



The Norwegian Brain Strategy – a case study

Anette Storstein MD PhD

Vice-chair, Board of the Norwegian Brain Council

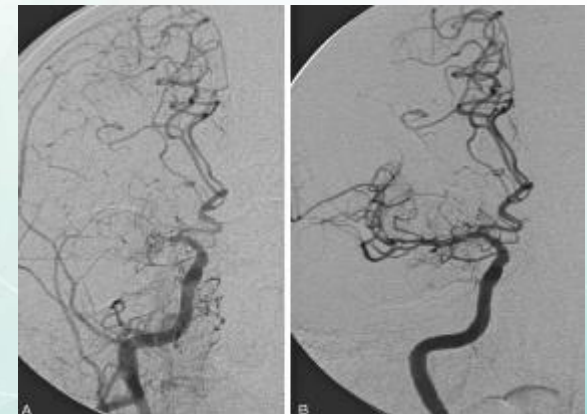
The Norwegian Brain Council (NBC)

- NBC was founded in 2007
- 53 member organisations:
Health professionals, user organisations, research groups and networks
- Provides an arena for interaction and collaboration
- 7 board members: Clinicians, researchers, user organisations and a politician
- Aud Kvalbein, CEO
- 2 reference groups: Scientific issues and Follow-up of national plans
- The development into a (semi)professional lobby organisation

The road to a national brain strategy 1: lobbying and consolidating

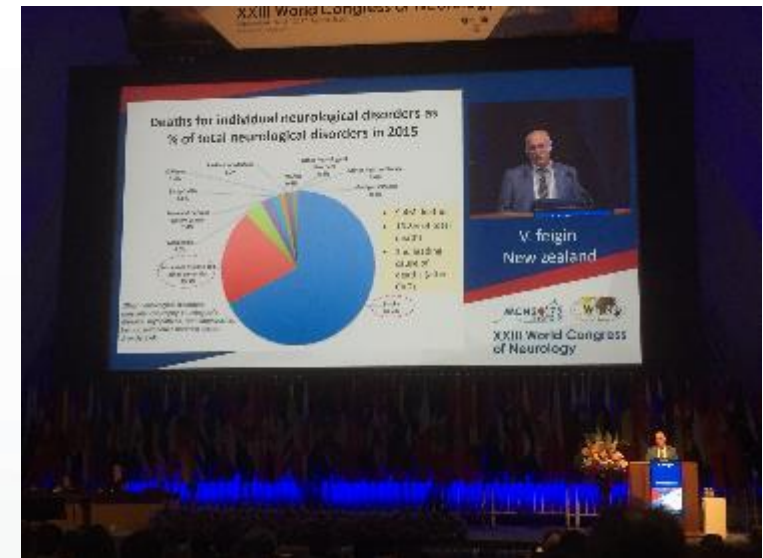


- 2014-2015: Patients' organisations (PO) lobby for a brain strategy
- 2015: NBC and PO join forces
- June 2015: The leading Parliament opposition party requests a plan for brain disease
- Autumn 2015: NBC receives public funding
- Autumn 2015: Parliament makes a formal request for a national brain strategy
- The Brain Health term is introduced



A Norwegian brain strategy: why?

- Burden of brain disease
- Life expectancy
- The "Four Great" of health politics
- Brain health issues are underestimated, undervalued and underfinanced
- Lack of focused disease prevention strategies and (curative) therapies
- Fragmentation of the brain field
- Psychiatric vs somatic brain gap
- Increasing public interest in brain disease and brain medicine



- ### Summary
- The leading cause of disability
 - The second (after injuries) leading cause of mortality
 - Affects 1 in 3 people (used to be 1 in 5), and the burden is increasing
 - Five top-ranked causes of disability (by DALY rates): stroke, migraine, ADD, meningitis, epilepsy
 - About 10-fold geographical differences in the burden (most of the burden in LMIC)
 - Significant gender differences (burden from ADD, MS and headaches is greater in W)
- XXIII World Congress of Neurology

The road to a national brain strategy 2: gaining momentum

- January 2016: The Minister requests a national brain health report from the Directorate of Health
- January – April 2016: NBC leans on the senior advisor in charge
- June 2016: NBC conference with the Directorate and member organisations: outlining NBC agenda
- Key professionals and the Norwegian Neurological Association offer assistance to the Directorate
- September 2016: The Directorate arranges an input conference
- The Brain Health concept catches the eye of the Minister's State Secretary

The road to a national brain strategy 3: walking to the same beat

- Clear and simple NBC messages
 - Adhering to the Brain Health term
 - Drawing lessons from cancer strategies
 - The brain field as a united field with common challenges
 - Life-long perspective – continual needs – individualized services
 - Cognition, psychiatry, children and adolescents
 - No regional differences
-
- High quality **research**, good **clinical practice**, **education** of competent professionals and patient **participation** is a continuum

The road to a national brain strategy 4: A report on national brain health care is warranted

- Autumn 2016: Task Force Group is assembled
- Deadline: Winter 2017
- Strong professional representation in the Task Force Group
- Round-table conferences
- Reference groups of relevant medical professions
- In retrospective: Patient perspectives could have been emphasized more

February 2017: Norwegian Brain Health report



The Brain Health report: conclusions

- Regional health care quality variations in primary and secondary care
- Insufficient interactions between levels of care
- Lack of low-threshold community measures for life-long perspectives
- Insufficient (specialized) rehabilitation services
- Changing perspective of the patient role demands adjustments
- Medical and scientific development
- Research is the foundation of clinical care
- Education and clinical implementation must be improved
- Clear indication that chronic diseases will be the priority

Progressing from a report to a strategy:

May, 2017: Brain Health at the PM's table



- The PM announces an upcoming Brain Strategy
- Specific funding for neuroscience research (outside of regular funding programs)
- The need for a unified brain disease approach
- Neurodegenerative disorders
- Brain Health concept branding

Working days with the health bureaucrats

- Sept 2017: Input conference with the State Secretary
- Sept 2017: National elections
- Sept – Oct 2017: continuous contact with the Directorate to help developing the strategy (according to the NBC visions...)
- Presenting Norwegian data from the Global Burden of Disease





Helse- og
omsorgsdepartementet

Strategi

Nasjonal hjernehelsestrategi (2018–2024)



The Brain Health Strategy 2018-2024: Dec 13, 2017



The four objectives:

1. Good life-long brain health, prevention and quality of life
2. Health care service tailored for the needs of the user and caretakers
3. Good health care from onset, diagnosis and treatment to habilitation and rehabilitation
4. Adequate knowledge and quality through research and innovation

Quotes from the introduction of the Strategy

When the brain is affected by disease or injury, a lot is affected. Getting the kids off to school in the morning and cooking dinner in the afternoon goes from normal to an oddity. Keeping up with to-do lists with important meetings and your little one's training timetable becomes impossible.

It might be difficult to do your job. It might be difficult to keep track of your body. It might affect your loved ones and what you love the most. It can change your life. It can shorten your life.

Therefore, we need a brain health strategy on how to best prevent disease and injury, and how to best investigate and treat them. How we can best help patients and their families to cope with disease and injuries that affect the brain.



Bent Høie

Minister of Health and Care Services

12th December 2017

Society benefits hugely from preventing brain diseases and improving the health services for those affected. Active and equal participation from users is vital to create better brain health within the population.

Prevention of brain diseases, good and equal treatment, follow-up and rehabilitation, as well as increased research and expertise, is a good social investment and an investment in the individual.



Henrik Peersen

Chairman of the Norwegian Brain Council

Current challenge: Implementing the Strategy

- Transforming the objectives of the strategy into concrete measures at all levels of health care service
- Models of life-long care for neurological diseases
- Working for an increase in research funding
- Competence is an investment
- Workshop meetings with all Parliament parties to ensure continuous political momentum - with national budget consequences
- What's been the key to success – in Norway?

Getting attention: Brain matters!

- Increasing public awareness means raising political attention
- Organizing public events and conferences
- Education and information on brain health issues
- Social media
- Political congregations
- When in Parliament....
- Close collaboration with user organisations



