

# New (Knowledge) Infrastructure for Patients with Severe Acquired Brain Injury: the Dutch Model

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# **New (Knowledge) Infrastructure for Patients with Severe Acquired Brain Injury: the Dutch Model**

Nobody should fall between the cracks

# Outline

- Background
- Expertise Network (EENnacoma)
- Chain of Care
- New Knowledge Infrastructure PDOC
- Lessons



# Unique Academic Medical Specialty

- Elderly Care Medicine (1990-2009: nursing home medicine)
- 3y postgraduate training program
- Incl. (geriatric) rehabilitation, long-term care, palliative care
- Advance Care Planning
- Specific target groups, e.g. severe ABI, PDOC



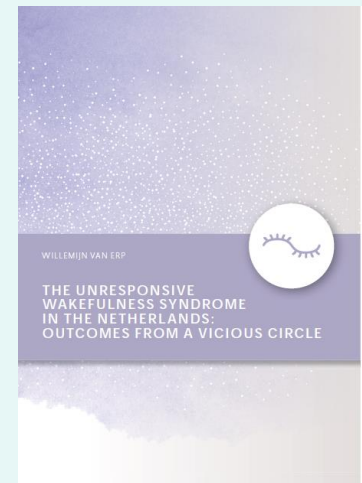
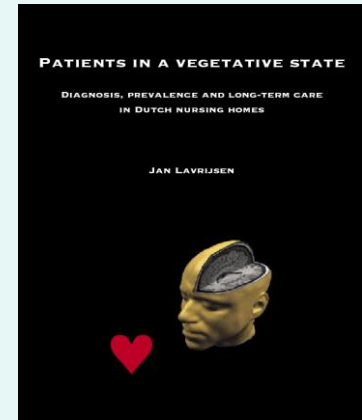
# Long-term care PDOC in the 80s

- Patients without consciousness, without rehabilitation
- Families without hope
- Professionals without specialty
- Everyone without knowledge
- First landmark case (Stinissen 1974-1990)
- Problematic long-term care



# PDOC in The Netherlands

- > 90s: ethical & medico-legal framework
- Lowest prevalence UWS: 0.2/100.000 (2003, 2012)
- Lowest prevalence MCS: 0.2-0.3/100.000 (2021)
- < 2019: specialized rehab. reimbursed up to the age of 25
- 2012: 54% UWS patients no access to rehab.
- 2021: 53% MCS-patients admitted to rehab.
- Cohort UWS 2021-2018: 50% withdrawal ANH, survival > 33 y



# Vicious circle < 2019

- Undertreatment in the acute and postacute phase leads to overtreatment in long-term care



## End-of-life decisions

Tendency to  
discontinue treatment

## Epidemiology

Low number of patients  
Chances of recovery  
unknown



## Care organization

Suboptimal treatment



# Expertise Network Severe Acquired Brain Injury (EENnacoma, > 2016)

- EENnacoma = *'ONE after coma'*
- Research Group: *'Nobody should fall between the cracks'*, Radboudumc (2012)
- 9 care organizations:
  - 1 Specialized Rehabilitation Center (PDOC)
  - 8 Nursing Homes
- Professionals in the lead
- 'Figureheads' to connect science and practice
- Mission and vision





# Appropriate Care for Patients with PDOC

- Based on science and best practice
- **Adequate rehabilitation**
- Network of expertise
- Chain of care, mobile team



# National Care Standard TBI

- Supraregional and national organization of care for adults with severe traumatic brain injury and PDOC

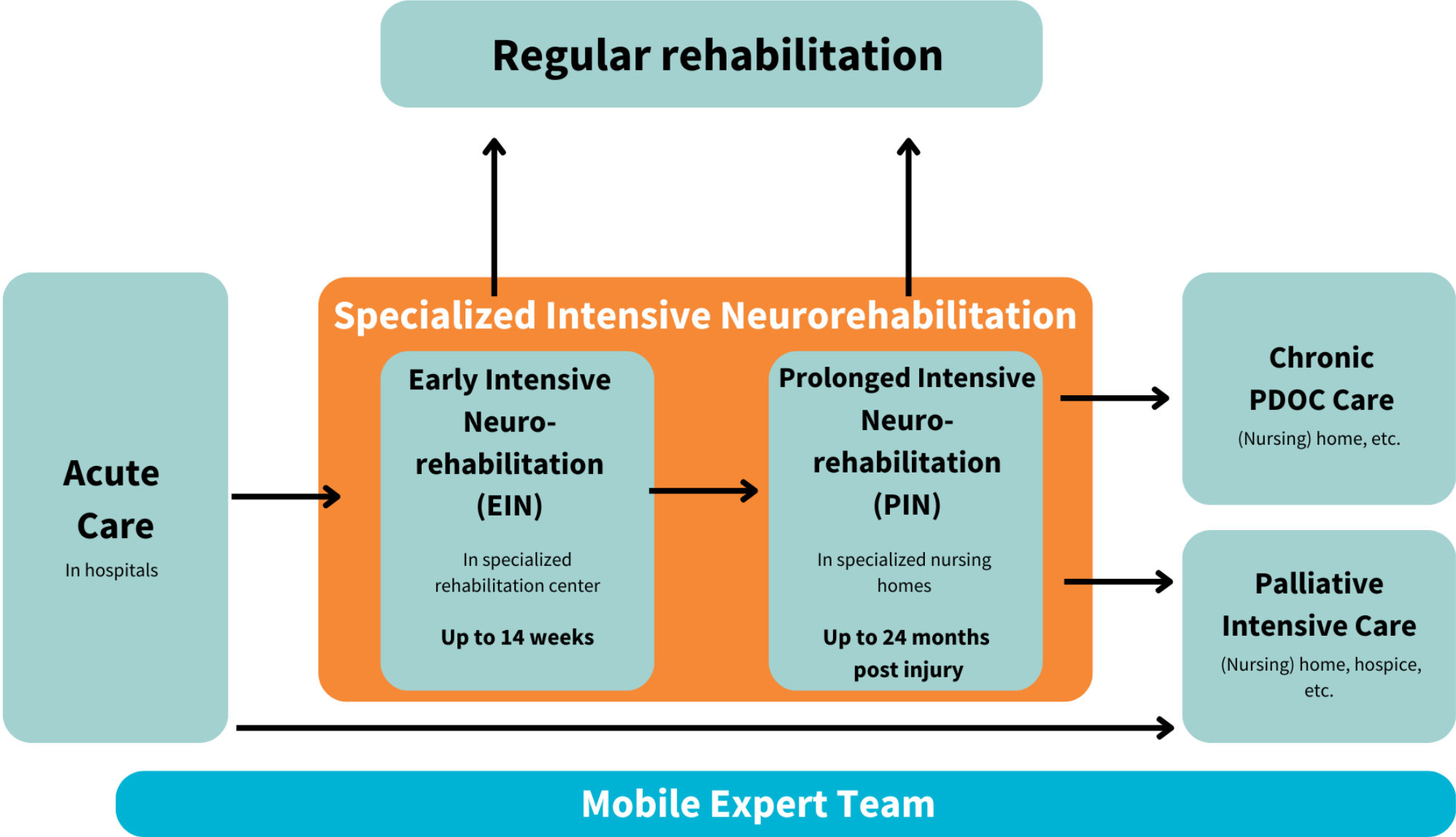
## Statement:

- ‘Let the content of this care be leading for organization and funding’
- *Upcoming:* New Care Standard TBI/stroke recommends access to the specialized chain of care



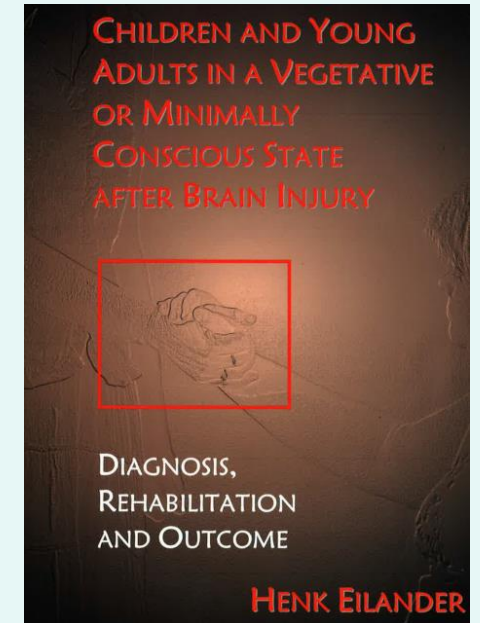
Care Standard Traumatic Brain Injury  
Brain Foundation Netherlands, 2014

# PDOC Chain of Care > 2019



# Early Intensive Neurorehabilitation

- 1987: developed for children & young adults (0-25y)
- 1994: specialized team (directed by rehabilitation physician)
- Two-thirds of patients regained consciousness
- < 2019 reimbursed up to the age of 25
- > 2019 for all ages
- Reimbursed by Dutch basic Health Insurance Act (Zvw)



# Early Intensive Neurorehabilitation

- Centralized in a single rehabilitation center
- Maximum of 14 weeks treatment
- 20-25 therapies weekly, 5x30 min daily
- Intensive counseling families
- 44% regained consciousness, 6% mortality



# Prolonged Intensive Neurorehabilitation

- After Early Intensive Neurorehabilitation
- In 3 dedicated nursing homes
- Up to 2 years postinjury, 4-8 beds
- Multidisciplinary team (directed by Elderly Care Physician)
- Intensive counseling families
- Advance Care Planning
- Care Program (2022)
- Reimbursed by the Long-term care act (Wlz)



# Nationwide prospective cohort study Intensive Neurorehabilitation (EIN & PIN)

## Quantitative outcomes

- Level of Consciousness
- Functional outcome
- Complications, mortality
- Quality of life
- Burden of relatives
- Cost effectivity

## Qualitative outcomes

- Quality of life
- Quality of dying
- Decision-making, ethical dilemmas
- Impact on relatives
- Impact on professional caregivers

# Chronic PDOC Care

- After Prolonged Intensive Neurorehabilitation
- In 2-4 Regional Centers of Expertise
- Minimum 2-4 beds
- Multidisciplinary team (directed by Elderly Care Physician)
- Care program (2022), including:
  - Advance Care Planning
  - Moral deliberations
  - End-of-life decision-making
  - Family guidance





# New support: Centers of Expertise in Long-Term Care

- Under direction of Ministry of Health & Welfare and Sports
- 8 target groups 'Low Prevalence, High Complexity'
- Including PDOC
- To improve quality of care, (knowledge) infrastructure
- Transitional phase > 2021
- Audit proof criteria, independent audits
- After approval ongoing funding:
  - Knowledge Center
  - Centers of Expertise long-term care



KPMG Advisory, report 2019  
Centers of Expertise Long Term Care

# Topics audit Knowledge Center PDOC

- Expertise
- Findability
- Research infrastructure, agenda
- Funding, grants
- Collaboration
- Competency profiles, education
- Development of products
- Implementation
- Shared data system



June 2023, Certificate Celebration PDOC

Met all criteria at maximum level: 4 y accr.



# Uniform registration in PDOC network



Preview  
Dashboard  
Example

# What was helpful?

- Facts, (prevalence) studies
- Unity among experts, EENnacoma
- (Com)passion
- Personal commitment, trust
- Support families, organizations, agencies
- No financial, religious or political incentives
- Societal impact, media attention, blogs, ..

## KWALITEIT

**dr. Jan Lavrijsen**  
senior onderzoeker ouderengeneeskunde, gepromoveerd op vegetatieve toestand in de langtermijnzorg

**dr. Henk Eikander**  
klinisch neuropsycholoog en senior onderzoeker, gepromoveerd op intensieve neurorevalidatie bij kinderen met bewustzijnsstoornissen

PATIËNTEN EN HUN NAASTEN BELANDEN IN MEDISCH NIEMANDSLAND

## Beter zorgen na coma

10 AD NIEUWS  
**'HET IS DROEVIG, MAAR HET IS NIET'**  
**Ouder dan 25?**  
Helaas, geen coma-revalidatie

TILBURG/NIJMEGEN • Tientallen volwassen patiënten die in vegetatieve of beschwaakte toestand verkeren, worden in Nederland aan hun lot overge-

Home Nieuws Programma's Publicis Cbs Canal

Nieuws en Co

09:30 - 11:30 uur

Later terug

Willemijn van Erp over haar onderzoek naar patiënten met het niet responsief waaksyndroom

Dondag 11 november 2020

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**'Niemand tussen wal en schip na een coma'**

Het is de 'vergeten groep' in de medische wereld: patiënten in een vegetatieve toestand, die alleen hun ogen open hebben, maar niet bij bewustzijn zijn. Het stellen van diagnoses gaat vaak mis, gespecialiseerde revalidatie is beperkt mogelijk en de zorg is verzuipend, stelt onderzoeker Jan Lavrijsen van het Radboudumc, specialist ouderengeneeskunde.

Mitchel Suijkerbuijk  
Nijmegen

Op de open dag tijdens het 'Weekend van de wetenschap' greef hij een college over patiënten in deze toestand. Zij hebben in coma gelezen door bijvoorbeeld een ongeluk of zuurstofte-



▲ Jan Lavrijsen: onderzoeker met een missie. FOTO: GEHARD VERSHOOTEN



# Lessons to cross bridges

- Appropriate care in each phase is possible
- Nobody with PDOC falls between the cracks!

