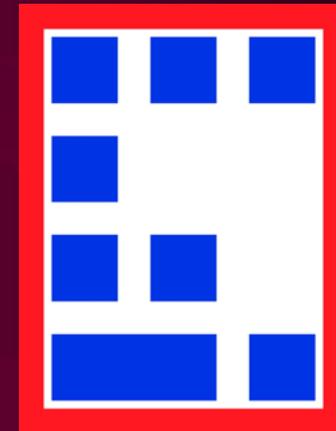


Living with epilepsy



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- Legislation → Outdated + Based on prejudice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:

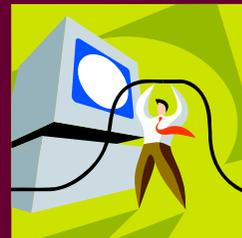
kitchen, bathroom, bedroom

» 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 1st 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

EPILEPSY
out of the shadows



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

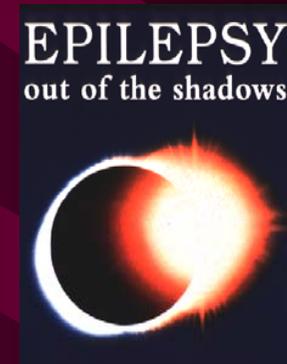
Epilepsy: Serious brain disorder!



Legislation  Outdated + Based on prejudice

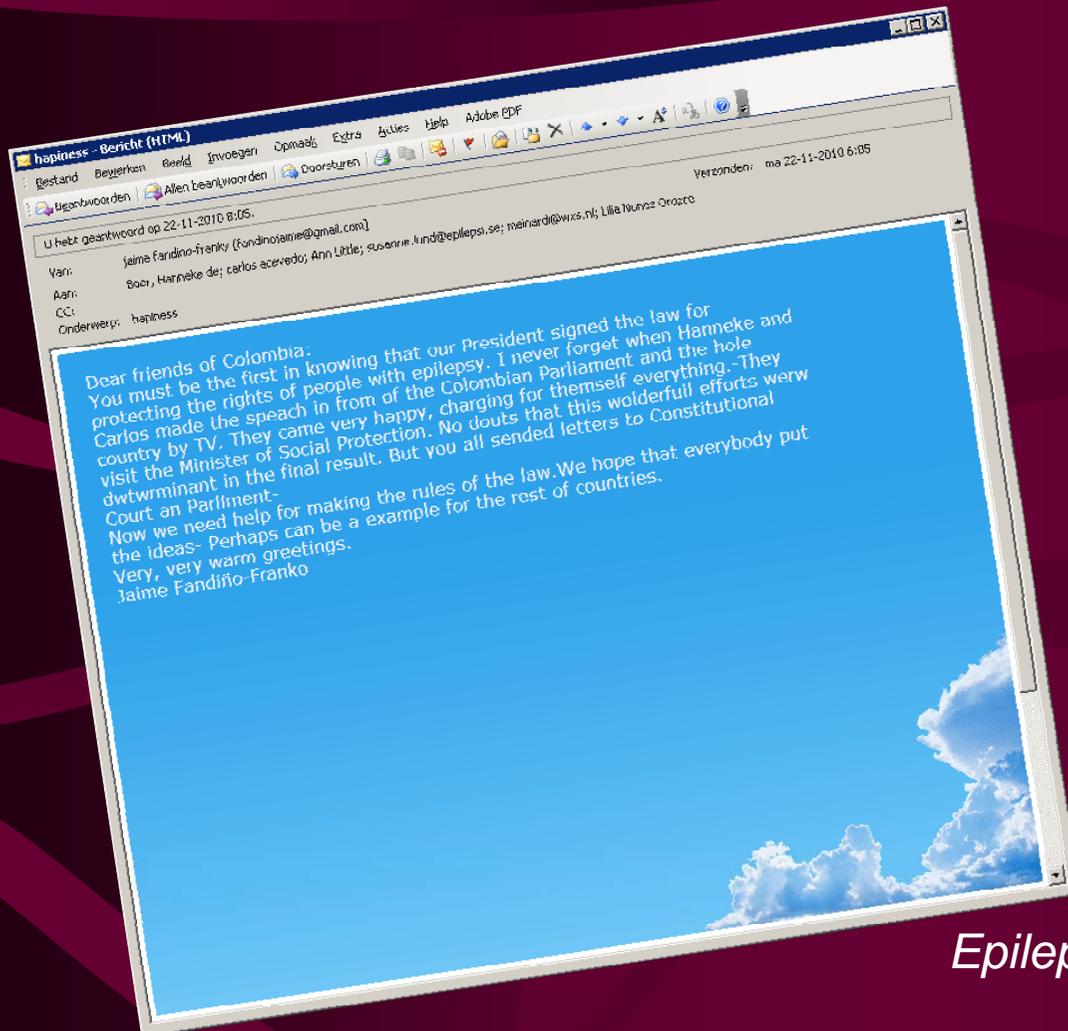
Global Campaign Project on Legislation

- 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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