

NATIONAL GUIDELINES FOR EPILEPSY IN NORWAY

Epilepsy and Society

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National Guidelines for Epilepsy in Norway

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Background

- The Norwegian Epilepsy Association (NEA) has been discussing the variation and quality of the treatment people with epilepsy are receiving, with both politicians and the health department over the last years.
- Discussion with the several ministers of health about the needs to design some National guidelines for epilepsy in Norway.

Background

- Originally should the guidelines be ready by April 2005, but it was prolonged first to June 2006, and thereafter to September/October 2006.
- This will mainly affect the part regarding the recommendations, not the data collection and the "Living with epilepsy" report.

Making the report

- The work with the Norwegian guidelines has therefore concentrated on the need for comprehensive care and the epilepsy service.
- Approximately 80% of the costs related to epilepsy is caused by psychosocial problems. Even if a lot of people with epilepsy (PWE) gain seizure freedom, some will thus have learning trouble, severe psychosocial problems, isolation and lack of employment.

Making the report

- Since it is the association that has taken the initiative to the guidelines was it vital that PWE should be able to give their comments to the epilepsy service.
- NOVA – Norwegian Social Research was engaged to describe the life situation of people with epilepsy. In cooperation with the NEA was a questionnaire written and mailed to our members.

Data collection and results

- Since antiepileptic drugs (AEDs) is more and more used in psychiatric care, migraine a.o. was it difficult to isolate the use for epilepsy only.
- But in the rural part of northern Norway was the daily use (dosage pr. day) of AEDs significant lowest, and the use of "old" AEDs was the highest with a share of 71%
- A high share of old AEDs can mean that to few people are offered tailor made treatment with fewer side effects.

Data collection and results

- Answers from GPs showed us that they was not satisfied with the period of waiting before their patients could see a specialist.
- The diagnosing of epilepsy should be done by a specialist, and not in the primary care

Data collection and results

- The comprehensive care varies a lot. Only half of the respondents have a epilepsy nurse.
- Individuals with epilepsy and their families need much information and often a great deal of reassurance, support and understanding in accepting the condition. It is therefore important for hospitals to give information about the condition to PWE and their families.

Data collection and results

- The report "Living with epilepsy"
- A questionnaire were mailed to members of the NEA (children/youths as well as adults). With a response rate of 44% (946). It was not possible to send a reminder, due to lack of time.
- People with severe epilepsy as well as people who experience only trivial consequences of their epilepsy are most likely overrepresented among non-responders.

Data collection and results

- Almost all respondents used medication to control their epilepsy.
- Side effects of medication were frequently reported, like fatigue, concentration and memory problems.
- Epilepsy has consequences for social life and for employment. A considerable proportion of people with epilepsy is outside the labour force.

Data collection and results

- Transportation can constitute a particular problem for many, being without a driving licence.
- About one in six is in need of transportation assistance or more such assistance.
- Only one in five has been offered habilitation/rehabilitation.

Data collection and results

- There is considerable variation in reported quality of life. On the whole, quality of life was reported to be better at the time the questionnaire was filled in, than it was five years ago, and it was expected to be even better five years ahead.

Data collection and results

- There is no particular “epilepsy services” at the municipal social services office. Therefore, we experienced that it was difficult to find the right person to give information about services for people with epilepsy.
- Social services could be organized differently in different municipalities, they were under city or municipal council control and economic restrictions.

Data collection and results

- Responses in the questionnaires from PWE and in the interviews with employees at the various local agencies differed in terms of judgement of the adequacy of benefits and services.
- Many users expressed dissatisfaction with their contact with pedagogical/psychological services (PPS), social security offices and labour market authorities.

Recommendations

- All people that might have epilepsy must be forwarded, from GP to specialist care/hospital for a diagnose within 30 days.
- All PWE must be secured a follow up on their epilepsy.
- Habilitation/rehabilitation must be a extended part of the treatment.
- A epilepsy nurse in every neurological or paediatric ward.

Recommendations

- Epilepsy education and information as a part of the extended treatment. Given at one of the 37 "Learning and mastering" centres.
- Labour market authorities and social service must improve their knowledge of epilepsy.
- Sufficient transportation to avoid isolation and unemployment.

Recommendations

- In cooperation with other chronic diseases, establish a coordinator to help individuals in contact with local services and municipal social security offices.