# Employment and epilepsy in the open labour market

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Epilepsy is a diverse set of chronic neurological disorders

Most people with epilepsy are able to work and usually without any restrictions

-About 2/3 seizure free with medication



#### **EPILEPSY AND EMPLOYMENT**

- PWE still face significant challenges in employment and working in the open labour market
- PWE consistently have higher levels of unemployment compared to the general population (see for example Epilepsy Across the Spectrum: Promoting Health and Understanding 2012)



#### **EPILEPSY BEYOND SEIZURES**

- Epilepsy affects to physical, psychological, cognitive and social functioning
- Comorbidites in epilepsy must be taken into account
- → Comprehensive care of epilepsy is essential and this is more than just medication!



### John Chaplin 1994: Epilepsy and Employment (PhD thesis)

"The problem of epilepsy and employment cannot be looked at from a single perspective. It is medical, social and psychological in its nature. The problems for people with epilepsy at work must be seen as emerging from the interaction of the various elements that make up the concept of epilepsy and cannot be pinpointed to any one variable."



John Chaplin 2005: Vocational assessment and intervention for people with epilepsy – 4 groups

## **Group 1:** Those people with no problem in obtaining open employment

People whose seizures are satisfactory controlled. They have had a good education and have a satisfactory work record. They are unlikely to have experienced problems with stigma, although they may possibly have experienced some underemployment. If an intervention is required outside of the normal career services, then some assistance with disclosure management might be useful.

# **Group 2: Those people with a mild employment problem**

 people whose seizure control is acceptable, but they have unrealistic career goals. They also may have experienced stigma problems or feel that they have been stigmatized. The most suitable intervention here would be some planned vocational assessment and training.



## **Group 3:** Those people with severe employment problems

the seizure control is unsatisfactory; emotional problems or intellectual deficits may be present, which in turn may have led to higher levels of anxiety and depression. Intervention here is more clearly in the role of employment rehabilitation training and may require medical and psychological evaluation.



# **Group 4:** People not able to maintain a job in open employment and who require sheltered or nonpaid work

This group of people has severe or frequent seizures and may have additional medical conditions or handicaps that complicate the situation. They may have missed educational or training opportunities or been unable to take advantage of these because of cognitive deficits. Interventions here require specialist training facilities and supported work opportunities.



#### **HOW TO FIND A SUITABLE JOB?**

- The ability to work depends on the severity of the symptoms and the effects of the disease
- Realistic self-image: understanding and perception about one's epilepsy and its symptoms
- Adaptation and coping styles Education
- Professional expertise / competence to do the work

Levels of employment		
Society	Workplace/employer	Employee
Attitudes towards epilepsy		
Understanding about epilepsies	Colleagues, managers and employers	Perception and orientation to epilepsy
Globalization and economic situation	Corporate social responsibility	Education, suitability for the domain, working experience
Changes at the labour market	Public support and benefits for employment	Place of residence (for example vacancies and public transportations available)
Policy: labour, education, vocational rehabilitation	Circumstances, nature of the tasks, Development of know-how, Leadership and recruiting	Personality; motivation, social skills  Health and life situation



# YOUNG, RICH AND BEAUTIFUL – WHAT ABOUT THE MOST OF US?

- Ability to work varies individually from person to person whether one has epilepsy or not
- The current labor market demands more from everybody; you need to be talent, competent, friendly, flexible and fresh looking



#### **DISCRIMINATION IS ILLEGAL**

- Legislation is used to ensure equality and prevent discrimination in working life.
  - this is situation in all developed countries
    - The Finnish Constitution prohibits discrimination
    - The Finnish Non-discrimination Act:
       Employers must make reasonable adjustments to adapt working conditions to make them suitable for persons with disabilities.



# REASONABLE ADJUSTMENTS ACCORDING FINNISH LAW

- At the workplace
  - allocating tasks in the right way
  - customizing the working time/hours
  - providing special equipment or opportunities for training and guidance
- This can be economically challenging for small employers
- Positive approach to find solutions for employment both the employer and the PWE



### Thank you!



### Riitta Piironen, 58 years, actress

I've always managed though, one way or the other. I still have many years of working ahead of me, and I like to work.

But then again, I am very afraid to lose the capability to work. It would be horrible for me if I had to give up work, I love it so much. I don't even dare to think about it. It is a difficult issue.

I've always managed, but everyone, including me, has their fears.

Despite my fears I'm a stubborn person and love this work so enormously. I just don't give up.

I choose to go forward, despite a little fumbling along the way.

See the document www.epilepsia.fi/kampanja\_2013





### Mika Lokkila, 47 years, entrepreneur

Openness is a very positive thing, as is speaking out with courage. Many times in life I've sensed or experienced a sort of hint or message. When I have followed this bravely, doors have opened for me. It may have to do with the positive energy involved, a sort of good will.

When you help yourself, you'll also be helped by someone else.

I definitely recommend being open and telling people about your illness.

Everyone has troubles and personal problems in their lives.

There is no need to hide an important thing like this.

See the document www.epilepsia.fi/kampanja\_2013





### **Employment and Epilepsy Project**

Run by the Finnish Epilepsy Association 2012-2015 Gets governmental funding

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