

The Zeepreventorium: a search for autonomy...



What's in the Title?

- Autonomy
- Search
- The Zeepreventorium
- ...



Autonomy

- Coming from the Greek word > Autonomia: auto (self), nomos (law)
- Self-imposed laws and the independence of an external board
- We do find some derivatives in:
 - politics
 - Medicine, psychology, philosophy: the ability of a patient to decide what can happen
- Be careful: a condition to operate autonomously is to recognize that the personal capabilities are limited
- In other words: sometimes we need help
- To recognize that help is needed is sometimes the most difficult part

Autonomy in childhood and adolescence

- To raise autonomy in childhood:
 - The parents are companions, not leaders in the proces
 - Constant repetition (taking an inhalation is like using toothbrush)
 - Unconditional trust
 - Playful
 - Failure is possible and allowed
 - We motivate the child to search solutions

(Kessler E. (2008). *liefdevol opgroeien*)

Autonomy in childhood and adolescence

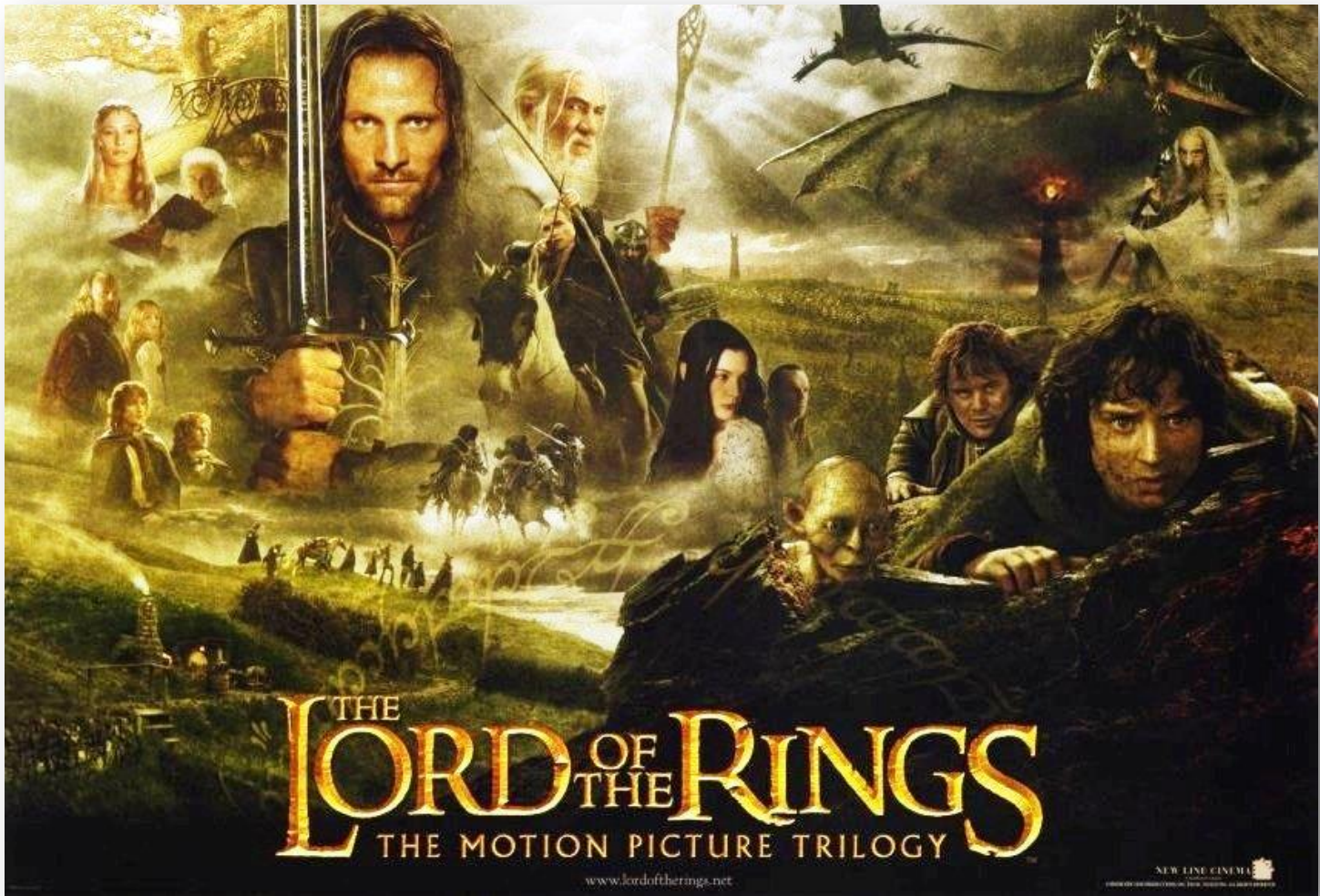
- Adolescence:
 - The search for autonomy is set on many levels:
 - » School
 - » Friends
 - » Hobbies
 - » Life-style
 - » The sexual identity
 - » But also in selfcare
 - In adolescence selfcare is sometimes difficult because:
 - » From his self-centered thinking an adolescent is focused on short-term goals
 - » Conflicts enter puberty mostly about the daily activities: to help with the household, homework...
 - Adolescents with CF have more daily activities: medication, physiotherapy, cleaning up the inhalation device...
 - » exceptional activity is easier done
 - Goal: to seek a balance between keeping control (as a parent) and gain self-control (adolescent)

(Brysbaert, M. (2006). *Psychologie*)

A search

- Synonyms are treasure hunt, expedition, quest
- Inherent in the word search/quest is that it can take a while to find something
- And the road can be full of obstacles

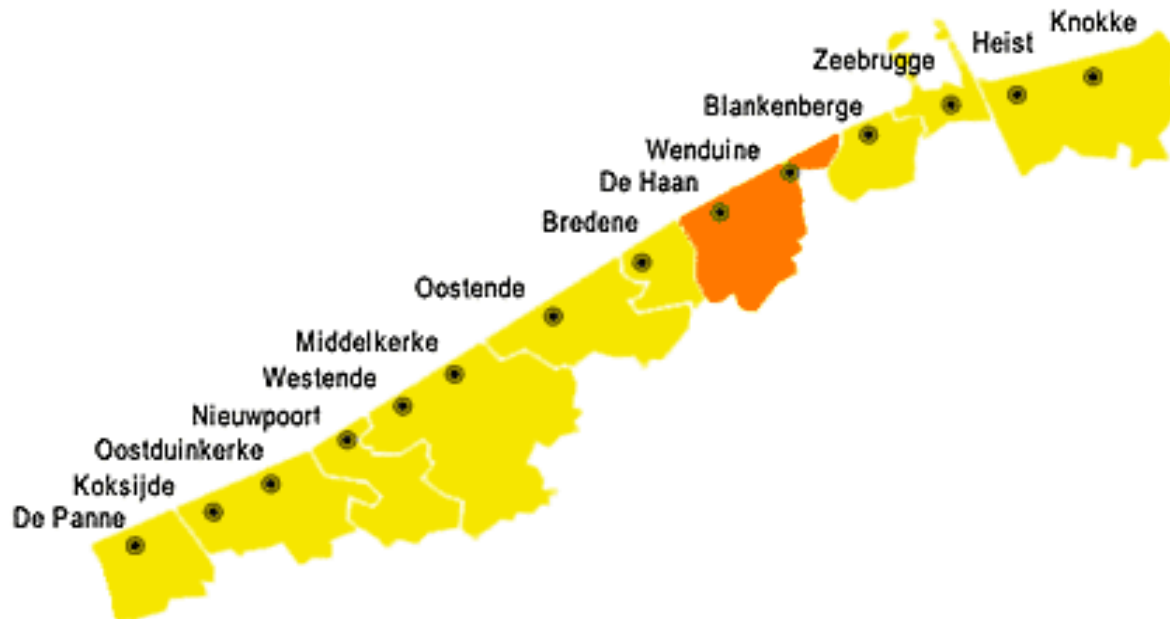




Zeepreventorium



Location



1923: Zeepreventorium



1960: Zeepreventorium: TBC – centre -> asthma centre



1981: CF - centre



Zeepreventorium, today

- Rehabilitation centre for chronic ill patients:
- CF – population:
 - International population (Belgium, France, Germany...)
 - Always in reference to a hospital and in communication with the general practitioner.
 - From birth till adulthood
 - Segregation - policy and hygienic measures
 - With 4 types of admission (minimum 3 weeks)
 - First admission: acquiring therapeutic skills
 - Re - adjustment: to optimize skills
 - Medical crisis: IV - treatment
 - Pre - transplant: to obtain a maximum physical condition
- Other pathologies:
 - Asthma
 - Diabetes
 - Obesity
 - Renal failure
 - ...

Zeepreventorium, conviction

- Self management is improved by services such as education, emotional support, the development of skills and adaptations necessary to carrying out the individual's specific health care regimen (Lindsey W.Williams et al. Journal of rehabilitation 2012, volume 78, No.3, 20-26)
- Self management is increasing at a good (therapeutic) education, counseling and individual adjustment
- Here again, failures allowed
- Do not go to prison, go to restart



CF rehabilitation



- Minimum goal: Improve general health and / or stabilize
- Promoting efficient and effective self management
 - With 4 types of admission (minimum 3 weeks)
 - First admission
 - Re - adjustment (after failure or to optimize skills)
 - Medical crisis
 - Pre - transplant

Daily programme

- 7h am wake up
- 7h30 breakfast
- 8h00 -9h30 respiratory kinesiology
- 9h30 sports programme in function of the individual capacity (fitness or swimming)
- 10h 15 refreshment
- 10h 45 school / or activity during the holidays
- 12h30 pm lunch

- 1h30 school / or activity during the holidays
- 3h00 refreshment
- 3h10 during afternoon: 50 minutes of mobilisation, thorax exercises, relaxation,...
- 4h00 - 5h30 respiratory kinesiology
- 6h00 dinner

- Evening programme (sports, study, individual time)
- 9h00 bedtime

CF - rehabilitation

- Trying to keep the boat stable on the sometimes turbulent sea
 - Together with the child / adult and the parents (the boat)
 - Facing the illness (the turbulent sea)
- Interaction between child and parent is crucial
 - Rehabilitation is planned together
 - Time is needed to build up trust
 - Result: growth towards more autonomy
 - The parents get breathing space
 - The CF-team is the guide in the expedition
 - The point of view: to apply at home what's learned – minimum 3 weeks of admission
- Multidisciplinary approach in communication with reference centre and feedback, exchange of expertise

Benefits

- Time
 - For treatments
 - Quality – time for the family in the weekend
- Acceptation (I am not alone, others have to live the same life)
- Re-admissions when failure
- Multi – disciplinary team
 - Doctors
 - Nurses
 - Dietitians
 - Labo
 - educators
 - Psycho – social team
- Sports
- School

Promoting Autonomy



- Main goal of every admission
- Asking the patient to participate in an active way
- The result is hopefully shared care
- And less “stress care”

■ ■ ■

- It is easy to write it down
- Medical reality
- Family context
- Financial situation
- ...



To finish!

- All together we must be the co driver on the road with our patients
- It is up to them to pass the difficult curves
- I know a lot of patients who managed



