Improving quality of health care for people with dementia

Gunhild Waldemar
Key points

• Rehabilitation and psycho-social support at all stages of dementia are important for the well-being and quality of life.

• To maintain good quality of life people with dementia also need access to high quality health care.

• Adequate health care for people with dementia is dependent on
  ✓ accurate and timely diagnosis
  ✓ access to appropriate local programmes for post-diagnostic support
  ✓ education and competences among professional carers and physicians

• People with dementia need assistance and special attention from dedicated health care professionals in order to
  ✓ maintain a healthy life style
  ✓ Identify and get appropriate treatment for co-morbid conditions
  ✓ benefit from primary and secondary health care services.
Some figures for Denmark

- Estimated number of people with dementia
  ≈ **80,000**

- Registered with a dementia diagnosis
  ≈ **35,000**

- Total health care costs per year
  ≈ **DKK 24 billion (EUR 3.2 billion)**

- Employees working with dementia in DK
  ≈ **100,000**

- Danes with a spouse, parent or close relative with dementia
  ≈ **400,000**
Purpose of health care?

- Diagnosis
  - Psycho-social support
  - Healthy lifestyle
  - Treatment comorbidity
- End-of-life care
The importance of an accurate and timely diagnosis

To understand the disease and know what you are able to do as well as the possibilities for treatment, support and help.

Being able to express personal wishes for the future care, treatment, housing, finances etc. and then receive customized care.

To maintain the social network and be able to develop new contacts. To meet peers and their relatives. To feel included in society.

To receive help and support from the surroundings to manage the disease and to maintain quality of life and resilience.

To identify patients with other treatable disorders.
<table>
<thead>
<tr>
<th>Potential benefits of early diagnosis</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>Symptoms may be due to a reversible/treatable condition</td>
<td>yes</td>
</tr>
<tr>
<td>Most patients with early stage dementia would wish to be told of their diagnosis</td>
<td>yes</td>
</tr>
<tr>
<td>A diagnosis provides access to a pathway of evidence-based treatment and support across the disease cause.</td>
<td>yes</td>
</tr>
<tr>
<td>Some interventions are best implemented - in the early phase</td>
<td>yes</td>
</tr>
<tr>
<td>Better prognosis and long-term outcome ?</td>
<td>no</td>
</tr>
<tr>
<td>Will help caregivers understand and get access to support</td>
<td>yes</td>
</tr>
<tr>
<td>Empowering people to</td>
<td>yes</td>
</tr>
<tr>
<td>• participate in their own legal, financial and long-term care planning</td>
<td></td>
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<tr>
<td>• planning activities for the future</td>
<td></td>
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<tr>
<td>• seek information about their disease</td>
<td></td>
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<tr>
<td>Important impact on cost-effectiveness of interventions</td>
<td>yes</td>
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</tbody>
</table>
Validity of dementia diagnoses

Validation of diagnostic accuracy of all people in the Danish population registered with a dementia diagnosis:

• Elderly (≥65 år):\(^1\) 86% correct
• Young: (<65 år):\(^2\) 53% correct
• Ethnic minorities:\(^3\) 37% correct

Barriers

Person with dementia
• Memory loss prevents adequate reporting of symptoms
• Stigma
• Lack of insight

Health care professionals
• Therapeutic nihilism
• Lack of support available
• Time constraints
• Concerns about stigma
• Diagnostic uncertainty
• Discomfort in disclosing diagnosis
• Lack of competencies

Organizational and financial barriers
Maintaining a healthy life style
Maintaining healthy life style: barriers

• Lack of independence: need assistance to get out for a walk, for physical exercise, social activities

• Weak social network

• Not able to prepare own meals - difficult to make shopping lists

• Impaired hygiene

• May no longer check blood pressure, body weight, glucose, cholesterol, etc.
Co-morbidity

Co-morbidity = other diseases in a person with dementia

• At increased risk of infections, malnutrition, incontinence, dehydration, adverse effects of certain medications, epileptic seizures, and neuropsychiatric symptoms
• New co-morbidities may go unnoticed in people with dementia
• Lack of treatment - or mis-management - of pre-existing physical disorders may worsen symptoms of dementia, and lead to pain, physical disability, hospitalizations or death
• Inappropriate medication may worsen symptoms of dementia (e.g. long term antipsychotic or opioid treatment)
• People with dementia may not get the same treatment as people without dementia
• Conditions leading to acute hospitalization may be prevented (e.g. falls, hip fracture, infections)
Dementia: from 30% to 20%  
No dementia: from 4,5% to 2,9%

Use of opioids in Danish elderly population

Fig. 2. Percentage receiving an opioid in 2010 stratified by dementia, age group, and living status.

Jensen-Dahm 2014; more info at P22 Nov. 2
Health care contacts (Denmark, 2014)

Somatic hospitalizations

Physical contacts in general practice (incl. home visits)

Somatic out-patient visits (incl. home visits)

E-mail and phone calls

Barriers

People with dementia

• Have difficulties reporting symptoms following guidelines and making appointments with health care services
• May not be offered appropriate evaluation and treatment

are totally dependent on

• a family caregiver who coordinates all contacts with a wide range of health care professionals
• health care provision from primary care, specialists and hospital staff, who are pro-active and have basic knowledge about dementia
Care coordination and case management

- Primary care health services and rehabilitation, hearing aids, dentist...
- Primary care physician
- Volunteers
- Family and friends
- Person with dementia
- Family caregiver
- Somatic and psychiatric hospital departments
Solutions?

• Better care coordination and access to specialists when needed

• National professional networks

• Easily accessible educational programmes

• National quality indicators

• Raising awareness about inequality in the access – and about the impact of improved health care
National quality indicators

- Strengthen collaboration between the health sectors and among professional groups
- Reduce inequality in the access to care
- Make results of local investments and strategies visible
- Transparency – public availability of data
ET TRYGT OG VÆRDIGT LIV MED DEMENS

OPLÆG TIL DEN NATIONALE DEMENSHANDBLINGSPLAN 2025

HØRINGSVERSION • EFTERÅR 2016
Proposed national indicators

Proportion of people diagnosed with dementia, who receive a specific diagnosis (goal: national average above 80%)

Proportion of people with a dementia diagnosis, who receive antipsychotic treatment (goal: national average max. 10%)

Number of dementia-friendly municipalities (goal: 98/98)
Defeating Alzheimer’s disease and other dementias: a priority for European science and society

Executive summary
Alzheimer’s disease (AD) is the leading cause of dementia, private investment in the care of patients and the search for AD therapeutics.

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Thank you