Involving people with dementia in a new dementia strategy

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Norway, 5 Million inhabitants
Background

- 78,000 people with dementia in Norway
- Almost 300,000 family carers
- In-home and nursing home care are provided around the clock by public services

And:

- Norwegian Health Association is a voluntary, humanitarian organization that:
  - Promote the interests of persons with dementia and their carers
  - Run local dementia groups (clubs) throughout Norway (> 140).
  - Has an Advisory Board that communicate with national politicians and various stakeholders.
  - Has a working group of people with dementia
The Norwegian dementia plan

• In autumn 2006 The Ministry of Health and Care Services proposed the Dementia plan

• The Norwegian Directorate of Health Affairs was asked to make a report to outline the challenges and needs and to recommend focus areas for actions. The report “Forgetful but not forgotten” was published in spring 2007.

• Draw against this report the Ministry of Health and Care Services published “the Norwegian Dementia Plan 2015 – making the most of the good days”. The plan was set into action in autumn 2007
The overall aims of the plan

• To increase knowledge about dementia in the society and among family and professional caregivers, and thereby improve the quality of care for persons with dementia and their family carers

• To develop and offer a variety of day care activity programmes

• To adapt living facilities (residential care) to the patients needs under the slogan “SMALL IS BEAUTIFUL”
In 2015

All municipalities (n=428) shall have:

- A dementia team
  - For diagnostic assessment and follow-up
- Various day care activity programmes
- Adapted living facilities for person with dementia
- Educational programmes for family carers
- Educational programmes for professional caregivers
New plan?

• The Norwegian Health Association started lobbying for a new dementia plan in 2013

• Goals from the current plan was not achieved

• The need to involve people with dementia
It worked

The Minister of Health and Care Services decided to launch a new plan in 2016:

Dementia plan 2020 (2016-2020)
Dialogue meetings

To involve people with dementia and to hear their voices in the new plan:

- **7 dialogue meetings were organized**
  - About 700 - persons with dementia, carers and health professional participated

- **In the 7 meetings the 700 participants discussed the goals of the new plan (in 70 working groups)**
The meetings

• The program of the dialogue meetings:
  – Opening by Ministry of Health and Care Services
  – Persons with dementia shared their stories
  – Group discussions (6-8 people): Input to the new dementia plan

The group discussions:
• Were structured and detailed minutes were written
• An adapted version for people with dementia
Outcomes of the dialogue meetings – What should be the goals of in the new plan?

- Implementation of activities/treatments to prevent dementia
- Timely diagnosis of dementia and post diagnostic support
- Meaningful daily activities for pwd that could improve independent life
- Improve knowledge of dementia and skills among health care professional and in the society in general (dementia friendliness)
- Improve the quality of care in nursing homes
The new plan is now out for consultations and all the goals that were discussed in the dialogue meetings are part of the plan

- Cooperation between:
  - Ministry of Health and Care Services
  - Norwegian Advisory Unit on Ageing and Health
  - National Health Association

- User involvement all the way secures legitimacy
Thanks to all who participated in the dialogue meetings

Thank you for your attention