Norway – a collective approach to supporting people with dementia and their care partners

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NORWAY (5.3 mill inhabitants)



Due to the oil exploration in the North Sea the state of Norway is considered to be richest country in the world "The World Bank"



Care for old persons in Norway is a public service

Municipality health and social service (Municipalities are responsible)

- Health care (GPs)
- Home care around the clock (district nurses and home-helps)
- Nursing home care with special care units (housing) for PWD

Specialist health service (The government is responsible)

• All hospital services, including geriatric psychiatry and geriatric medicine

Dementia care

Services designed for people with dementia and their care partners are based on:

2007-2015: The first national Dementia plan
2015-2020: The second national Dementia plan
2017: The national guidelines for dementia care

* The plans and guidelines are developed by national health authorities

The Norwegian national guidelines for dementia care

Based on:

>An evidence based evaluation of the literature

> The principles of the two national dementia plans

> The act of patient's rights and health personnel's responsibility and duties

Ethical principles

Ethical principles, such as respect for individual autonomy and dignity should be followed.

People with dementia <u>shall</u> have the same right to high quality social and health services regardless of ethnicity, gender, age, place of residence and income.

A person centred approach should be the basic for all services offered to PWD

Goals: all municipalities (n=422) shall have:

>A memory/dementia team or coordinator

- For diagnostic assessment and follow-up
- > As resource persons for the primary care health personnel and family carers
- > Day care programmes special designed for person with dementia
- Adapted living facilities for person with dementia
- Educational programmes for family carers
 - Carers' school and support groups
- > Educational programmes for professional caregivers at all levels

Local memory/dementia teams or coordinators

- Assessment and diagnostic in collaboration with GPs
- Regular follow-up every six month
- Give support to family carers (low threshold)
- Guidance and education of other health personnel



Today about 90% of all municipalities have such teams of registered nurses and occupational therapists (in about 50% a GP is pat of the team)



To improve the coordination of care and information European models of care management exist.

"Single points of contact" (guidance to increase access to care) Dementia adviser Dementia care manager Dementia case manager Dementia coordinator Dementia practice coordinator Dementia counsellor **Dementia navigator** Dementia nurse Dementia support worker Dementia team – Norway (assist the GPs in diagnosis and follow-up) Link worker (regular follow-up) **Resource worker** Pathway coordinator

Strategies to increase the dementia diagnosis

- >Establishing municipality dementia teams to assist the GPs in the assessment
- Sive GPs standardized tools for the dementia work-up
- Give GPs advice when to refer to a memory clinic (younger age, minor ethnic, learning disabilities, atypical signs)





A toolbox for dementia assessment



The toolbox consists of checklists and evaluation scales

- IQCODE
- CDR
- MMSE
- Clock Drawing test
- Cornell scale for depression in dementia
- Lawton and Brody's PADL and IADL scales
- Relatives' stress scale (Greene)
- Checklists for safety measures
- Checklist for the GPs for physical and psychiatric examination, blood tests, use of CT and MRI, diagnostic criteria, etc...

Diagnostic work-up of dementia in Norwegian primary health care



Specialist health care Disclosure of diagnosis

Follow-up

After the diagnosis

- Information to the patient and carers:
- Disclosure of the diagnosis
- >Information about the importance of the various symptoms
- >Information of the short-term prognosis
- >Information about drug treatment and possible side-effects
- >Information of access to social and health services
- >Information of how to behave towards friends and family
- > The importance of being physical and social active
- Discussion abut driving and giving up driving

The follow-ups

Shortly after the disclosure of the diagnose (2 weeks) ≻A phone call !!!!

Every 6 months, or in cases of emergency

- The GP should assess effects and side-effects of the use of drugs, both anti-dementia drugs and the use of psychotropic drugs
- The local dementia team should assess the patient's cognitive and ADL function; and needs for social and health services
- > The local dementia team should assess the next-of- kin's burden and needs

Day care activities



Day care activity centres (free transport, 2 meals and activities)

In 2007: 28% of municipalities had a special designed day care programme for persons with dementia

In 2018: 71 % of municipalities had a special designed day care programme for persons with dementia.

16% of municipalities had day care units design for patients younger than 65 years of age.
14% of day care centres were located on farms ("green care")

From 2012 to 2020 the Government give grants to the municipalities establish day care centres From 2020 all municipalities <u>shall</u> have day care centres special design for pwd

Mindre stress og mer prat på Hellerud omsorgssenter

Ny vri gir mer hygge

Enkle grep har gjort Hellerud omsorgssenter til et hyggeligere sted for beboerne. Noen pleiere avsettes til «hotellarbeid», resten skal bruke tiden til å være sammen med de gamle.

ANNIKEN HOGSTAD JAN TOMAS ESPEDAL (foto)

- Her får man hjelp før man ber om det. Selv om de kanskje ikke husker det om en halvtime, så setter pasientene pris på de gode opplevelsene, sier Sølvi Selli, ledende aktivitør på Hellerud omsorgssenter.

Senteret fikk ideen etter å ha hørt eldrepsykolog Lise Næss forelese om kvalitetssikring og endring av rutinene i eldreomsorgen. Næss driver Senter for gerontologi i Bergen.

- De fleste som driver eldreeller omsorgssentre her i landet, har bakgrunn fra sykehus. Derfor tar de sykehusmodellen med seg, påpeker hun. - De er flinke fagfolk, men det er viktig å huske at de to stedene ikke skal være like. På et sykehus er man i en viss periode for å bli



Spilloppmakere. Beboerne og de ansatte ved Hellerud omsorgssenter fyller dagene bl.a. med spill og andre aktiviteter. Fra venstre: pleier Mehri, Åse Lie og pleier Faduma.

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Nursing home



Care in Norwegian nursing homes

- Medical service: A GP or geriatrician is consultant and visit the NH at least once a week (depending on the size of NH).
- Daily care is carried out be registered nurses (1/3), nurse's aids (1/3) and people with no formal health education 1/3)
- Activities are offered according to the residents needs and interests
- The care should be person centred.

Special care units (municipality service)

- "Small is beautiful" (6-10 residents in each unit)
- Home-like environment.
- Many units have a scent garden
- Special trained personnel

Special care units (SCU) for person with dementia

SCU (people with severe dementia) : 10 000 places of a total of 38 000 places in NH Staff ratio in SCU= 2 residents : 1 staff

Group living accommodation (people with moderate dementia): 2000 places Staff ratio= 4 residents : 1 staff



SCU

Special care unit for people with dementia












Treatment of challenging behaviour

The standard: first line treatment of NPS is non-pharmacological

> Psychosocial interventions

> Education of personnel in nursing homes in Persons Centred Care

Make the environment simple and understandable for people with dementia
Organize care in nursing home in small home- like units

However, antipsychotics, are in use all over the world to treat challenging behaviour seen in PWD, although there is a "black box" warning according to most national guidelines

	ALL STUDIES		STUDIES WITH DEMENTIA ONLY		1
	N	POOLED % (95% CIS)	N	POOLED % (95% CIS)	N
Germany	6	31 (29-32)	4	45 (41-49)	2
UK	3	31 (30-33)	2	43 (38-48)	2
Sweden	4	28 (26-29)	3	26 (24-28)	1
Norway	7	25 (24-26)	4	24 (22-27)	3
France	4	25 (25-26)	1	26 (14-38)	3
Finland	2	27 (25-30)	1	29 (21-37)	1
Austria	2	45 (42-47)	1	49 (33-65)	1
Belgium	1	32 (30-35)		_	1
Spain	2	26 (24-27)	1	51 (42-61)	1
Ireland	1	36 (22-51)	1	36 (22-51)	
The Nether-lands	5	29 (27-31)	5	29 (27-31)	
Italy	1	29 (24-35)	1	29 (24-35)	

ANTIPSYCHOTIC DRUG USE

Use of antipsychotics to treat challenging behaviour in dementia

Several meta-analyses have concluded that antipsychotic medication has only a modest effect on agitation, aggression and psychotic symptoms

Wang et al 2014, Birks et a 2006, Ballard et al, 2009, Maher et al 2012, Tan et al, 2013, Seitz et al 2013, Matsunga et al, 2015, Maust et al 2015)

Long-term effect of antipsycotics

Effect on aggression using atypical antipsychotics

Treatment in 6-12 weeks	Modest effect
Treatment in 6-12 months	No effect

Ballard et al, 2009 – reviewing 18 RCTs

So, why do we use psychotropic drugs in people with dementia?

(The use of antipsychotics has dropped from 25% to 16% in Norwegians NHs during the last 5 years)

Some comments on the programme "Younger persons with dementia"

- Diagnostics and follow-up in memory clinics
- Specialised designed day care centres
- Specialised designed care homes
- Use of assisted technology
- Examining the needs of spouses and children



Support to family carers

«Carer school» (in 2018 about 5,000 participated)

For all carers For carers of younger people with dementia For carers of people with learning disabilities and dementia For carers of Sami people with dementia

Support groups (special groups for carers of YOD) Support persons Activity friends (more than 2,000) Cafe

Family carers' "school"

- The "schools" are a collaboration between a local Alzheimer club (volunteer) and the municipality. Funded 100%
- 4-5 evenings, each 3 hours (one specific theme is chosen)

Lecture; 45-60 minutes

Coffee break

Group discussion

Summary

• Today about 90% of all municipalities have schools





Education of personnel About dementia in general About palliative care About music therapy About dementia in people with learning disabilities

- A 2 years educational program.
- Booklets, films, e-learning
- Group (8-10 participants) discussions every second week for 2 hours
- Seminars twice a year

Results ABC learning by 31.12. 2018

The most successful measure of the dementia strategy

49,200 have finalized the ABC educational program 6,600 are in the educational program

Summary

- The Norwegian Dementia plans and the national guidelines have led to many new initiatives that have improved the care for persons with dementia and family carers
- The cheap initiatives have been easy to implement (educational programs and carers' schools), whereas the costly initiatives (day care activities) have been more difficult to implement. However, the government has decided that all municipalities shall organise day care activities for PWD.
- The memory/dementia teams in the municipalities could develop to be the cornerstones in the future dementia care, as they should not only be involved in assessment and follow-up of patients but also in running carers' schools and be the experts of dementia care in the municipalities.