

# Involvement of an experience expert with ABI in a support group for ABI patients

EBIS study day

Bordeaux, May 20<sup>th</sup> 2016

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# personal background

- private 2006:
  - husband and 3 children (7,5,2 yrs)
- profession 2006:
  - clinical pathologist in an university hospital in the Netherlands and
    - PhD on genetic changes in borderline tumours of ovary
- 2006:
  - biking accident
  - coma (GCS 4), ABI

# rehabilitation

- 5 months included in rehabilitation clinic Adelante
- spring 2007 at home
- since then rehabilitation is focussing on:
  - physics (pilates/biking/yoga)
  - cognition (philosophy)
  - psychics (ZEN meditation)

# 2016, almost 10 years later

- private life:
  - family is doing great
  - physically mobile and independent
  - slower cognition
- professional life
  - unable to work as a pathologist
  - ABI-coach
  - since October 2015 working in Adelante's 'Discovery' group

# support group 'Discovery'

- 6/7 ABI patients in Adelante
- early phase of rehabilitation
- frequency twice a week
- on voluntary basis
- working team: social worker, nurse & experience expert
- focus is to further recognition, perception and acceptance of ABI patients

# goals of 'Discovery' (1/2)

- patient gets the opportunity to express his/her feelings and whatever comes to mind (loneliness, fear, relational issues etc.)
- patient feels respected and his/her personal story is heard
- patient gets a good view on what has happened (ABI)
- patient explores his/her feelings about what has happened

# goals of 'Discovery' (2/2)

- patient gets a view of the consequences of what has happened (cognitive disorders) and its influence on his social participation and other aspects of life
- patient becomes aware of present positive possibilities
- patient is opt to be introspective
- patient gets the opportunity to raise questions regarding all aspects of life with ABI



# experience expert

required profile:

- has a history with ABI
- has learned to deal with the consequences of ABI
- has a good view on the psychological and social impact of ABI
- stands open for sharing his/her experiences with others
- is a good listener

# observations after 6 months

- most items brought forward relate to home situations and familial matters
- sessions can be very emotional, both laughing and crying
- active and sincere participation of patients
- patients give positive feedback of 'Discovery' group

# preliminary conclusions

- both patients and team members acknowledge the added value of the experience expert
- patients feel understood and encouraged by experience expert to deal with their challenges related to life with ABI
- members of the professional team are enthusiastic about working in the Discovery setting

# acknowledgements



Dr. Wilbert G.M. Bakx  
Michel Schoonenberg