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Epilepsy in Children: Interdisciplinary Aspects

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What do we mean by interdisciplinary aspects?

- ✦ Epilepsy has long been considered from a biomedical perspective.
- ✦ Multidisciplinary health teams.
- ✦ The core members of a team are:
 - ✦ the consultant neurologist or paediatrician,
 - ✦ a specialist epilepsy nurse,
 - ✦ psychologist and
 - ✦ social worker
- ✦ Doctor is the first contact



Interdisciplinary teams in rehabilitation

- ⌕ Experience shows that multi-disciplinary teams can experience problems.
 - ⌕ Achieving cohesive teamwork is difficult.
 - ⌕ Individual disciplines have rigid boundaries.
 - ⌕ Difficult to agree on goals for the patient.
- ⌕ Need to take another look at the nature of the problems experienced





A 3 year European project.

- ✦ Partners - Sweden, Germany, Netherlands, France, Greece, Great Britain, Italy
- ✦ Aim - to develop a methodology and survey instruments to assess health related quality of life in children.



Populations surveyed

- ✦ Children between 4 and 16 years
 - Nine disability groups
- ✦ Initial research using focus groups
 - ✦ Insight into children and the families' experience of epilepsy.
- ✦ Three major areas of importance
 - ✦ school,
 - ✦ family,
 - ✦ medicine



1. School

- ⊕ Stigma at school is a major factor
 - ⊕ *“My little brother has told everyone” (Girl 8-12)*
- ⊕ Telling people about the epilepsy
 - ⊕ *“The worst thing is to have to explain” (boy 13-16)*
- ⊕ Interventions:
 - ⊕ Parents intervene at school (difficult at secondary)
- ⊕ Teachers need training in presenting epilepsy.



Parents' concerns about school

- ⊕ Bullying – more common in secondary schools
 - ⊕ *“The teachers don't know what happens during the breaks.”*
- ⊕ Cognitive effects
 - ⊕ *“He is in a lower class because of his concentration problems”*
- ⊕ Missing school (children do less well)
 - ⊕ *“it was good he got epilepsy early so that he didn't miss any school”*
- ⊕ Medication is not sufficient intervention / Problems even if seizure-free



2. Family

✦ Restrictions and overprotection

- ✦ *“My parents check up on me more than on my brothers”*
- ✦ Emotional reactions / feelings of guilt
- ✦ *“The seizures are not so bad, it is the way the family reacts to them that is hard.” (boy 13-16)*
- ✦ *“His father can’t deal with it at all”*

✦ Difficult balance between risks and overprotection



Parent's family concerns

- ⊕ Sibling rivalry / Secondary stigma
 - ⊕ *“His sisters are jealous that he gets more attention than them”*
 - ⊕ *“Her sister is very sad, she is very sensitive. ”*
- ⊕ Family disharmony / working together
 - ⊕ *“If I forget to give her the medicine, my husband becomes very angry. ”*
- ⊕ Need for family support, child behaviour counselling, and psychological counselling.
- ⊕ All professionals need to agree the goals.



3. Medicine

⊕ Compliance

- ⊕ *“The medicine tastes awful” (girl 8-12)*
- ⊕ *“It is boring to take tablets every day” (boy 13-16)*

⊕ Cognitive effects / Long term effects

- ⊕ *“We are worried about the long term effect” (parent)*

⊕ Drug interactions

- ⊕ *“Kids experiment with drugs these days - how will this affect his epilepsy?” (parent)*



⊕ Information / over 50% dissatisfied

⊕ *“We would have like more information about the epilepsy medicines”*

⊕ Support / Discuss

⊕ *“You need support – someone you can talk to straight away”*

⊕ *“Problems occur even without seizures “*

⊕ Depressed mood

⊕ Specialist epilepsy nurse can bridge the gap between the medical and the social spheres.



What lessons have we learnt

- ⊕ Epilepsy affects the child
 - ⊕ within the family,
 - ⊕ within the school and
 - ⊕ in relationships with friends.

- ⊕ Problems are experienced even by children who do not have seizures.

- ⊕ These problems are complex, changing as the child gets older.



- ⊕ Problems do not always fit into one professional area.
- ⊕ A mixture of assessment approaches may be needed.
- ⊕ Problems are complicated and interactive, they might occur due to:
 - ⊕ Side-effects,
 - ⊕ other people's reactions,
 - ⊕ lack of knowledge in schools,
 - ⊕ emotional reactions.



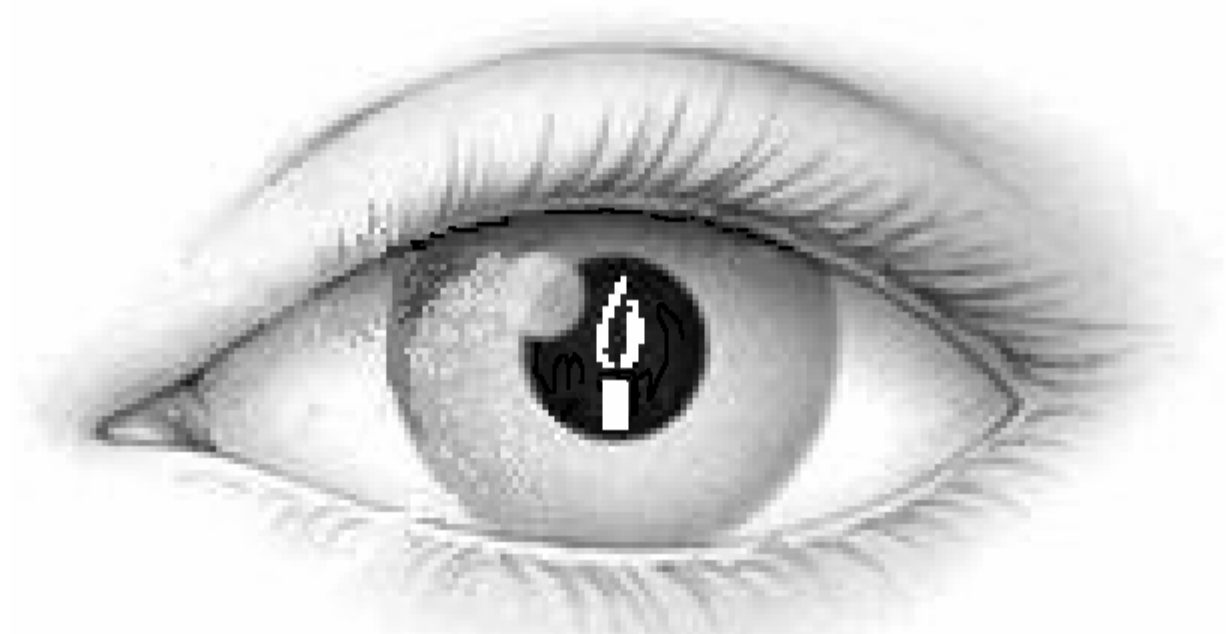
Putting the lessons into action.

- ✦ Success may depend on how well we are able to blur professional boundaries.
- ✦ Training in each other's disciplines.
- ✦ We must work on the agreed joint priorities.
- ✦ Move from multi- to inter- to trans-disciplinary teams.
- ✦ Involving the child and family more in the decision making process.



New ways of working

An internet-
based epilepsy
self-help group
for young people



Epilepsy and Youth in Europe (EYiE)



EYiE aims and structure

✦ Aims:

- ✦ Improvement of self-confidence
- ✦ Exchange of experience and information
- ✦ Informal mutual help
- ✦ Elimination of prejudice

Structure

- ✦ Objective to interest young people
 - Multi-national meetings
 - Computer / internet
 - Cultural exchange



EYiE5

South American youth exchange
40 young people with epilepsy

Involving:

Doctors, Psychologists, Social
workers, Family therapists,
Sports trainers, Young
people with epilepsy.

Blending of skills creates a
unique experience for young
people and the team

- Germany
- Ireland
- Sweden
- Malta
- Holland
- Mexico
- Argentina
- Chile



Conclusions

- ✦ Epilepsy is a multi-faceted condition
- ✦ Many disciplines are blended together in solving the problems experienced by the child.
- ✦ Prepared to be trans-disciplinary.
- ✦ The child must be at the centre of what we do.



- ✦ An interdisciplinary team, including doctors, specialist nurses, psychologists, therapists and social workers is essential.
- ✦ An emphasis on interdisciplinary collaboration ensures a seamless integration of services.
- ✦ New and innovative methods of dealing with interdisciplinary aspects of epilepsy will be developed.



