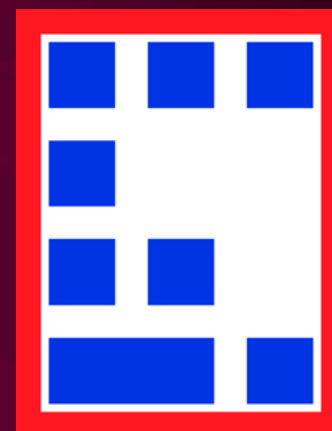


# Living with epilepsy



Hanneke M. de Boer  
Stichting Epilepsie Instellingen Nederland  
Heemstede  
The Netherlands

# Living with epilepsy

## Epilepsy: the facts

- \* no racial, national/geographical boundaries
- \* universal condition
- \* serious physical, psychological + social consequences
- \* seizures can cause misunderstanding, fear, secrecy, stigmatisation + social isolation

# Living with epilepsy

Ann Jacoby:

*“All chronic medical conditions have  
impact on quality of life,*

*but*

*impact of epilepsy is greater”*

# Living with epilepsy

## Epilepsy



- Seizures → Risks → (Blanket) restrictions
- Social issues → Friendship, marriage, education, employment
- Stigma → Discrimination
- Legislation → Outdated + Based on prejudice

# Living with epilepsy

## Epilepsy

- Seizures → Risks → (Blanket) restrictions

» Risks

» At home:

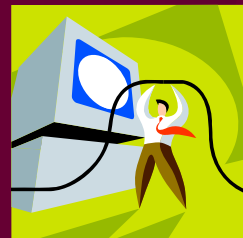
kitchen, bathroom, bedroom

» At work:

heights, machinery, public roads

» Leisure:

travelling, cycling, sports (swimming), disco's



# Living with epilepsy

Social issues



Impact of Epilepsy

- Children suffer from overprotection
  - Teachers not well informed
  - Fear of having seizure in classroom
- Adults problems obtaining and retaining employment
- Elderly lose confidence and functional independence



# Living with epilepsy

Dr. Richard Masland former Secretary  
General International Bureau for Epilepsy:

***“Unfortunately, pre-occupation with the control of seizures, both on the part of the physician and the patient, often seems to overshadow an adequate concern for the other factors. Yet in terms of disability, for many patients it is these other factors, which determine whether they will or will not make a satisfactory life adjustment”***

# Living with epilepsy

## Epilepsy in children

- Profound psychological and social consequences related to
  - Severity of condition
  - Public's concept of epilepsy
- Children and Adolescents
  - More comprised quality of life
  - Parents overprotective
  - Parents anxious
  - Siblings jealous
  - Families by-pass child in communication

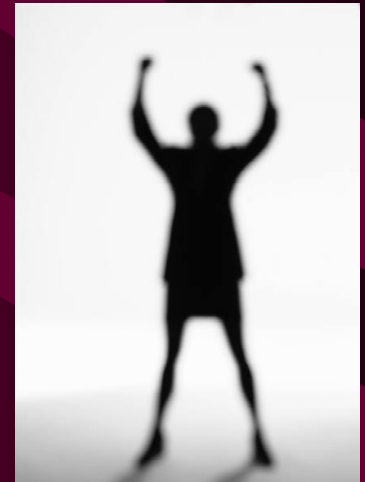
*Assessing the impact of epilepsy goes beyond counting the seizures*



# Living with epilepsy

## Epilepsy in Age group 20-60: incidence low

- People with epilepsy face:
  - formal legal restrictions (driving, employment)
  - misconceptions, stigma, discrimination
- People with epilepsy feel stigmatised
  - 51% stigmatised, 18% highly stigmatised (A. Jacoby)
  - 30% did not tell prospective husbands/wives
  - 30% used euphemisms
  - 50%+ did not tell employers
  - 18% mentioned impairment of career



# Living with epilepsy

## Epilepsy in elderly

- Generally thought:
  - Epilepsy in elderly: uncommon and unimportant
- 20th Century:
  - Incidence of epilepsy in people 75+: higher than in 1<sup>st</sup> decade of life
  - Incidence of epilepsy in people 65+: 1-2%
- Consequences Diagnosis:
  - shattered expectations: epilepsy to be kept quiet
  - different lifestyle
  - loss of independence through uncertainty and unpredictability
  - social isolation through loss of driving licence

# Living with epilepsy

## The Concept of Epilepsy

Leon Eisenberg:

*“Epilepsy is an ancient disease that has been “explained” for as long as it has been perceived. Its manifestations invite arcane theories of its causes and meanings. Seizures are dramatic, public and frightening. They occur with unpredictable frequency in unexpected places. The forced cry, the loss of unconsciousness, the fall, the twitching and the foaming at the mouth, they all suggest possession by the spirit”.*

# Living with epilepsy

Stigma



Discrimination

## Definition of Stigma

- Free-on line dictionary: symbol of disgrace or infamy
- Encarta: sign of social unacceptability shame or disgrace attached to something regarded as socially unacceptable
- Dictionary.com: mark of disgrace or infamy, stain or reproach, as on one's reputation.

# Living with epilepsy

Stigma



Discrimination

Definition cont.

Stigma can be seen as attitude, located at individual level, based on ignorance, prejudice and fear of particular group.

UK Institute of Psychiatry initiative, Mental Health Care:

- Stigma is best defined in three words:
  - Ignorance
  - Prejudice
  - Discrimination

# Living with epilepsy

## People with Epilepsy (PWE)

- “being chosen”
- “being possessed”
- “hidden disease”
- “burning disease”
- “shameful disease”

# Living with epilepsy

## The Concept of Epilepsy

### Africa

- Cameroon: inhabited by the devil
- Liberia: witchcraft and evil spirits
- Swaziland: sorcery
- Senegal: high esteem *and* “*shameful disease*”

### Asia

- Indonesia: karma or punishment
- India: evil spirit
- Nepal: weakness, possession evil spirit

# Living with epilepsy

## The Concept of Epilepsy

### Western world

- USA: 54% of parents don't know
- Germany: 20% epilepsy mental disease
- The Netherlands: attention seeking behaviour



# Living with epilepsy

Stigma

Rajendra Kale

*“The history of epilepsy can be summarised as 4000 years of ignorance, superstition and stigma followed by 100 years of knowledge, superstition and stigma”*

# Living with epilepsy

Legislation → Outdated + Based on prejudice

- Laws impacting people with epilepsy's lives outdated,
- Laws fail to adequately promote and protect human rights
- Laws sometimes actively violating rights.
- In many countries total absence of legislation
- Examples of legislation based on centuries of stigmatisation in many countries.

# Living with epilepsy

## Epilepsy

### – Serious brain disorder!

- Seizures
- Social issues
- Stigma
- Legislation



### Risks

Friendship, marriage, education  
employment

Discrimination

Outdated + Based on prejudice



# Living with epilepsy

Seizures



Risks

## – Home

- » Kitchen: induction and microwave cooking, temperature-control water tap
- » Bathroom: shower, temperature-control water tap
- » Bedroom: mattress on floor

## – School

education parents, teachers + children

## – Work

guidance taking into account job requirements + known facts about person's epilepsy + seizures.

## – Driving

legal restrictions

## – Leisure

discos, swimming, etc.

***NO BLANKET RESTRICTIONS - USE YOUR COMMON SENSE!!***

# Living with epilepsy

- Social issues

- » Friendship    join club, develop hobby – be a friend!
- » Education    parents: do not overprotect your child  
(seek advice)
- » Employment    including driving

# Living with epilepsy

## Social issues: Employment

“The majority of pwe require no special help to become economically active”.

“When assessing an employee, the employer needs to understand some of the basic facts about epilepsy and its possible impact on employment”

“It is easy to discriminate against pwe unintentionally”

# Living with epilepsy



## Social issues: Driving

### Background

- Right to drive is vital component of acceptable quality of life + important for people with epilepsy
- Driving enlarges potential for work + leisure
- People without driving licence have difficulty in finding appropriate professional job
- Proportion of people with epilepsy with driving licence lower (44%) than general population (67%)

### Regulations

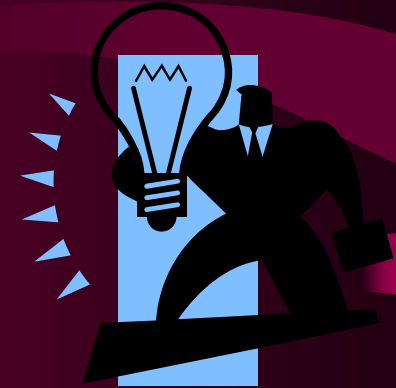
- Current regulations in most EU countries permit people with controlled seizures right to obtain driving licence
- Regulations provide for one-year seizure-free period for Group-I vehicles

# Living with epilepsy

Stigma



Discrimination



## – Public education

- » Epilepsy is a common brain disorder
- » Epilepsy produces recurring seizures which are a symptom of brain dysfunction
- » Epilepsy is not contagious
- » Epilepsy can be caused by many conditions which injure or affect brain function
- » Epilepsy is not caused by any supernatural force
- » Epilepsy is not dangerous to others and is nobody's fault
- » Epilepsy can affect anybody. It affects people of all ages, races and social classes
- » Between seizures most people with epilepsy are no different from anybody else
- » Epilepsy can be effectively treated. In most cases seizures can be stopped



# Living with epilepsy

Stigma

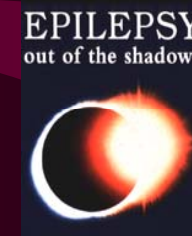


Discrimination

– Patient education

- » Statement developed and adopted during congress for people with epilepsy plus relatives (1995)
- » “Information gives people with epilepsy knowledge of their condition. They can then make informed choices, thus achieving more personal control and a better quality of life”

# Living with epilepsy



Legislation



Outdated + Based on prejudice

Global Campaign Project on Legislation

## Background

Well-crafted legislation based on internationally accepted human rights standards can prevent violations and discrimination, promote and protect human rights, enhance the autonomy and liberty of people with epilepsy and improve equity in access to health care services and community integration.

## Project

Collect information on existing legislation + regulations related to epilepsy in areas of civil rights, education, employment, residential + community services and provision of appropriate health care from countries globally to review comprehensiveness + adequacy thereof in promoting + protecting civil + human rights of people with epilepsy.

# Living with epilepsy

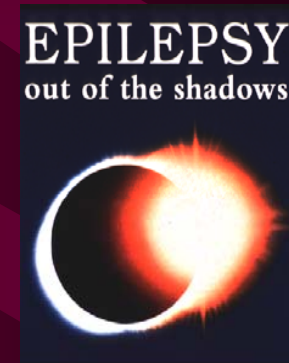
Epilepsy: Serious brain disorder!



Legislation → Outdated + Based on prejudice

## Global Campaign Project on Legislation

- Document developed + ready for publication
  - Results useful for policy makers, health planners, administrators, legislators, lawyers, health professionals + patient groups at a national, regional + global level
- Project served as source of information + offered support to IBE/ILAE members involved in development anti-discriminatory legislation in connection with epilepsy



# Living with epilepsy

EPILEPSY  
out of the shadows



*Epilepsy: Serious Brain Disorder!*

*Legislation Outdated + Based on prejudice*

*Global Campaign Project on Legislation*



- 50 million of people with epilepsy.
- 2.5 million new cases per year.
- Up to 70% controlled with medication.
- 80% people not being treated.
- An estimated 150-600 thousand deaths contributed to epilepsy

- *We urgently need to:*
- Stand up for epilepsy.
- Treat today, cure tomorrow.
- Stop prejudice, start a new life.
- Increase funding for research.
- Investigate the high mortality in epilepsy.

**The Time to take action is now  
Stand up for Epilepsy!!!**

# **EPILEPSY** out of the shadows

## Mission Statement

To improve the acceptability, treatment, services and prevention of epilepsy worldwide

## Strategy

- I. Provide platform for general awareness
- II. Assist Departments of Health in the development of National Epilepsy Strategies

## Objectives

- to increase public and professional awareness of epilepsy as a universal, treatable brain disorder
  - to raise epilepsy to a new plane of acceptability in the public domain
- to promote public and professional education about epilepsy
- to identify the needs of people with epilepsy, on a national and regional basis
- to encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services and prevention

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