

The epilepsy-counsellor

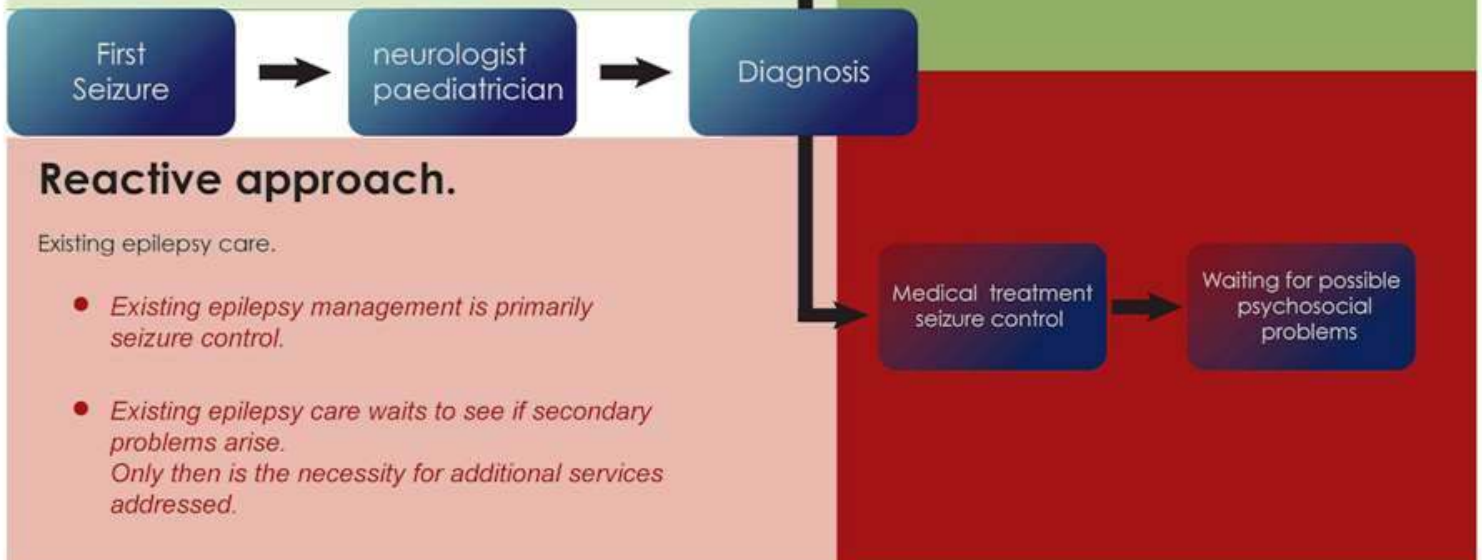
The missing link in the field of comprehensive epilepsy care in the Netherlands

Th. Heisen, social worker / projectleader

Proactive approach.

Comprehensive epilepsy care with the Epilepsy Counsellor

- The epilepsy patient requires shortly after initial diagnosis counseling to address the impact of epilepsy on their life.
- Important issues for the epilepsy-counsellor are: Empowerment, prevention, epilepsy-education, information about the possibilities of care.



Reactive approach.

Existing epilepsy care.

- Existing epilepsy management is primarily seizure control.
- Existing epilepsy care waits to see if secondary problems arise. Only then is the necessity for additional services addressed.

In the Netherlands a pilot study has started with eight epilepsy-counsellors located in general and academic hospitals.

Within two months of the diagnosis of epilepsy the epilepsy-counsellors will meet **all** recently-diagnosed epilepsy patients and discuss important issues about the impact of epilepsy.

After a year a consultation meeting is arranged with the neurologist, the EC and the patient to determine whether the treatment has had the desired result. Additional contacts may be arranged in between as necessary.

Evaluation.

The pilot study will be evaluated

during the first three years by the Dutch Institute for Research in Health Care (NIVEL).

Hypothesis for the pilotstudy.

Good integrated epilepsy management begins with medical diagnosis and treatment by the neurologist and an initial meeting with the epilepsy consultant.

 **Nationaal Epilepsie Fonds**


Epilepsie Vereniging Nederland


Stichting Epilepsie Instellingen Nederland

The project has been initiated by:

- Mr. M. Boer, director president of the Dutch National Epilepsy Fund (NEF)
- Mr. T. Tempels, director of the Epilepsy Association in the Netherlands (EVN)
- Dr. M. Veering, board of directors of the Epilepsy Institute in the Netherlands (SEIN)

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In the Netherlands a pilot study has started with eight EC's located in general and academic hospitals. Within two months of the diagnosis of epilepsy the EC will meet with the recently-diagnosed epilepsy patient and discuss important issues, such as:

1. General information and education on epilepsy.
(information and education)
2. Information about epilepsy care.
(knowledge about epilepsy care)
3. The impact of epilepsy on a person's life.
(early psychosocial attention)
4. How to anticipate potential problems and the possible steps to prevent them.
(prevention)
5. How to stimulate an active role of the patient in the treatment of his/her epilepsy and its psychosocial consequences.
(empowerment)

After a year a consultation meeting is arranged with the neurologist the EC and the patient to determine whether the treatment has had the desired result. Every newly diagnosed epilepsy patient will have a meeting with the EC within two months of diagnosis and after one year. Additional contacts may be arranged in between as necessary.

The pilot study will be evaluated during the first three years by the Dutch Institute for Research in Health Care (NIVEL).

Hypothesis for the pilotstudy.

Good integrated epilepsy management begins with medical diagnosis and treatment by the neurologist and an initial meeting with the epilepsy counsellor

The epilepsy-counsellor

Epilepsy and what now?

Most people are very shocked when they hear that they or a family member have epilepsy. It raises many questions such as.

- What is epilepsy? Can it be cured?
- What should happen next?

Epilepsy can have a serious impact on the well being. It is not only the seizures but also the constant worry what might happen in the future.

This can lead to:

- Loss of self-esteem.
- Loss of self confidence.
- Loss of independence, fear, insecurity & risk reduction.

Epilepsy doesn't concern the patient only. As a partner, parent or a friend of a person with epilepsy you are confronted with questions and insecurity.

Epilepsy can also have an impact on:

- Living on your own.
- Your work, school, training.
- The development of young children
- Mobility, driving.
- Sport and other social activities.
- Friendships and relationships.
- Family planning.

The epilepsy-counsellor: a new professional in the field of comprehensive epilepsy care.

The epilepsy-counsellor (EC) is a new professional in the Dutch comprehensive epilepsy care whose goal is to empower people with epilepsy. The function of EC is based on three premises:

1. Comprehensive epilepsy care is not just the struggle against seizures.
2. Living with epilepsy means living with seizures and living with the psychological and social consequences of seizures.
3. Good comprehensive care starts immediately after the diagnosis of epilepsy. Apart from starting medical treatment it is necessary that the patient is informed early about the social and legal impact of seizures, and about issues such as stigma and psychological consequences resulting from seizures.

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