

Epilepsy and Family Dynamics



BC Epilepsy Society
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*Family functioning
before epilepsy*



*Family responses
to epilepsy*

Epilepsy



*Social-emotional functioning
of the child*



Which children are *most* likely to have problems in social-emotional adjustment?

(Epilepsy factors 1)

Those children who have:

Epilepsy plus- underlying brain condition due to injury, disease, malformation of brain, e.g. (*symptomatic epilepsies*)

Adverse epilepsy syndromes- Lennox-Gastaut, West syndrome, eg.

Seizures: incompletely controlled; presence of EEG seizures

Medication: more than one

Co-existing conditions: cognitive or attentional impairments

Age of onset: early

Which children are *least* likely to meet with adjustment difficulties? (Epilepsy factors 2)

Those children (the majority) who have:

Epilepsy alone: No evidence for brain abnormality other than seizures
(idiopathic epilepsies)

Epilepsy syndrome: No epilepsy syndrome or benign syndrome such as
Benign Rolandic Epilepsy of Childhood

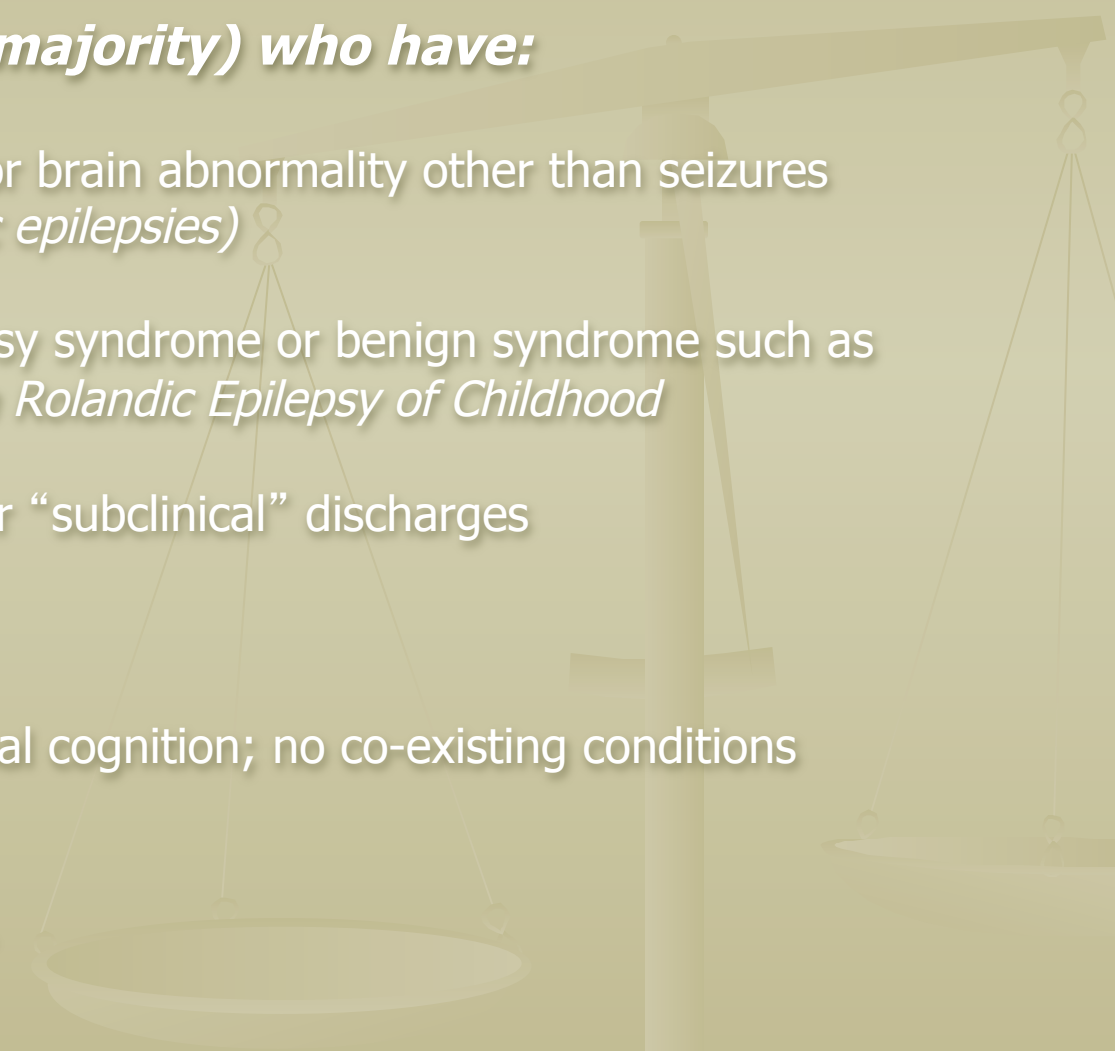
Seizures: Well controlled; fewer “subclinical” discharges

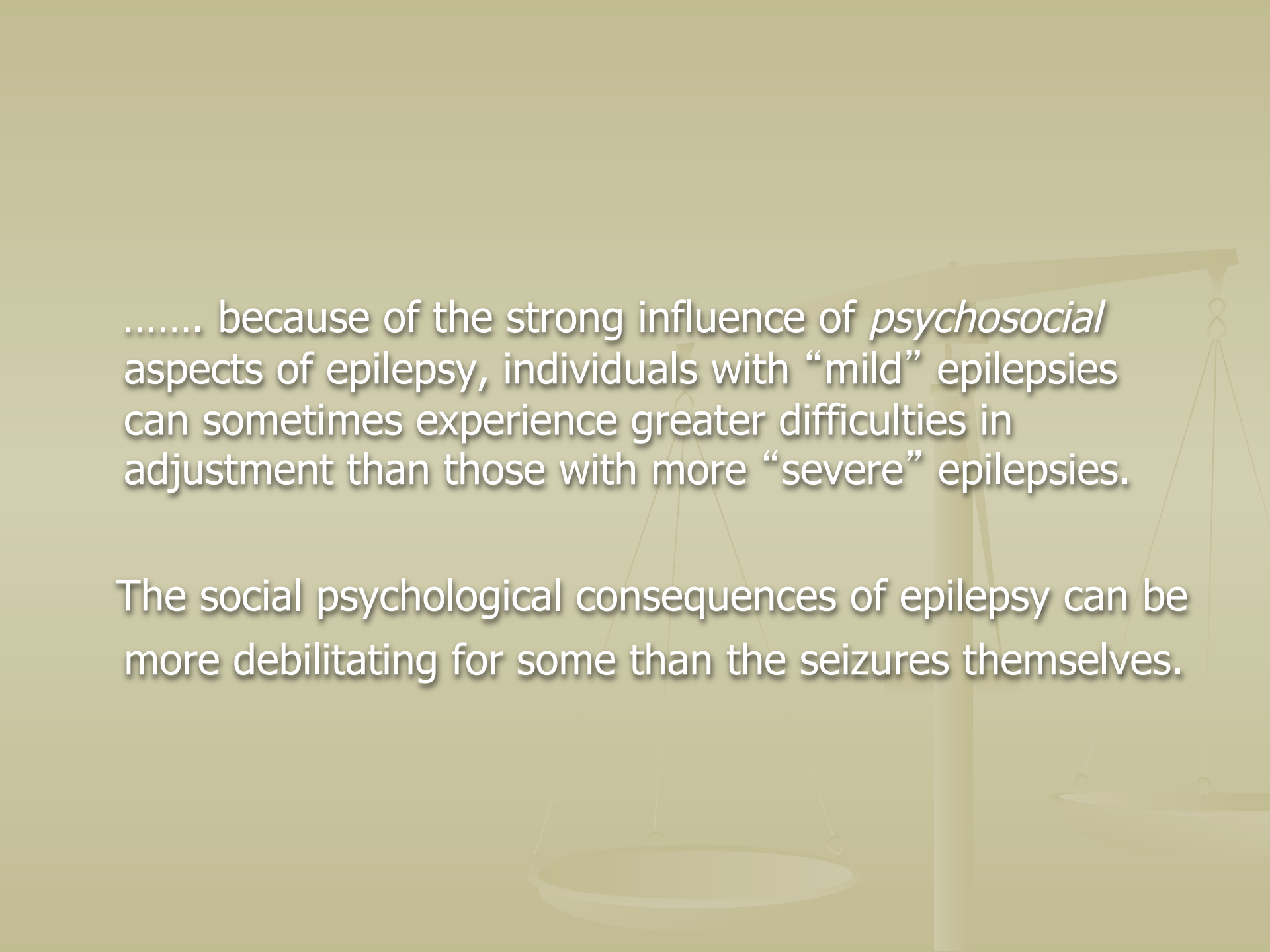
Medication: single

Co-existing conditions: Normal cognition; no co-existing conditions

Age of onset: later

But...

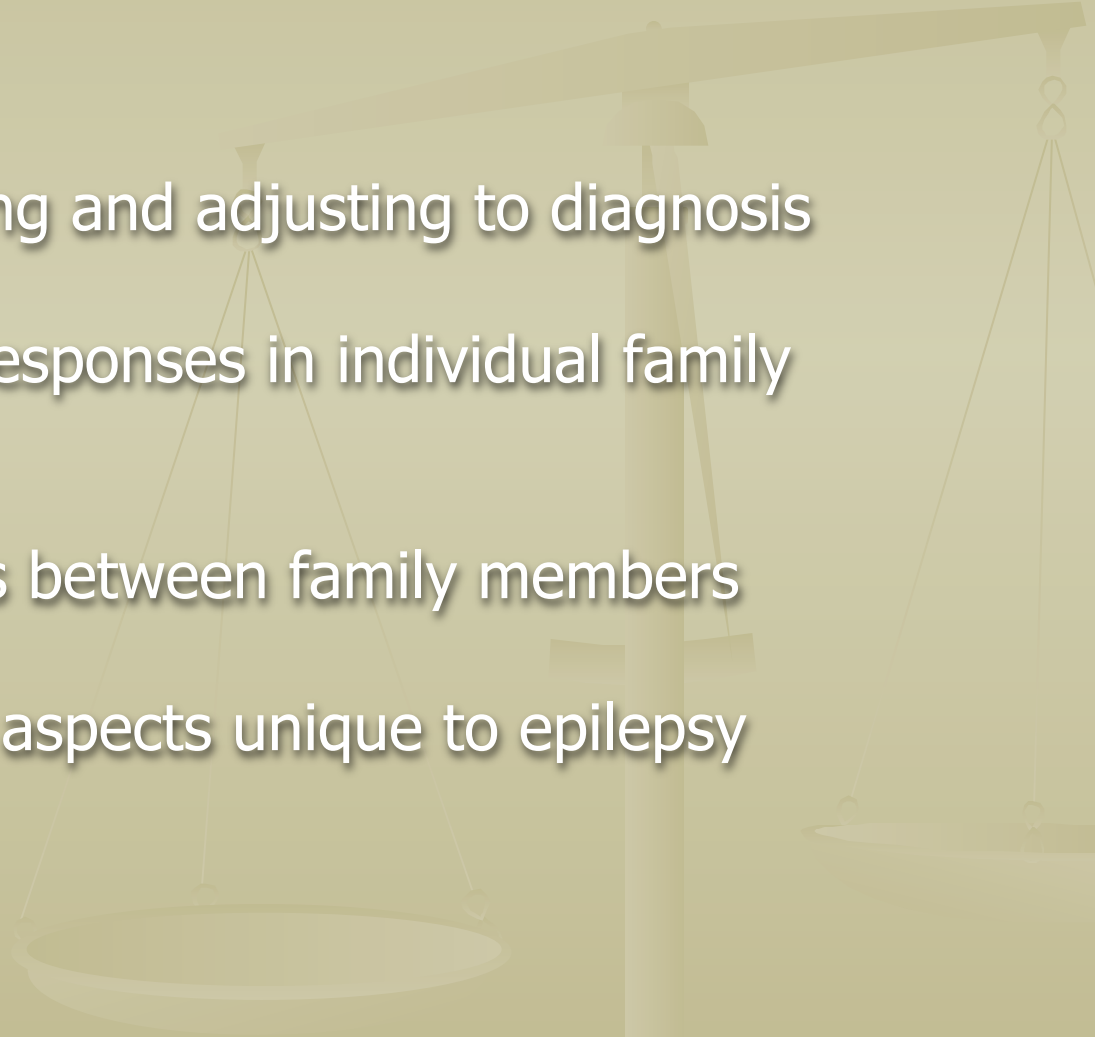




..... because of the strong influence of *psychosocial* aspects of epilepsy, individuals with “mild” epilepsies can sometimes experience greater difficulties in adjustment than those with more “severe” epilepsies.

The social psychological consequences of epilepsy can be more debilitating for some than the seizures themselves.

What are some *psychosocial stresses* that can influence the individual's functioning?

- Difficulties in accepting and adjusting to diagnosis
 - Negative emotional responses in individual family members
 - Strained relationships between family members
 - “Extra” psychosocial aspects unique to epilepsy
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What are some psychosocial stressors unique to epilepsy?

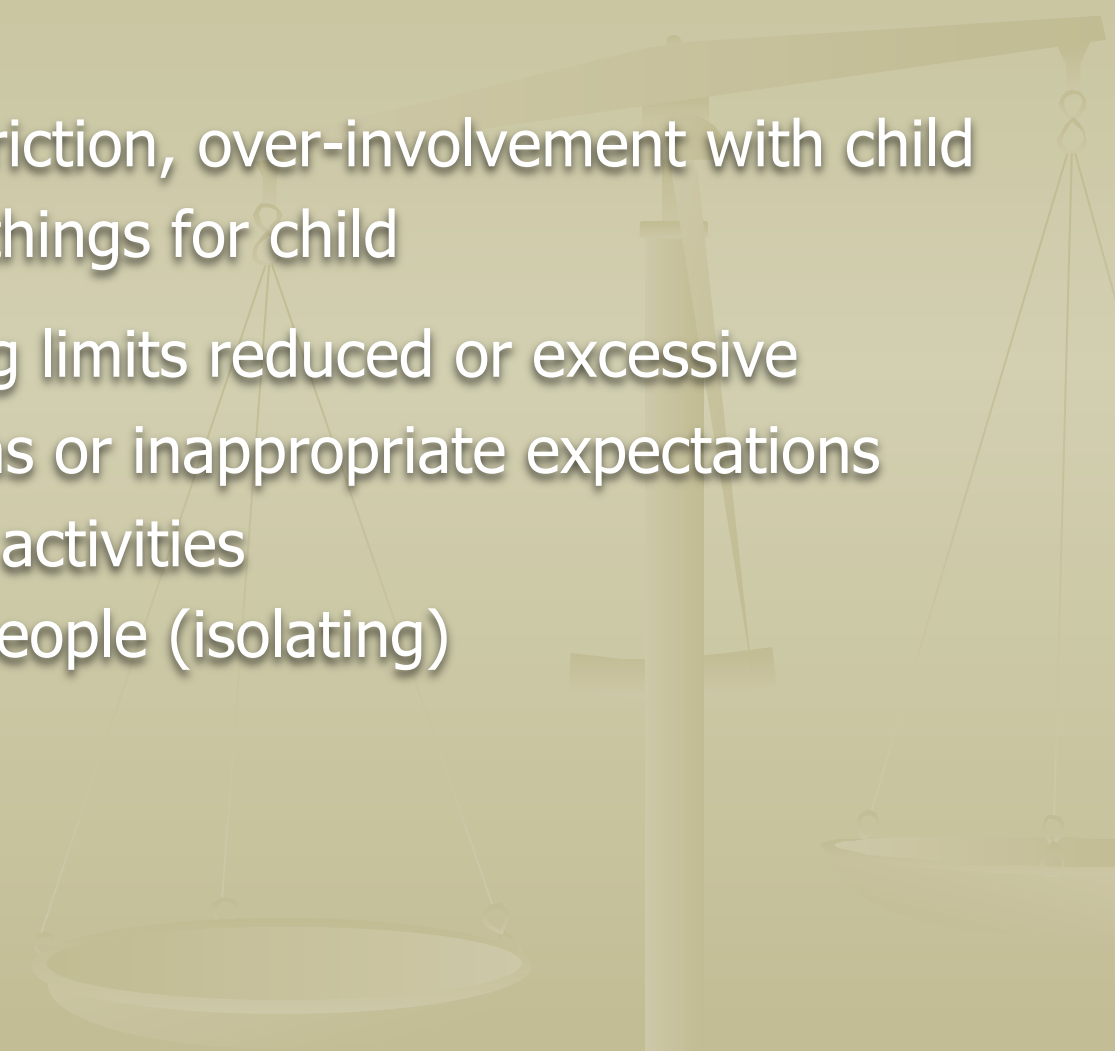
- ***Negative perceptions and attitudes of society towards epilepsy***
- ***Seizures:***
 - unpredictability of occurrence
 - sense of loss of control
 - worry about seizures because of danger
 - worry about seizures because of embarrassment
- ***Tendency to hide the condition and to withdraw socially***

What are some emotional reactions to the occurrence of epilepsy in the family?

- Fear, worry, anxiety
- Shame, embarrassment or guilt
- Anger, frustration, resentment
- Sadness, depression, hopelessness



What are some family responses when a family member has epilepsy?

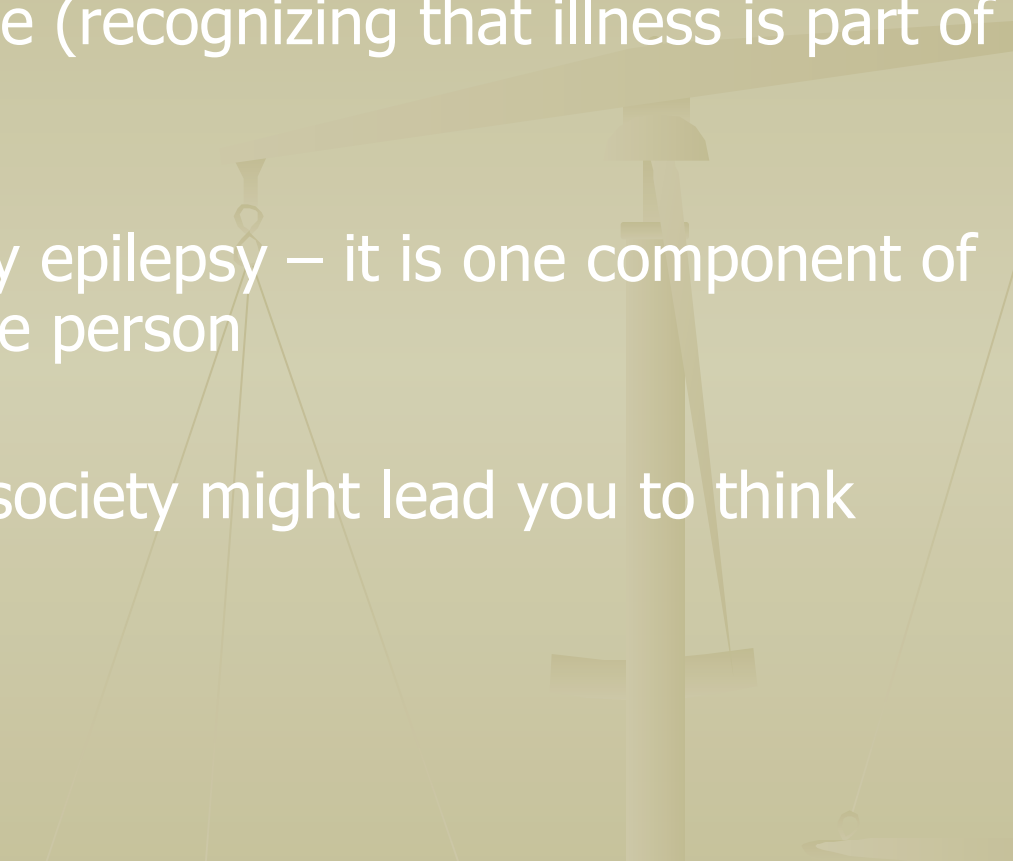
- Overprotection, restriction, over-involvement with child
 - Solve problems, do things for child
 - Discipline and setting limits reduced or excessive
 - Lowered expectations or inappropriate expectations
 - Restriction of family activities
 - Moving away from people (isolating)
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Recapitulation of recommendations

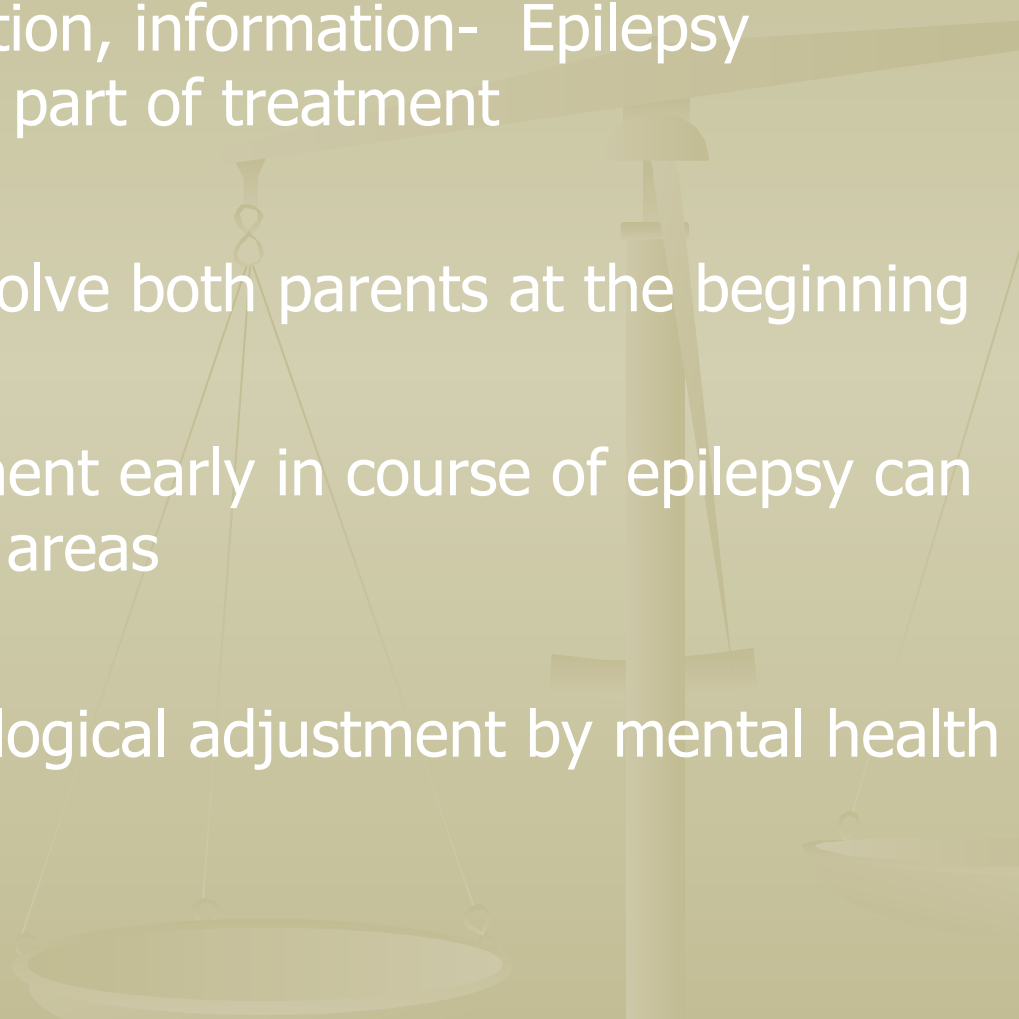
Recommendations

General attitudes

- Attitude of acceptance (recognizing that illness is part of life, e.g.)
 - Person not defined by epilepsy – it is one component of many attributes of the person
 - Epilepsy is not what society might lead you to think
 - Most people do well
 - Reach out to others
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Recommendations

At the beginning (and later)

- Information, information, information- Epilepsy education is a crucial part of treatment
 - As far as possible involve both parents at the beginning
 - Psychosocial assessment early in course of epilepsy can help pinpoint trouble areas
 - Monitoring of psychological adjustment by mental health professionals
 - Reach out
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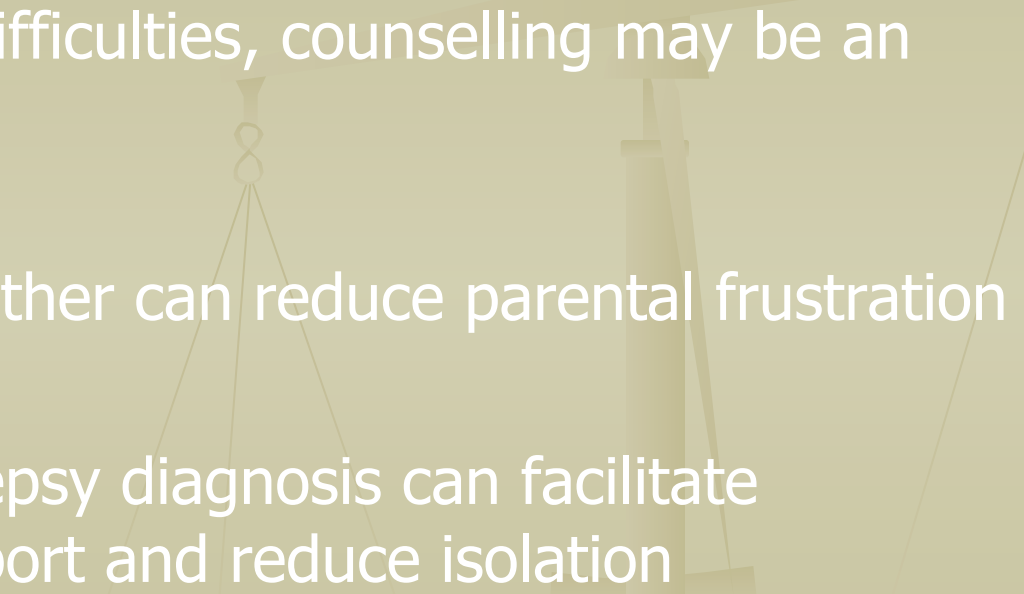
Recommendations

Helping with difficult emotions and relationships

- ***Education*** – find out the seizure risks, what to do
- Reach out to family, friends, support groups, epilepsy societies- avoid what may be a tendency to isolate
- If there is a more serious depression or anxiety, mental health access may be appropriate
- Work on developing a warm, nurturing and cohesive family environment where attitudes and feelings can be openly discussed

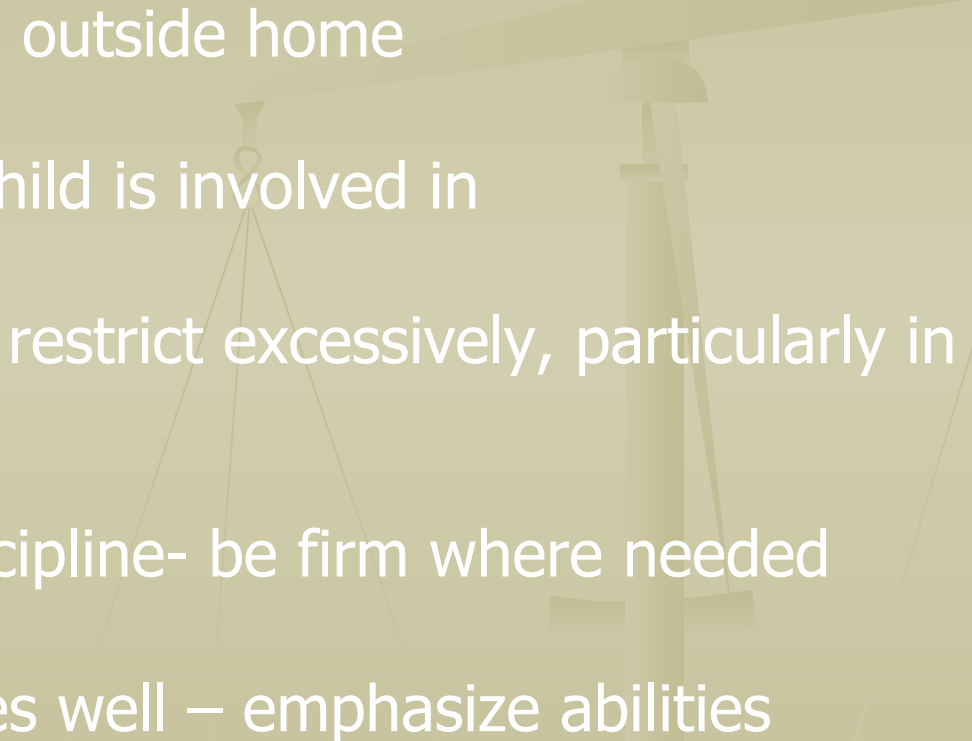
Recommendations

Helping with difficult emotions and relationships

- If there are marital difficulties, counselling may be an option
 - Parents working together can reduce parental frustration
 - Open sharing of epilepsy diagnosis can facilitate extended family support and reduce isolation
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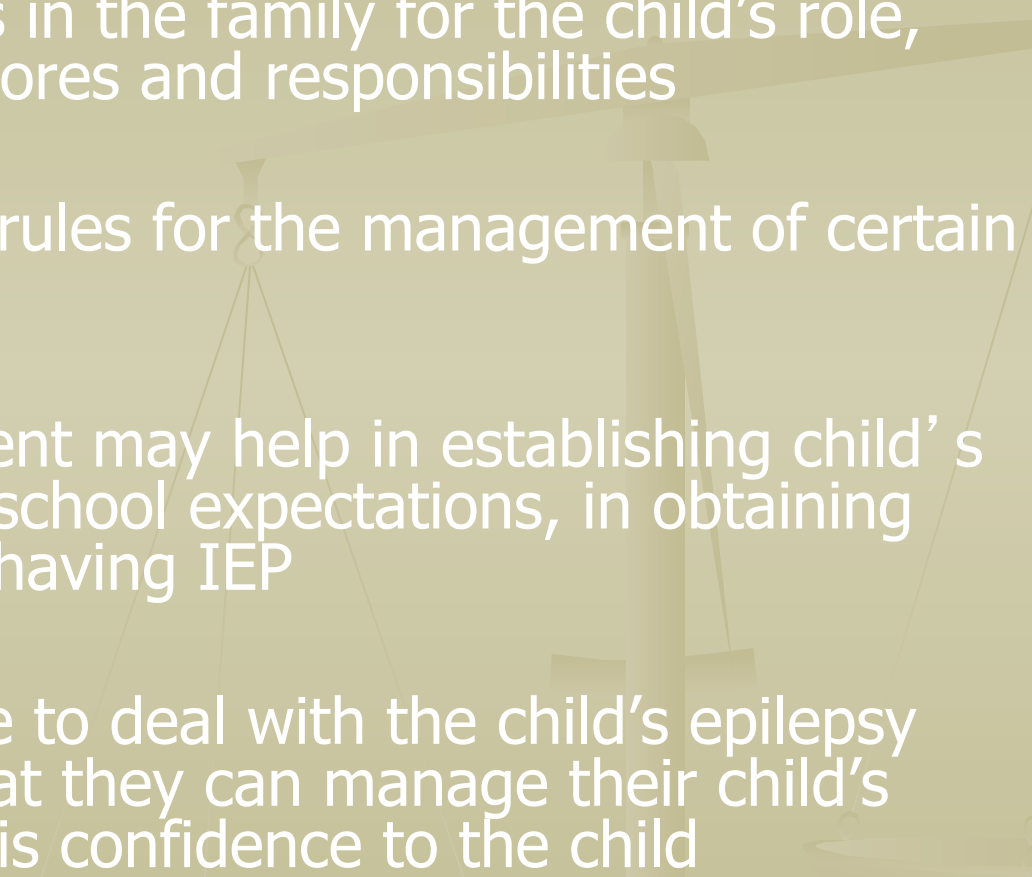
Recommendations

Encouraging self-esteem and independence

- Involve child in world outside home
 - Normalize activities child is involved in
 - Don't overprotect or restrict excessively, particularly in teens
 - Give child normal discipline- be firm where needed
 - Notice what child does well – emphasize abilities
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Recommendations

Encouraging self-esteem and independence

- Realistic expectations in the family for the child's role, ability-appropriate chores and responsibilities
 - Establish reasonable rules for the management of certain behaviours
 - Educational assessment may help in establishing child's abilities and realistic school expectations, in obtaining teacher support and having IEP
 - Families who are able to deal with the child's epilepsy and feel confident that they can manage their child's problems, transfer this confidence to the child
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Recommendations

Siblings

- Treating child & sibling with the same expectations and standards eliminates double standard
- Consistency in parenting gives structure and predictability
- A built-in special time for the healthy sibling reduces focusing on the sick child and enhances sibling & parent-child relations

Recommendations

- Research confirms that the coming together of people in trouble serves to increase self esteem, decrease anxiety and depression, and raise levels of overall well being (epilepsy ontario).

