

# Hvordan imødekommer man et menneske i lidelse?

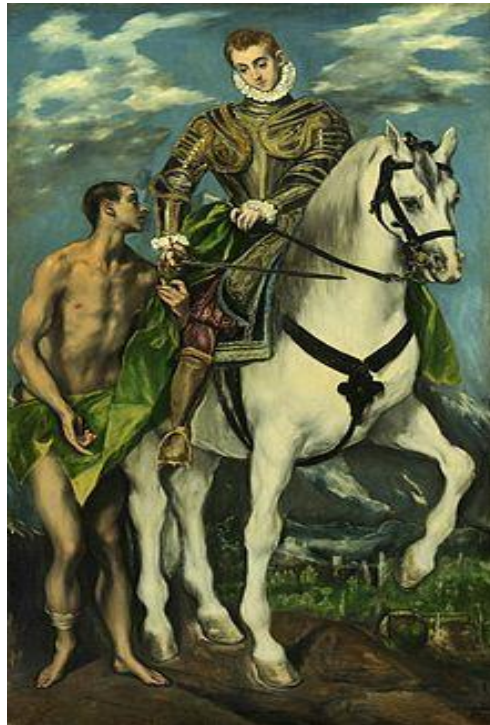
Klinisk sygeplejespecialist Janni Mendahl

Lindrende Behandling  
Herlev & Gentofte Hospital

# Hvad er lidelse? Hvad er håbløshed?



# Palliation - lindring af lidelse

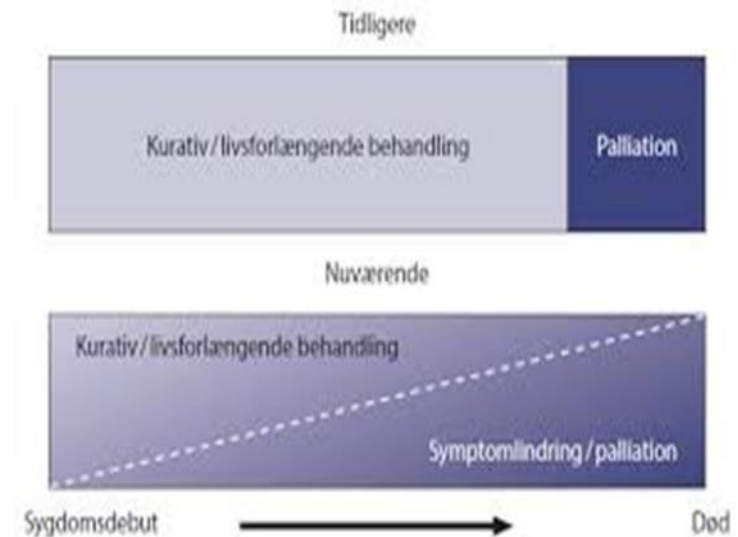


Den romersk fødte mand Sankt Martin (315-397) deler sin kappe med en fattig tigger

Pallium = kappe

# World Health Organization, 2002 Definition af lindring og lidelse

Den palliative indsats har til formål at fremme **livskvaliteten** hos **patienter og familier**, som står over for de problemer, der er forbundet med **livstruende sygdom**, ved at forebygge og lindre **lidelse** gennem tidlig diagnosticering og umiddelbar vurdering og behandling af smerter og andre problemer af både **fysisk, psykisk, psykosocial og åndelig art**'.



# Anbefalinger for den palliative indsats

Formålet med anbefalingerne er:

- skabe lighed i adgangen til de palliative behandlingstilbud overalt i landet uanset diagnose
- at løfte kvaliteten i indsatsen, særligt i forhold til den basale palliative indsats

VIDENSKAB

## Palliativ indsats er for alle, også patienter med livstruende medicinsk organsvigt

# Adgangen til specialiseret palliation 2020

- Patienter med livstruende sygdomme får ikke systematisk identificeret deres behov for palliation, og der er risiko for, at patienter med behov ikke henvises til specialiseret palliation.
- Mange henviste patienter når ikke at blive modtaget, inden de bliver for dårlige eller dør, og mange af de patienter, der når at blive modtaget, venter for længe på specialiseret palliation.

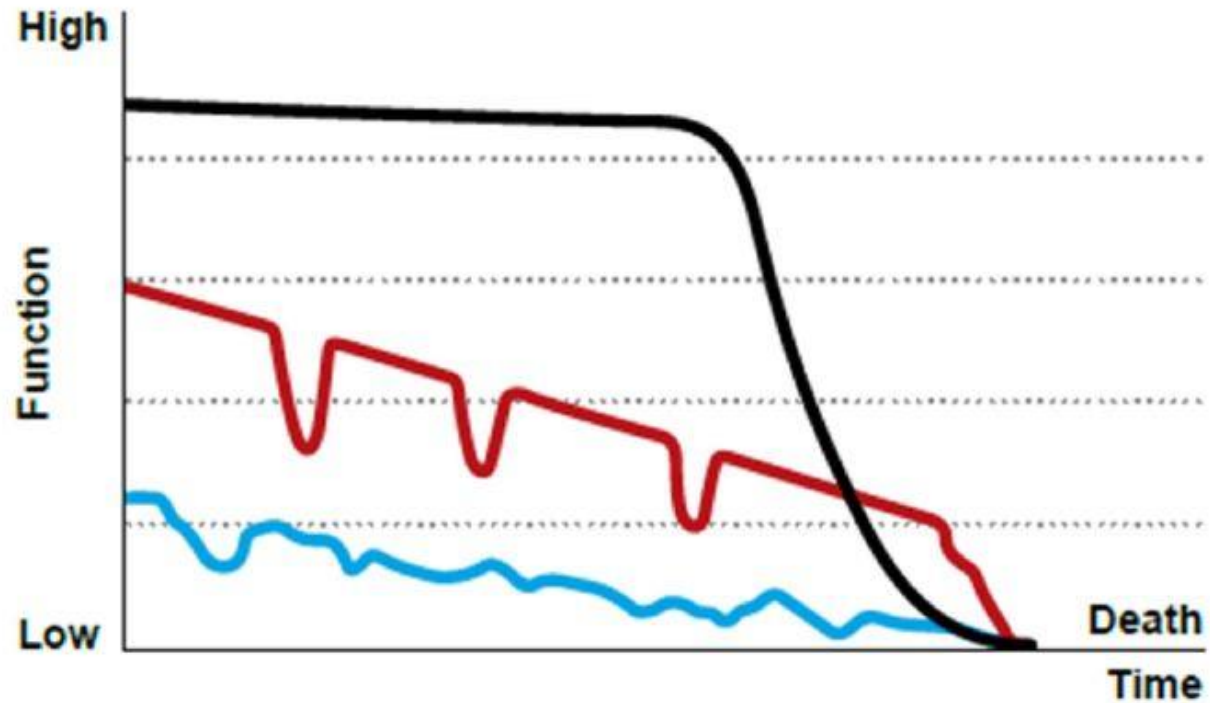
FOLKETINGET  
RIGSREVISIONEN

FOLKETINGET  
STATSREVISORERNE




Der blev henvist 640 patienter til specialiseret palliation pr. 1.000, der døde af kræft i 2018. For patienter, der døde af andre sygdomme, blev der henvist 34 patienter pr. 1.000 døde



# Disease Trajectories



Source: Murray, S.A. et al<sup>1</sup>

-  Cancer
-  Organ failure
-  Physical and cognitive frailty



St Joseph's  
Hospice



# Hurtigt og langsomt fremadskridende sygdomme



**Hvad har vi i værktøjskassen?**



# “4, 2, 4, 2 modellen”

4 patientforløb  
2 typer af faglig viden  
4 dimensioner  
2 roller

• Marsaa K, Mendahl J, Nielsen S, Mørk L, Sjøgren P, Kurita GP. Development of a systematic multidisciplinary clinical and teaching model for the palliative approaches in patients with severe lung failure. *Eur Clin Respir J* 2022; 9. DOI:10.1080/20018525.2022.2108195.

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RESEARCH ARTICLE

OPEN ACCESS

Development of a systematic multidisciplinary clinical and teaching model for the palliative approaches in patients with severe lung failure

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**ABSTRACT**  
Palliative medicine has traditionally focused on people affected by cancer with rapidly advancing disease progression. However, as more people live longer time with serious illnesses, including lung diseases, the need of palliative care for these patients is also increasing. There is a lack of research and clinical knowledge about what palliative care is for people affected by chronic obstructive pulmonary disease and interstitial lung disease. The aim of this paper is to describe the development process of an easy to use and clinically relevant model for the palliative care approach in people affected by serious illnesses. The developed model consists of four components, which originated the title “4-2-4-2 model”. Each number has a specific meaning: the first 4 = the four disease trajectories that patients may experience; 2 = the two forms of knowledge, objective and intuitive that must be achieved by the health professionals, to gain an understanding of the situation; 4 = the four dimensions of suffering physically, mentally, socially and existentially/spiritually; and 2 = the two roles that health-care professionals must be able to take in when treating patients with serious illnesses. The 4-2-4-2 model proposes an easy-to-use and clinically relevant model for palliative approach and integration of PC and pulmonary medicine. Another important purpose of this model is to provide eFPs with different educational backgrounds and from different medical fields with a “golden standard approach” to enhance the focus of the palliative approach in both the clinic and teaching. The effect and consequences of the use of the 4-2-4-2 model should be explored in future clinical trials. Furthermore, it should be investigated whether teaching the model creates a change in clinical approach to patients with serious illnesses as well as whether these changes are long-lasting.

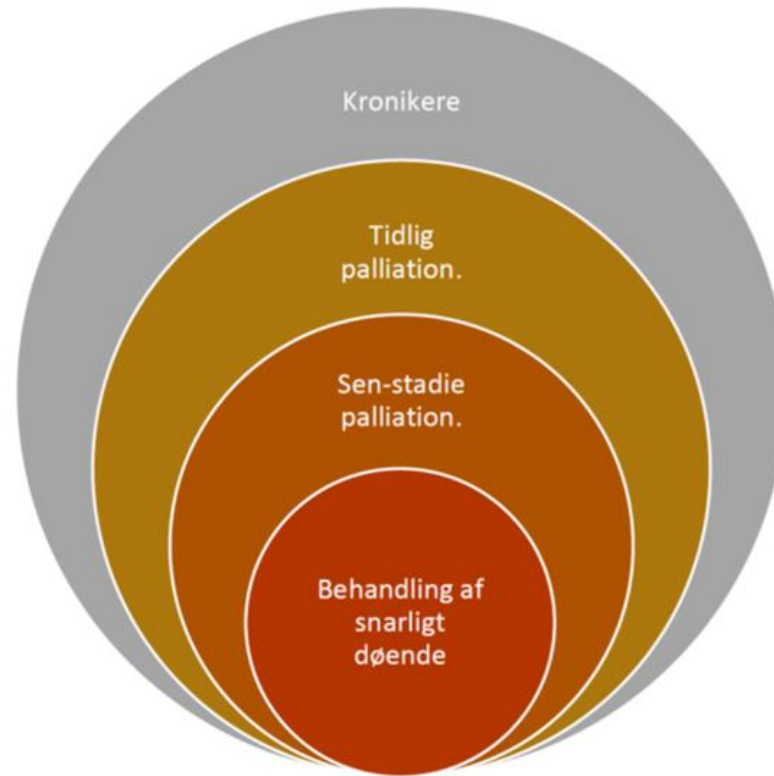
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**KEYWORDS**  
Model development; education; palliative care approach; palliative care; COPD; ICD; integration; rehabilitation and palliative care; chronic care

**Introduction**  
It has been estimated that 40 million people will die with serious health-related suffering due to severe illnesses in 2030, which means 47% of all deaths globally and represents an increase of 67% from 26 million in 2016 [1]. International health-care associations, palliative care (PC) researchers, and engaged clinicians have promoted the concept that PC can be involved in any phase of the disease trajectory including the early phase, in both cancer diseases and other severe illnesses [2–4]. Palliative care in its modern form started with St. Christopher’s hospice in 1967 [5]. There was in the first international definition of palliative care WHO 1990 a clear cancer focus as it was described that the PC should start when curative treatment had been abandoned [6]. Later in 2020, the WHO wrote that PC should be extended to patients with life-threatening illnesses [7]. In 2020, the international association of hospice and palliative care (IAHPC) came up with their new definition where they use the term serious illness [8]. This has origin on a from a definition published 2014, which describes serious illnesses within three main themes:  
1. Disease that carries a high risk of death over the course of a year, but cure may remain a possibility  
2. induced physical function and quality of life and  
3. caregiver stress [9].  
Thus, in the definitions, there is a movement away from solely end-stage cancer focus and towards an early introduction of palliative care. Integrating palliative care with other health-care services has shown improved treatment of severe COPD patients [10–12].

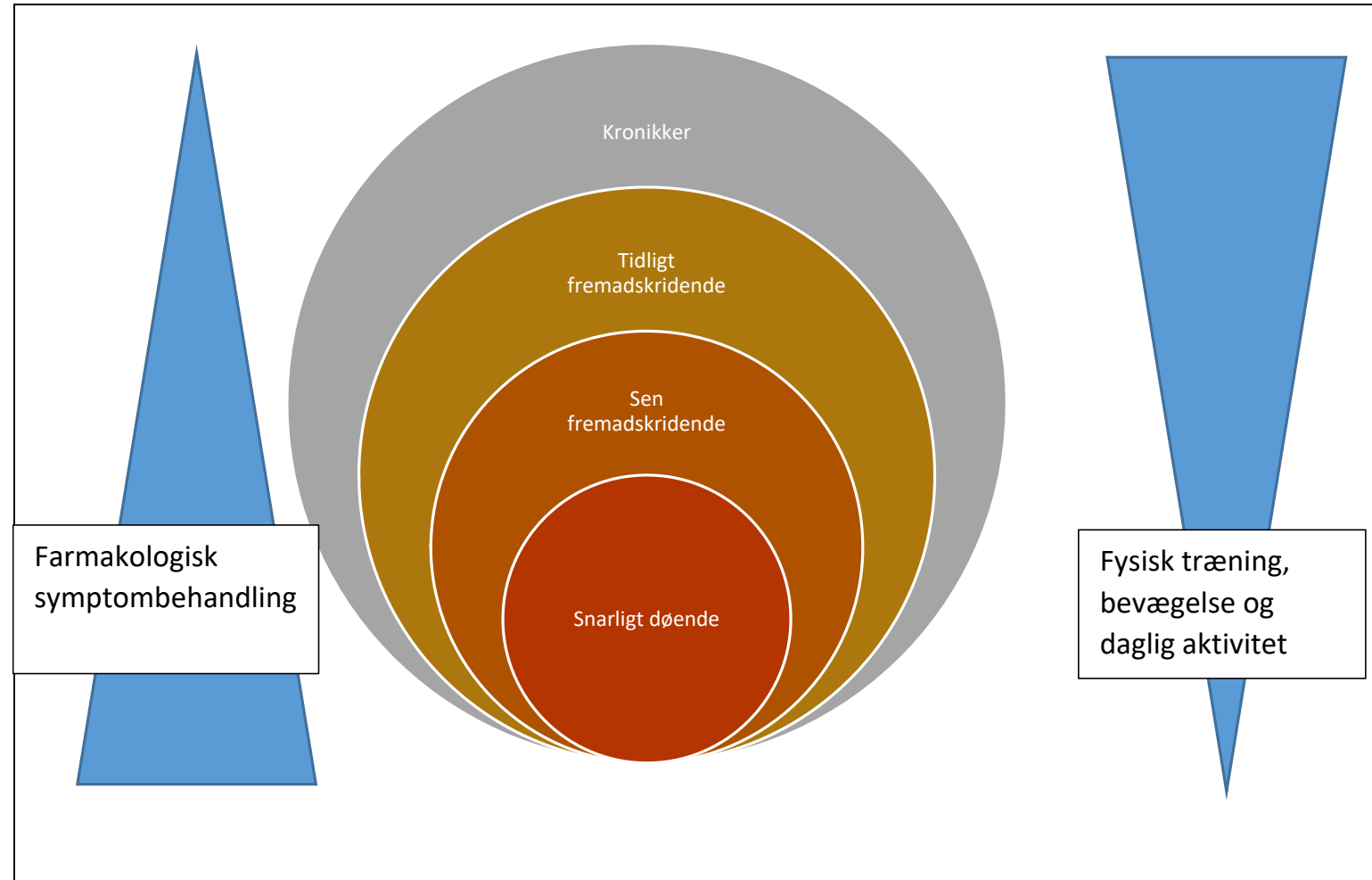
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# De 4 patientforløb (4,2,4,2)



*Fig 2. Prognose modellen for patienter tilknyttet lindrende behandling*

# De 4 patientforløb (4,2,4,2)



# 4 Dimensioner (4,2,4,2)



Fysiske genese  
+ psykologiske problemer  
+ sociale besværligheder  
+ kulturelle faktorer  
+ åndelige bekymringer

---

= ” *Den totale smerte* ”

## Den totale smerte.....

- Dyspnø
- Fatigue
- Kvalme
- Obstipation
- Diarré
  
- .....

## Det fysiske symptom

**+ psykisk**  
**+ socialt**  
**+ eksistentielt**

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**Den totale...**

# Smerter, træthed og åndenød.....



Take my breath away...





# Forskellen på en oplevelse og et symptom handler om.....

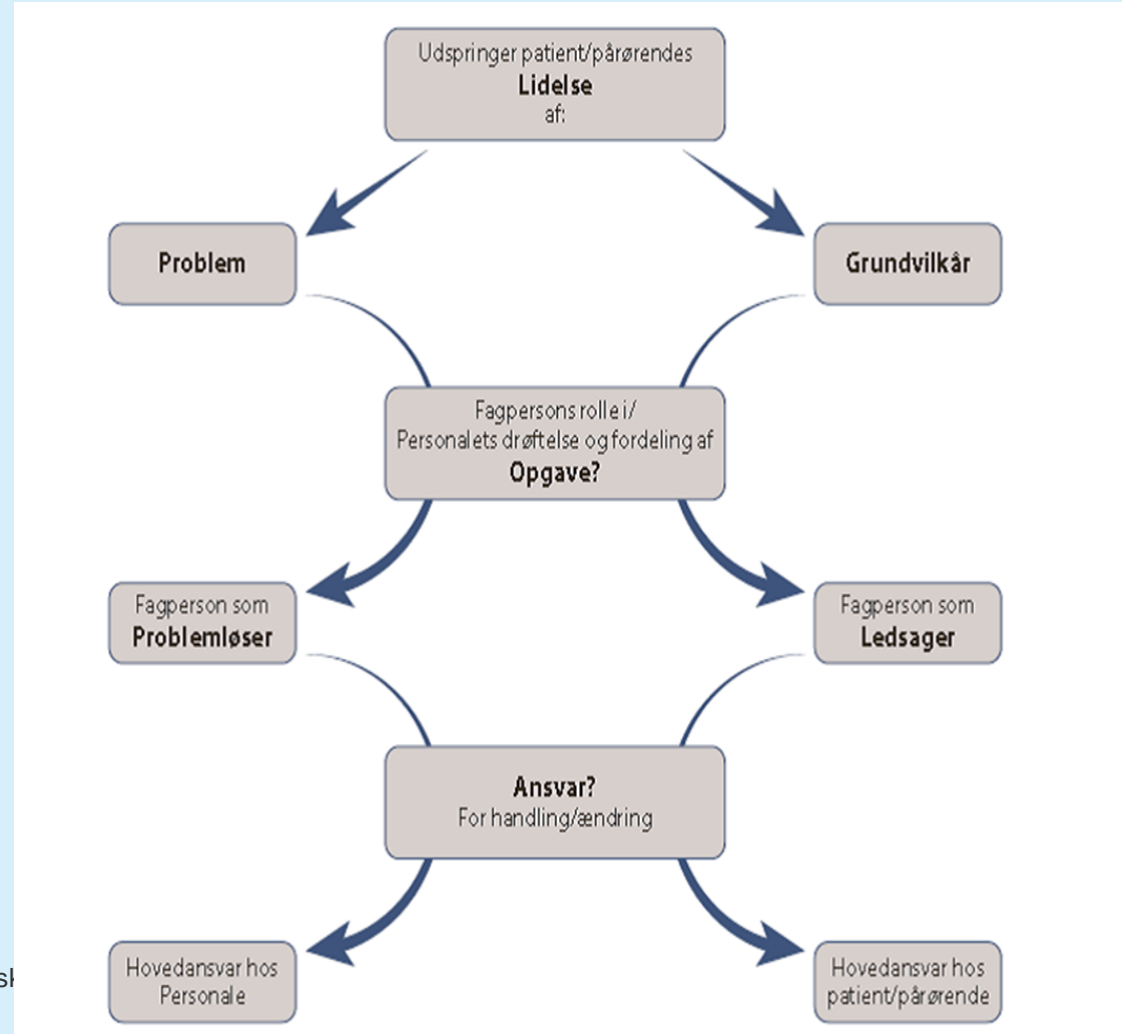
**[KONTROL]**

## Hvordan behandler vi et symptom?

Målet er, at støtte patienten i at genvinde kontrol.....

Måske ved at understøtte mening og værdighed?

## 2 roller/tilgange (4,2,4,2)



## Med patientens egne ord....



”Jeg har det efterhånden så dårligt, at det er en kamp at komme op morgenen.....Det er hårdt. Det er urimeligt hårdt. Jeg synes jeg har alt for lidt god tid”.

”Har jeg mere at leve for??? Det mener jeg ikke negativt. Men har jeg?? Nej, det her er ikke et liv. Det er et helvede”.

## 2 typer af faglig viden (4,2,4,2)

### Objektiv viden:

- Biokemi, EWS, scanningsvar og PROM skemaer

### Sansende /intuitiv:

- ”Det kliniske blik”
- Klinisk vurdering
- Interaktion med patient og pårørende

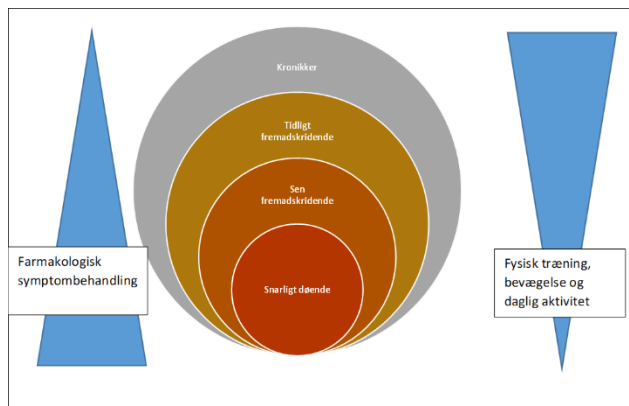
## SMS fra en patient

”Vil bare lige informere dig om de sidste (sørgelige) 24 timer. Jeg fik taget blodprøver, røntgen, scanning og LFU kort efter ankomst.... men ellers har jeg bare ventet. Det er som om jeg ikke eksisterer”

”Jeg er ikke blevet tilbudt mad eller drikke, så jeg venter bare, men ved ikke på hvad...” Jeg venter i hvert fald på, at de får øje på mig”.

# Så hvad sagde hende damen egentlig...

- 4 patientforløbstyper

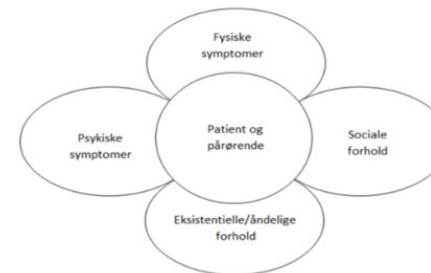


## 2 typer af faglig viden

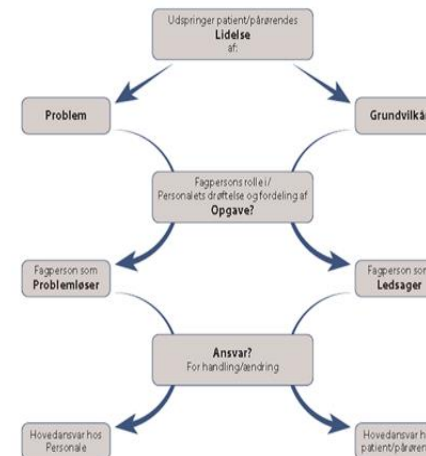
Objektiv og intuitiv/sansende viden

- 4 dimensioner

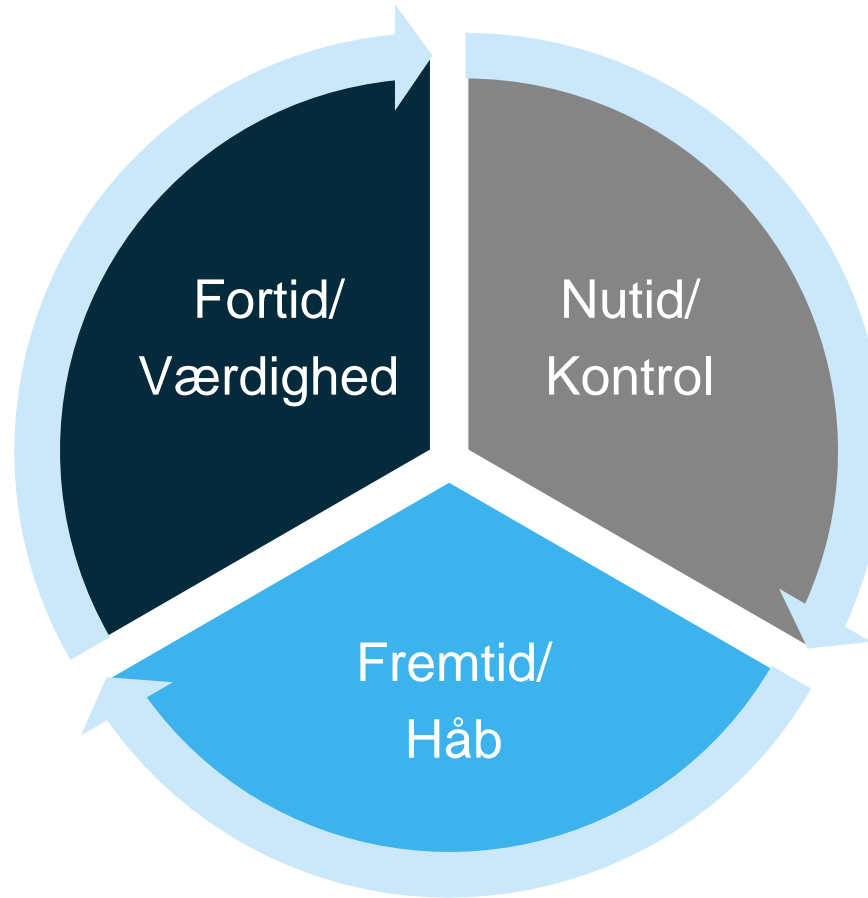
Figur 2: Palliative behov hos patienter med livstruende sygdomme og deres pårørende



- 2 roller



# Eksistentiel lindring i kommunikation





# Hvad er håb?

**Håb....**

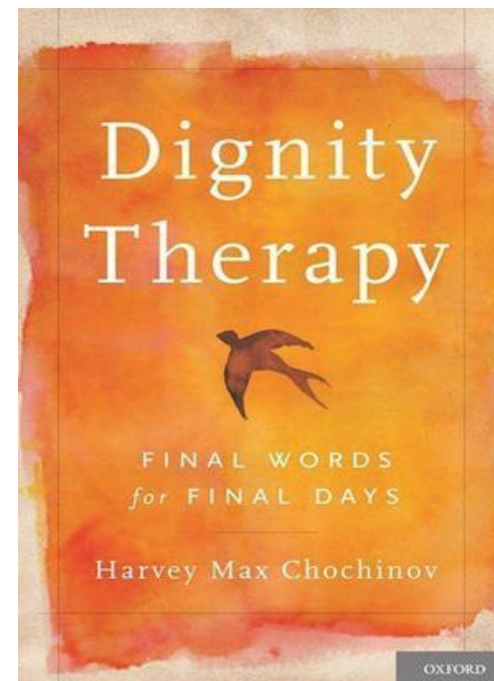


**Håblinge...**



# Værdighed

- **Det som du har gjort**
- **Det som du har været for andre**
- **Det som du tænker du vil blive husket for**



# Det meningsbærende i livet

- At være elsket
- At være noget for andre
- At have relationer



# Ikke død, men liv

## Ikke døds-, men (lives)vigtige samtaler

”Målet med samtaler med patienter i den terminale fase er ikke at dæmme op mod behandling, men at sikre en grundig afdækning af personlige ønsker, som medvirker til at sikre, at der træffes de beslutninger, som er bedst for patienten”.



# Advance Care Planning – en række af samtaler:



- ACP samtalen:
- Afholdes for at afdække patientens **ønsker for fremtidig pleje og behandling** for derved – sammen med patient og pårørende – at kunne **tilrettelægge en indsats, der hjælper bedst muligt med at nå disse mål.**
- Sikrer **fælles forståelse af sygdomsstatus** - Regelmæssig afholdelse af samtaler, med **justering af behandlingsmål**, på baggrund af patientens og de pårørendes værdier og muligt ændrede holdning.

ORIGINAL ARTICLE

## Cluster-randomised trial of a nurse-led advance care planning session in patients with COPD and their loved ones

Carmen H M Houben,<sup>1</sup> Martijn A Spruit,<sup>1,2</sup> Hans Luyten,<sup>3</sup> Herman-Jan Pennings,<sup>4</sup> Vivian E M van den Boogaart,<sup>5</sup> Jacques P H M Creemers,<sup>6</sup> Geertjan Wesseling,<sup>7</sup> Emiel F M Wouters,<sup>1,7</sup> Daisy J A Janssen<sup>1,8</sup>

**Conclusion** One nurse-led ACP-intervention session improves patient-physician end-of-life care communication without causing psychosocial distress in both patients and loved ones.



Sydvestjysk  
Sygehus



Herlev  
Hospital



# Vi har alle drømme om fremtiden





# Men Ingen ved hvad fremtiden vil bringe



## Noget om håb... ”Velkommen nye dag”

Lev hver dag som var den livets første,  
nyd hver blomst, hver fugl du ser under himlens tag  
Liv og lys vi møder, lægger mørket bag.  
Kom og syng i livets kor – Velkommen nye dag  
Husk at leve livet, glem al stress og jag,  
Sig hver morgen disse ord, velkommen nye dag  
Velkommen nye dag





## Tak for jeres opmærksomhed

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