoing physical or psychological symptoms despite optimal tolerated therapy.
- Additional features include hyponatraemia (<135mmol/l), high BP, declining renal function, anaemia, etc.

**Chronic obstructive Pulmonary Disease (COPD)**

At least two of the indicators below:

- Repeated hospital admissions of at least 3 in real year due to COPD.
- MRC grade 4-5 – breathless at rest/after 100 metres or less.
- Disease assessed to be very severe (e.g. FEV1 <30% predicted), persistent symptoms despite optimal therapy, no interest for surgery or lung resect.
- Fatigue long term oxygen therapy advised (PAC12 <7.30%).
- Requires ITN/NI during hospital admission.
- Other factors e.g. night heart failure, anaemia, oedema, >4 weeks steroids in preceding 6 months, requires palliative medication for breathlessness still smoking.

**Kidney Disease**

stage 4 or 5 chronic kidney disease (CKD) whose condition is deteriorating with at least two of the indicators below:

- Patient for whom the surprise question is applicable.
- Repeated unplanned admissions (more than 3/year).
- Patients with poor tolerance of diuretics with change of modality.
- Patients choosing the no dialysis option (conservative, stage) withdrawal or not opting for dialysis if transplant has failed.
- Difficult physical or psychological symptoms that have not responded to specific treatments.
- Symptomatic Renal Failure in patients who have chosen not to dialyse – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

**Liver Disease**

hepatocellular carcinoma.

Liver transplant centre indicated.

Advanced disease with complications including:

**Liver Disease (continue)**

- Haemocytocytosis
- Encephalopathy
- Other adverse factors including malnutrition, severe constipation, hepatorenal syndrome
- Refractory infection (current, treated, recent) not, hepatorenal, unless they are a candidate for liver transplantation or amenable to treatment of underlying condition.

**General Neurological Diseases**

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Symptoms which are complex and hard to control.
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, malnutrition or respiratory failure.
- Speech problems: increasing difficulty in communications and progressive dysphasia.

**Parkinson's Disease**

- Drug treatment less effective or increasingly complex regime of drug treatments
- Recurrent incontinence, needs ADL help.
- The condition is less well controlled with increasing "off" periods.
- Dyskinesias, mobility problems and falls.
- Psychiatric signs (depression, anxiety, hallucinations, psychosis).
- Similar pattern to frailty – see below.

**Motor Neurone Disease**

- Marked rapid decline in physical status.
- First episode of aspiration pneumonia.
- Increased cognitive difficulties.
- Weight Loss.
- Significant complex symptoms and medical complications.
- Low vital capacity below 70% predicted, apnoea, or isolation at NW.
- Mildly profound and less.
- Communication difficulties.

**Multiple Involvement**

- Significant complex symptoms and medical complications
- Dysphagia – poor nutritional status.
- Communication difficulties e.g. Dysarthria – talpa.
- Cognitive impairment notably the onset of dementia.

**Frailty**

For older people with complexity and multiple comorbidities, the surprise question must triangulate with a bar of indicators, e.g. through Comprehensive Geriatric Assessment (CGA).

- Multiple morbidities
- Deteriorating performance score.
- Weakness, weight loss exhaustion.
- Slow Walking Speed – takes more than 5 seconds to walk 4 m.
- TUGT – time to stand up from chair, walk 3 m, turn and walk back.
- FRSMA – at least 3 of the following:

Age over 85, Male, Any health problems that limit activity, do you need someone to help you on a regular basis?, Do you have health problems that cause require you to stay at home?, In case of need can you count on someone close to you?, Do you regularly use a stick, walker or wheelchair to get about?

**Dementia**

Identification of moderate/severe stage dementia using a validated staging tool (e.g. Functional Assessment Staging Tool (FAST) in identifying the final year of life in dementia, BGS). Triggers to consider that indicate that someone is entering a later stage are:

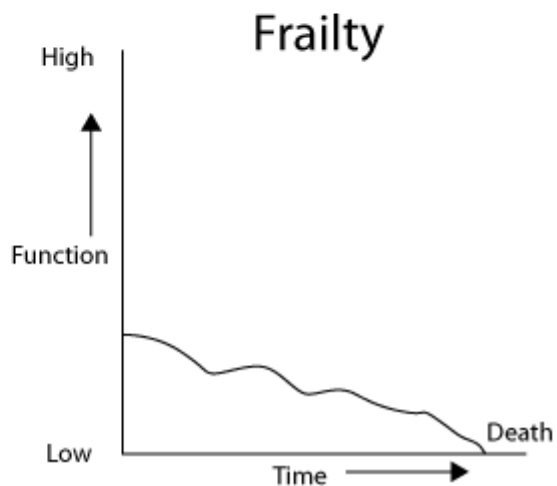
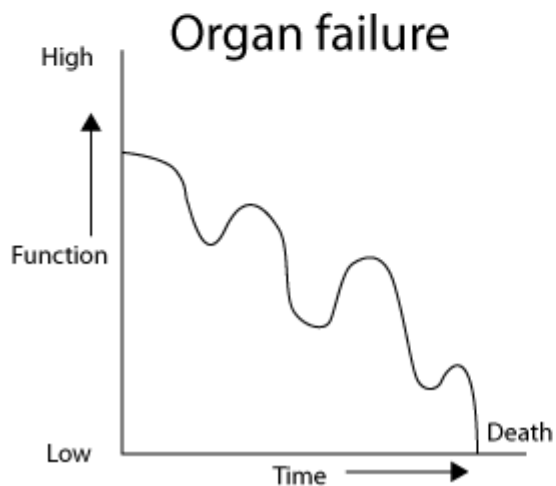
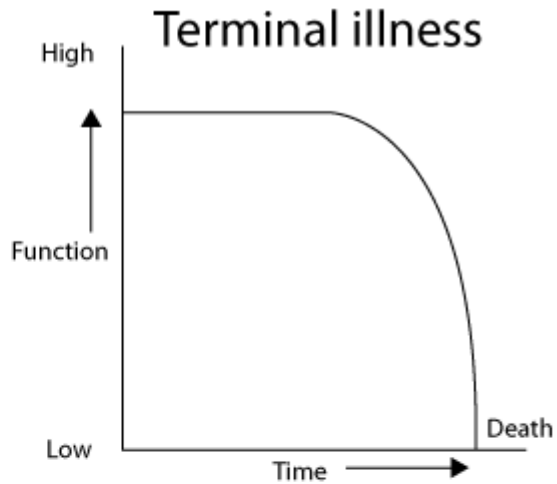
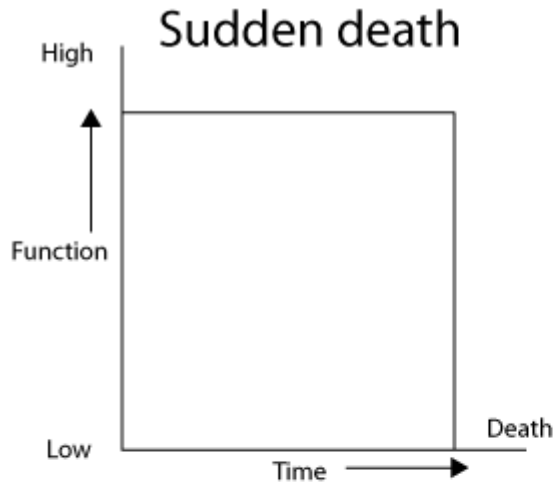
- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score >3

Plus any of the following: Weight loss, Urinary tract infection, Severe pressure sores – stage three or four, recurrent fever, reduced oral intake, Aspirin pneumonia, Nil Advance Care Planning discussions should be advised early at diagnosis

**Stroke**

- Use of validated scale such as NINDS recombinant.
- Persistent vegetative, minimal conscious state or severe psychosis
- Medical complications, or lack of improvement within 3 months of onset.
- Cognitive impairment / Post-stroke dementia.
- Other factors e.g. old age, male, heart disease, stroke sub-type, hyperglycaemia, dementia, renal failure.

# Scenáře zomierania





# Pravidlá starostlivosti

- rešpektovanie vývoja choroby a určenie prognózy
- identifikácia paliatívneho pacienta a dodržiavanie liečebného plánu
- komunikácia s ohľadom na negatívne správy
- výhradne symptomatická liečba
- KI invazívnych postupov v diagnostike a liečbe
- hospicový pacient nepatrí do ZZ
- dodržiavanie etických a právnych noriem



# Najčastejšie symptómy a liečba

- bolesť
- dyspnoe
- nauzea, zvracanie
- nutričný deficit
- dehydratácia
- obstipácia, hnačky
- krvácanie
- úzkostné stavy
- delírium
- oxygenoterapia, NIV
- toaleta DC
- zavedenie PMK
- i.v. liečba
- analgetiká
- antipsychotiká
- sedatíva
- anticholinergiká



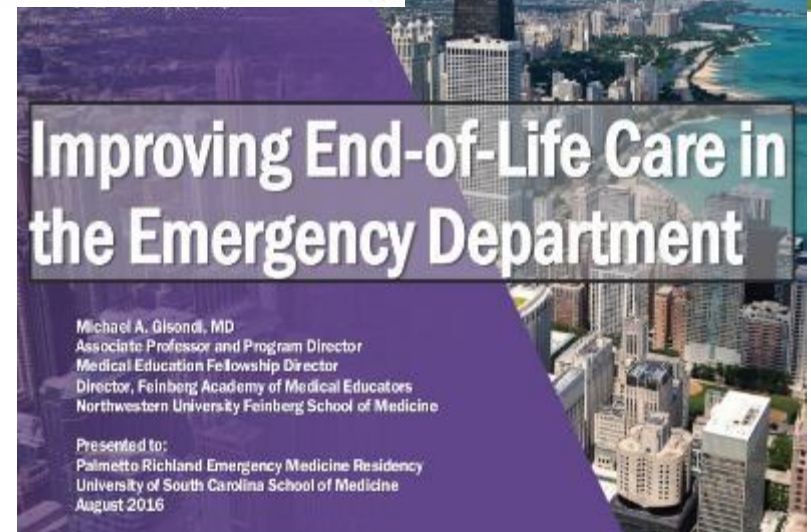
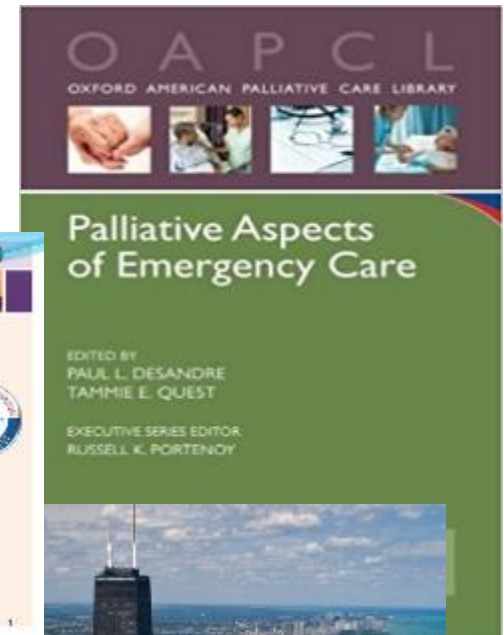
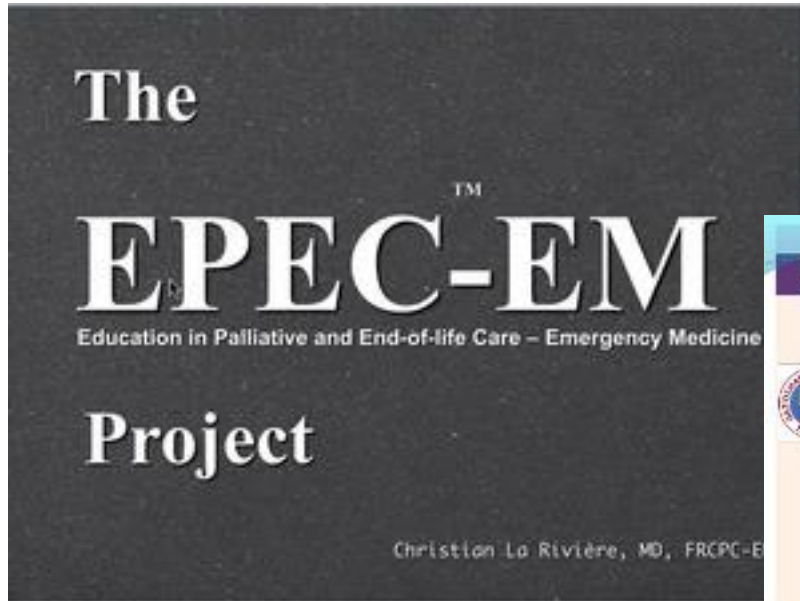
Good Heavens! Who linked you up? This one is Cable TV!

# Problémy?

- obmedzené vedomosti a pochopenie úlohy PM lekármi
- rozdiely v očakávaní (personál – príbuzní)
- určovanie prognózy a rozhodovanie o rozsahu liečby
- komunikácia
- defenzívny alibistický prístup, presun zodpovednosti do rúk špecialistov, OL a pod.
- logistické obmedzenia
- absencia jasných doporučených postupov
- etické a právne nejasnosti

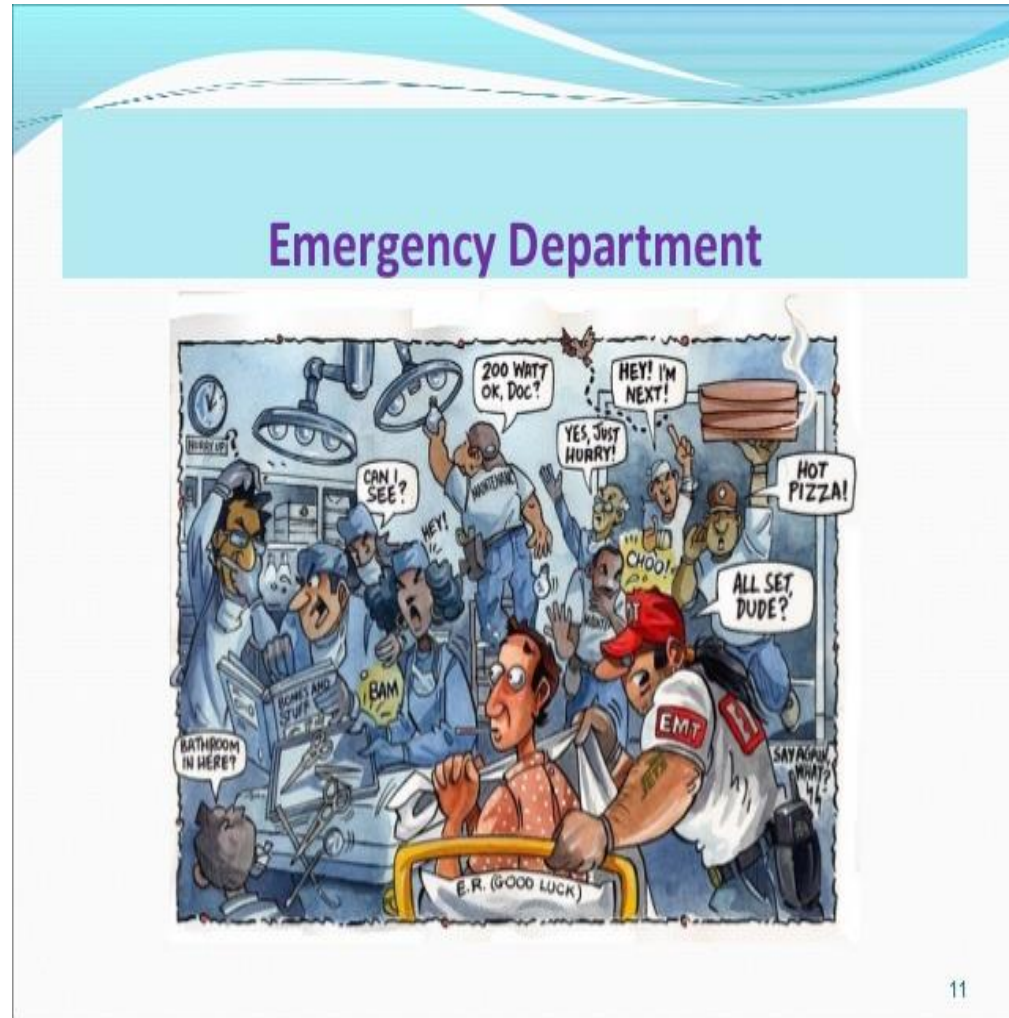


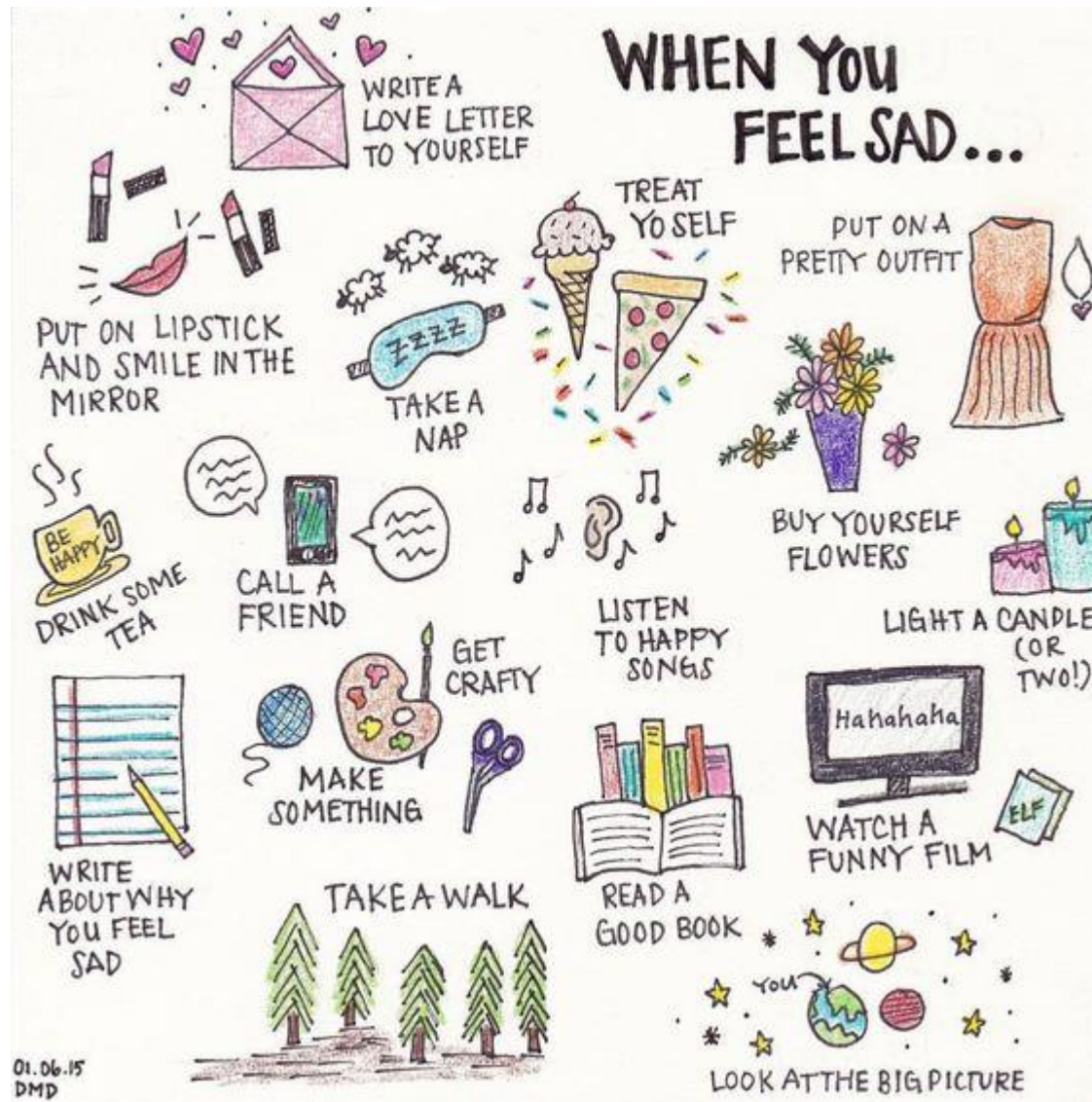
# Programy výuky



# Prínosy implementácie PM do UM

- šetrenie ľudských zdrojov
- pokles intenzity návštev
- pokles invazívnosti dg. a th. procedúr
- pokles počtu nepotrebných metód
- zvýšená spokojnosť s liečbou
- celková úspora nákladov na liečbu





Ďakujem za pozornosť