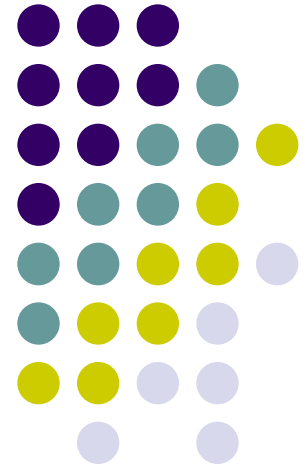


Live and let die...

palliative care in the community setting

Anette Fosse, Mo i Rana
General Practitioner
Nursing home doctor
Comprehensive care coordinator (PKO)



The basement:

Safety and trust

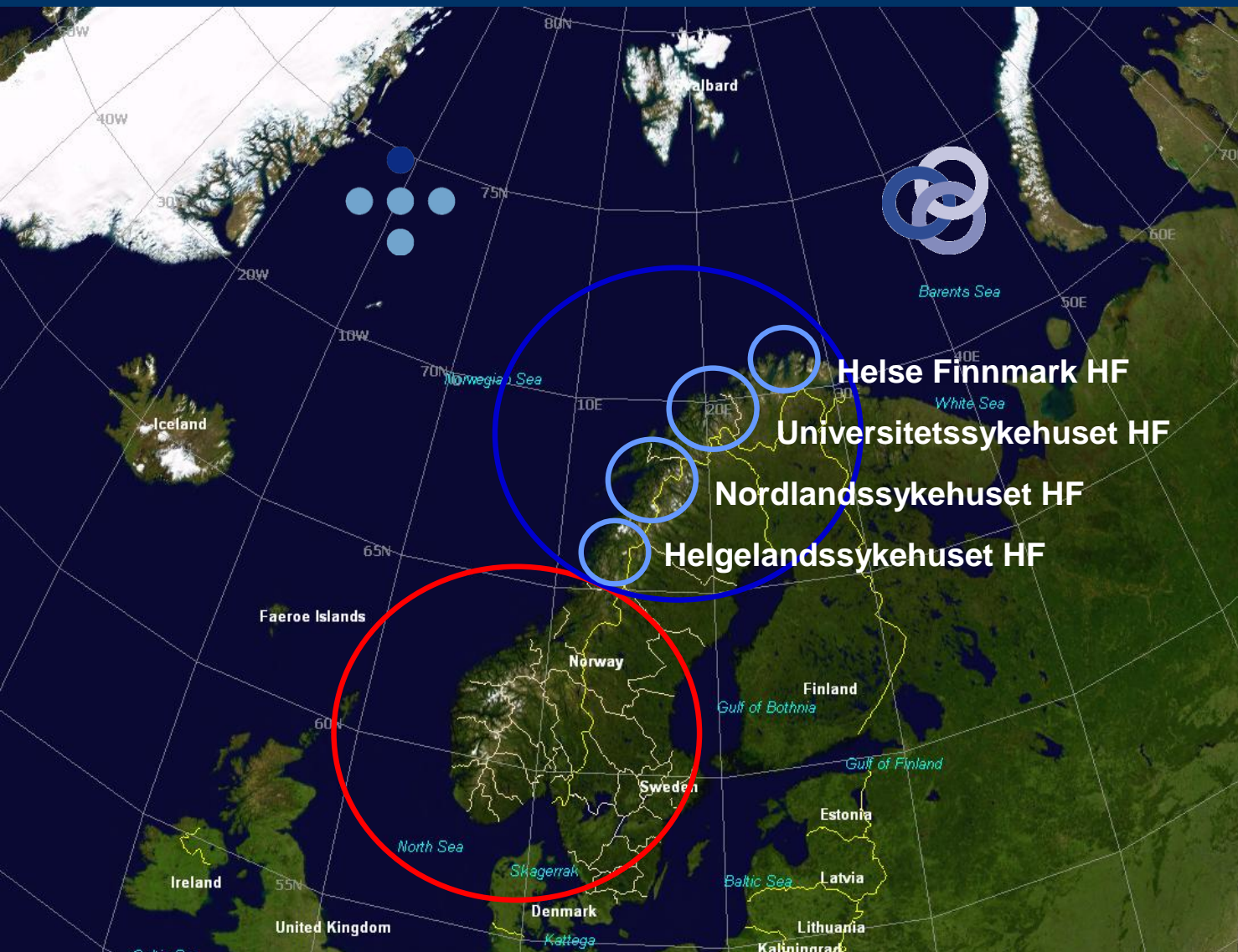
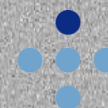


- Competence
 - Professional
 - Local
 - Personal
 - Comprehensive and cooperative
- Accessibility
 - 24/7
 - Geografically
 - Telephone
 - Electronic/telemedicine
- Continuity

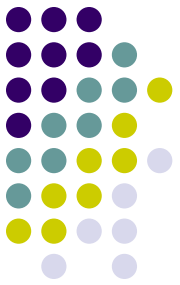


Pasientfokus og samhandling

HELGELANDSSYKEHUSET



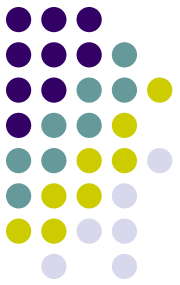
A short presentation



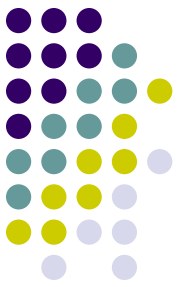
- My every day hats
 - GP for 864 inhabitants
 - Nursing home doctor in a short time unit
 - Palliative care, examination of function loss and dementia, rehabilitation
 - Comprehensive care coordinator and advisor (PKO) in Helgelandssykehuset, working on a system level with coordination of health care.

- Some other hats
 - Norwegian medical association and Norwegian college of general practice
 - Governmental working groups
 - Acute functions in general hospitals
 - Sick leave and disability
 - The coordination reform
 - Northern Norway regional health working groups
 - Comprehensive care
 - Frail elderly
 - Health trust board member
 - Helgelandssykehuset (Helgeland hospital trust)
 - Universitetssykehuset i Nord Norge (University hospital of Northern Norway trust)
 - Local
 - Working groups on dementia, intermediate care unit (Helseparken), safe medication
 - Member of the local community council
 - Member of [The Norwegian Council for Quality Improvement and Priority Setting in Health Care](#)

...and some other important hats...



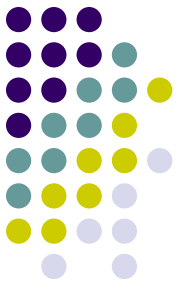
...and some other important hats...



Nordic Congress of General Practice 2011
Tromsø

Where do Norwegians die?

Norwegian statistical central bureau (SSB)



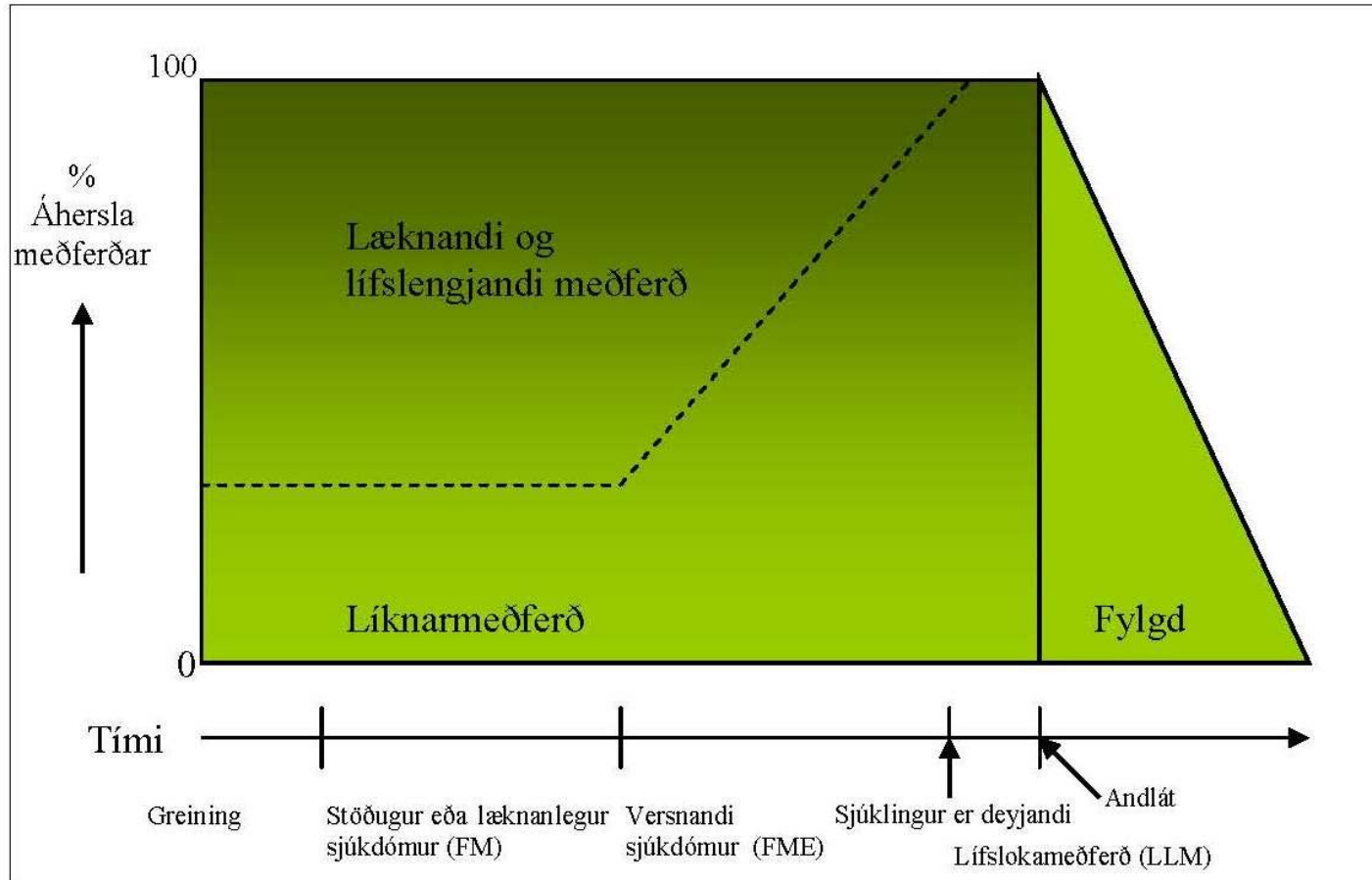
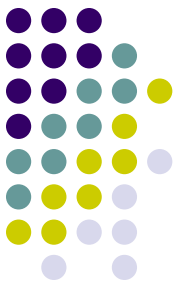
Place of death from any cause %	1991	2000	2009
Hospital	42	40	36
Nursing home	35	39	43
Home	18	15	17

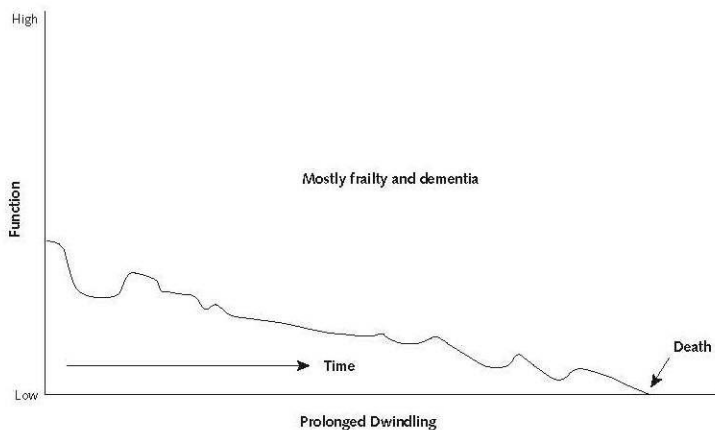
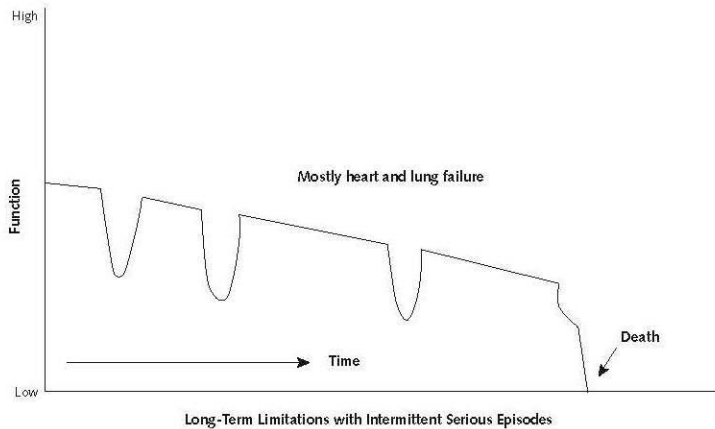
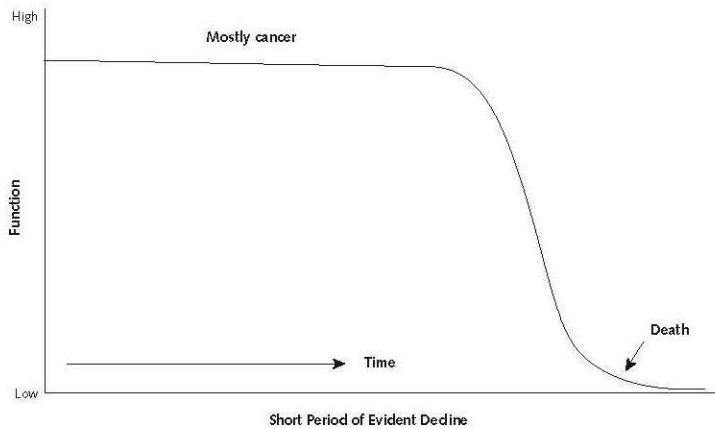


What is palliative care?

- The World Health Organisation (WHO) defines palliative care as follows
 - *“Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.”*

Palliation course





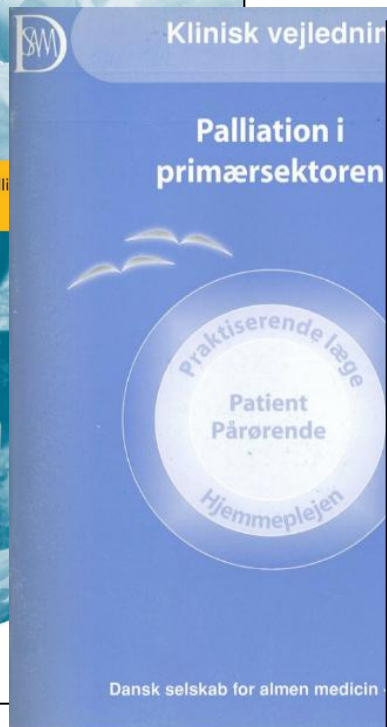
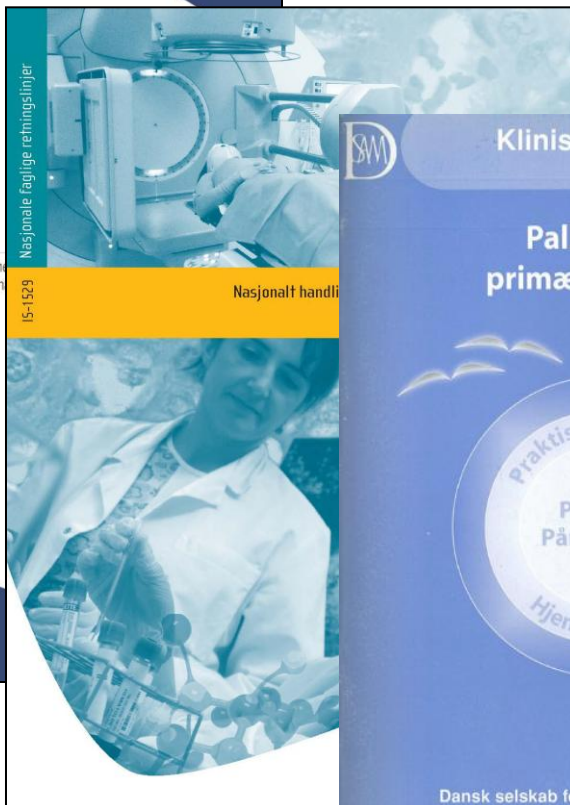
- Different courses – different challenges of palliation
- How and when to define "the turning point"?

Palliative care in the Nordic countries



Klínískar leiðbeiningar Líknarmedferð

Leiðbeiningar um ákvörðun meðferðar og miðla
með lífshættulega og/eða versnandi langvinnu



Primärvårdens och generalistens roll i den framtida hemsjukvården

Riksföreningen för distriktsköterskor, Svensk förening för allmänmedicin (SFAM), Familjemedicinska institutet (Fammi)

Syfte med dokumentet

Riksföreningen för distriktsköterskor och Svensk förening för allmänmedicin (SFAM) arbetar tillsammans med Fammi med att belysa och lyfta fram generalistens specifika och unika kompetens inom hemsjukvården. I dokumentet deklarerar vi gemensamma ståndpunkter för hur generalistens kompetens borgar för trygghet och tillit i dagens och morgondagens hemsjukvård. De flesta av dess ståndpunkter är inte unika för distriktsköterskor och familjeläkare utan gäller generalister inom alla professioner som arbetar med denna patientgrupp. De gäller dessutom oavsett om vården drivs i kommunal-, landstings- eller privat regi.

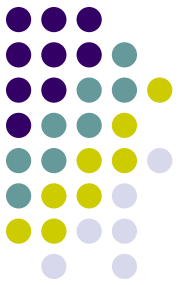
Inledning

Sjukhusvården expanderade kraftigt under det förra seklet och nådde sin höjdpunkt, vad vårdplatser beträffar, under 1970-talet. Vid sjukdom erbjöds man vård på sjukhus, ofta med långa värdtider och ibland efterföljande korvalescensvård tills hälsan återstälts eller rehabiliteringen avslutats. Under framför allt 80-talet har den medicinska utvecklingen och reduktionen av antal vårdplatser kraftigt förkortat värdetiderna på sjukhus. Patienter skrivs ut med betydande behov av fortsatt utredning, behandling och rehabilitering. Att detta är förenat med risker vid överföring från sluten till öppen vård och omsorg har uppmärksammats i ett flertal rapporter. Speciellt stora risker föreligger för människor med komplexa vårdbehov, individer som på grund av ålder, handikapp eller sjukdom har nedsatt autonomi och för sin trygghet och vardagsfunktion är beroende av andra människors vård- och omvårdnadsinsatser.

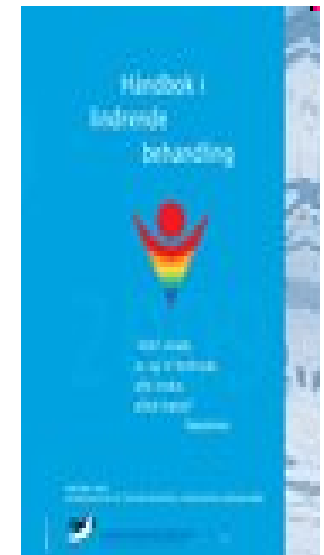
Denna förändring nödvändiggör en utveckling av hemsjukvården, som i framtiden sannolikt kommer att betraktas som en särskild vårdform vid sidan om sluten och öppen vård. Hemsjukvården ger människor möjlighet till ökad autonomi och livskvalitet jämfört med sjukhusvård, under förutsättning att den kan erbjuda säker medicinsk vård och trygghet i omvårdnad. Vår långa erfarenhet i våra yrken har givit oss en stor erfarenhet av de brister som finns i hemsjukvården, och vi har en gemensam ambition att verka för en utveckling mot en god och säker hemsjukvård där primärvårdens företrädare som generalister axlar ett huvudsansvar för vårdprocesserna. I denna utveckling behövs tydliga definitioner och mål för att stimulera utvecklingen över hela landet.

Även om hemsjukvården omfattar alla åldrar, så dominerar ändå gamla människor med komplexa vårdbehov. Dessa har nedsatt autonomi och är beroende av andra för sin omvårdnad och medicinska vård. Man beräknar att de utgör drygt 11 procent av alla över 65 år (siffrorna framtagna av Östergötlands läns landsting 2004). Utmärkande för dessa människors livssituation är att de p.g.a. sina omvårdnadsbehov får ge avkall på sin integritet, de tvingas ta emot främmande människor i sitt eget hem och bokstavligen in på bara kroppen. De som planerar dessa människors vård och omsorg måste vara utomordentligt lyhörda för den enskildes önskemål och anpassa vården till dennes förutsättningar. Deras problematik kräver att vårdgivaren har en längre tids kontakt och helhetsyn för att förstå vad som behöver göras. Det innebär att fortsatt vård inom hemsjukvården av ordinarie vårdgivare

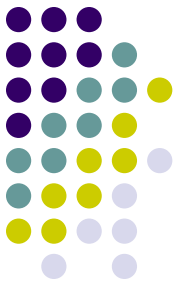
My own experiences in palliative care – learning by doing



- Important sources of my competence building
 - Patients and relatives
 - Other health care workers
 - LIN - Lindring i Nord
 - <http://www.unn.no/category11934.html>
 - NEL – Norsk elektronisk legehåndbok
 - <http://legehandboka.no/>
 - Courses and conferences
 - Medical journals and other literature



My wonderings...



- Recommendations on palliative care point out GPs as very important in this teamwork
 - What do GPs themselves think about participating in palliative care?
 - Are there differences between GPs in urban areas compared to GPs in rural areas? And between the Nordic countries?
 - Is involvement in palliative care compatible with everyday general practice?
 - How do we build palliative competence in primary care?
 - Does it make a difference if you are a nursing home doctor?
 - Do nursing homes have routines of palliation in "ordinary" death beds?
 - ...and so on...

A pilot survey study on general practitioners' experiences on participating in palliative care



- The Norwegian national recommendations on palliative care deeply involve GPs. I believe this is so in the other Nordic countries as well.
- My questions are if these recommendations are followed, and what GPs themselves think about participating in palliative care. Are there differences between GPs in urban areas compared to GPs in rural areas? Are there differences between the Nordic countries?
- The electronic survey study is done in cooperation with The Research Institute of the Norwegian Medical Association <http://www.legeforeningen.no/id/4719.0>.

The respondents



- Norway
 - Questback to 800 GPs
 - 177 respondents (22%)
 - 73 ♀ (42,7%)
 - 98 ♂ (57,3%)
 - Age 27-67
 - Years as a GP: 1-38
 - Patients: 550 – 2500
 - Nursing home doctor: 58(32%)
- Iceland
 - Questback to 190 GPs
 - 20 respondents (10%)
 - 4 ♀(20%)
 - 16♂(80%)
 - Age 41-64
 - Years as a GP:10-32
 - Patients: 720-2000
 - Nursing home doctor: 11(55%)

Participaton in palliative care in the patient`s home



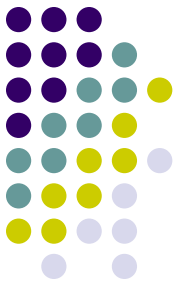
- The majority of the respondents (66-75%) had participated in palliative care in patients home
 - There were no significant differences based on geography and distance to hospital
- The majority offers home visits often or sometimes
- All agree that cooperation with home care and relatives is very important/important
- Differences between Norway and Iceland
 - In Norway the majority is accessible out-of-ours
 - In Iceland the majority is not accessible out-of-ours
 - In Norway the importance of cooperation with the hospital is ranked lower than in Iceland

Questions answered by nursing home doctors

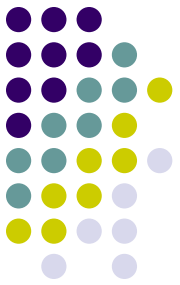


- Competence
 - 75% of the doctors have got some/good theoretical competence and practical skills in palliation
- Accessibility
 - 60% of the doctors are accessible in the afternoon/evening
 - 31% of the doctors are accessible in special cases
- Nursing home routines in palliation
 - 85% of the nursing homes have got routines on
 - palliation for both cancer patients and other patients with short expected life span and pain/discomfort
 - palliation for "ordinary" death beds
 - contact with relatives

Some comments on cooperation between GPs and hospitals

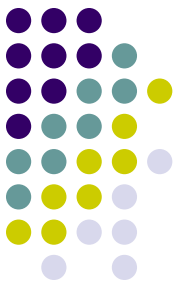


- "Cooperation with the hospital is cumbersome. I miss electronic communication and a "quick line" on the phone"
- "My patients use 5-6 different hospitals. It`s difficult to know which services are in what hospital"
- "There`s a struggle about the patients, I don`t think the hospital acknowledges primary care services"
- "I experience good competence and cooperation in both primary care and the hospital"
- "I experience good cooperation with home care and other primary care services in this kind of work"



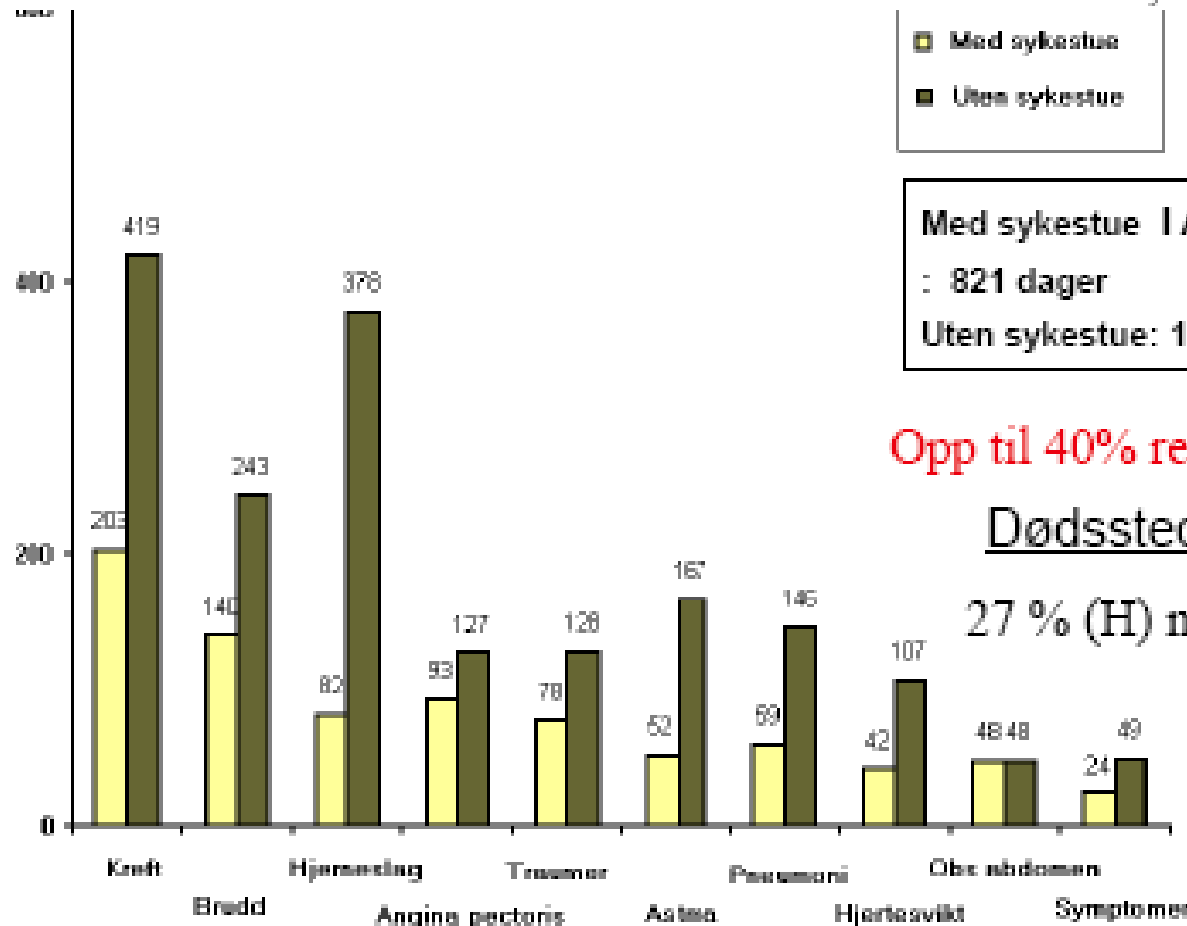
Some comments on GPs palliative work

- "There has been an increase in this kind of patients the last ten years"
- "An "ordinary" end-of-life process often requires 4-6 home visits"
- "I find this work very meaningful and an important part of my work"
- "Soon "somebody" has to tell what GPs are not supposed to do..."
- "I want more "self-going" nurses – it's a problem that many GPs don't do home visits any more"
- "I want internet-based competence building"
- "Our cottage hospital is very important as a competence center and partner in palliation work"



Liggedager på sykehus for ulike medisinske tilstander per 1000 innbyggere i kommuner med og kommuner uten sykestue

Kilde: Ivar Aaraas, NSDM, UiT



Med sykestue I ALT
: 821 dager
Uten sykestue: 1812 dager

Opp til 40% reduksjon!

Dødssted sykehus

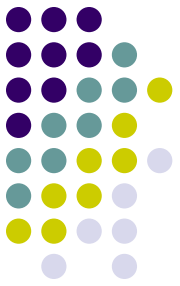
27 % (H) mot 60 % (N)

Cottage hospitals



- Ongoing project in Finnmark:
 - Cancer treatment in cottage hospitals - Interventions to improve the coordination of care
 - A three-municipality-network in cooperation with Lindring i Nord and other relevant hospital departments
 - Chemotherapy given by specialized nurse/trained nurse
 - Presentation by Erik Langfeldt, Nordkapp, Tromsø 15th May 2011
- Cottage hospitals are testing the boundaries of what treatment that can be given in the "grey zone" between primary and secondary care
 - Minimalize the impact of large distances
 - Exploring No-man-land and Both-man-land
- Some cancer treatments **can be given** where the patient live.
- Terminal care **should be given** in the local community

Where do palliative care and end-of-life care take place?



- Home
- Nursing home
- Intermediate unit
- Cottage hospital
- Local hospital
- Hospice
- University hospital

We must find – and agree about – the best pathways so that patients and relatives are confident that the one hand knows what the other is doing.

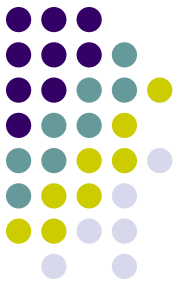


Challenges in the years to come

- Competence
- Quality
- Organization
- Funding
- Flexibility/local adjusting

The basement of community palliative care:

Safety and trust



- Competence
 - Professional
 - Basic education, life-long learning, networks
 - Local
 - Geography, possibilities and limits
 - Personal
 - Knowing the history
 - Talk about it!
 - Comprehensive and cooperative
 - Shared care, common pathways
 - Central framework – local adjustment
- Accessibility
 - 24/7
 - Home care, GP
 - Telephone!
 - Electronic/telemedicine
 - Transferring information, guidance, competence building
 - Geographically
 - Home
 - Near home
 - Nursing home (palliative unit), cottage hospital, local hospital
- Continuity
 - Recruitment, working conditions

Evig møte

Eternal meeting

av Anne Kristine Thorsby
april 2011

