Factors influencing information seeking behaviour of young people and parents of young people with epilepsy

- Timing and relevance affect readiness of young people to discuss epilepsy
- Readiness to accept their epilepsy
- Length of and level of relationship with HCP
- Whether the young person is being treated as an equal during consultation

Author’s ideas about young people and parents information needs

- Seizures and side effects of AED interferes with ability to retain and recall information
- Parents imparting incorrect information leads to young people developing misconceptions
- HCP impart information they perceive young people need
- They are unaware of what information is out there

Deliberately uncommunicative

Reasons why young people do not talk and ask questions

- Fear of negative consequences
- Risk of losing independence
- Risk of being rejected by peers
- Being ignored and intimidated by doctors
- Don’t know how
- Embarrassment
- Presence of parent

Parent’s needs

- Their child to be informed
- Information about management
- Information about their child’s cognitive and psychological development
- Sources of information and support
- To be an advocate

Consequence of not being knowledgeable about epilepsy

- Misconceptions
- Unrealistic view of their future
- No skills in day-to-day management
- Worsening of epilepsy
- Unable to make informed decisions

Result of being knowledgeable about epilepsy

- Improved adherence with treatment
- Improved seizure control
- More independence
- Skills in coping problem solving
- Improved ability to communicate
- Taking responsibility
- Improved psychological coping

Author Idea

- Knowledge gives boundaries in which to experiment and not comply

Consequence of parents not being knowledgeable

- Misinforming their child
- Unable to let go
- Unaware of co-morbidities relating to epilepsy
- Family breakdown