



Admission to SEIN

Information for patients

Centre of Excellence for Epilepsy and Sleep Medicine

About SEIN

Stichting Epilepsie Instellingen Nederland (SEIN) is a centre of expertise for people with (suspected) epilepsy and sleep disorders. The strength of SEIN lies in the multidisciplinary approach in the areas of both cure and care (medical care and residential care services). Besides diagnosis, treatment and offering care and support, SEIN is also involved in scientific research in epilepsy in collaboration with academic hospitals and international epilepsy centres. The mission of SEIN is to improve the quality of life of people with epilepsy.

SEIN has two clinics and twelve outpatient clinics spread throughout the Netherlands, residential facilities, a school for special education and three sleep centres.

This brochure provides information about what to expect during your stay at SEIN.

Queen Emma Clinic

The Queen Emma Clinic is situated on the grounds of location "Meer & Bosch" in Heemstede (nearly 25 km from Amsterdam). You will be admitted to one of the following units:

- Observation unit Children and Adolescents
- Observation unit Adults 1 (this unit is specifically for (young) adults with learning disabilities)
- Observation unit Adults 2
- Epilepsy Monitoring Unit (EMU).

The Queen Emma Clinic also houses the Child Epilepsy Centre and the Sleep/Wake Centre.

Each observation unit has eight single bedrooms, with private toilet and shower facilities. Each unit also has a central living room and a garden area on the ground floor (which may only be accessed after approval from the treating physician). A video observation system covers the entire building, with the exception of the toilet and shower facilities. Each room has three cameras, an infrared lamp (to make recordings at night) and audio-listening devices.

Admission

Your physician has requested a second opinion at SEIN. The aim of this second opinion may be: extensive testing to arrive at an accurate diagnosis, seizure observation or starting treatment and supervision.

The reasons for admission may be:

- An increase in frequency or type of seizures.
- The need to adjust the anti-epileptic medication and dosage.
- Screening to see if epilepsy surgery might be an option, if medication is not effective.
- To start a ketogenic diet. This is a treatment method for children with epilepsy, for whom medication does not have the desired results.

Please note that once the admission request is sent to SEIN it can take up to six weeks before an admission date is set. This time is necessary to review your patient file and set up the diagnostic programme.

Who works in the Queen Emma Clinic?

At SEIN we work with a multidisciplinary team to provide accurate diagnoses, or to draw up (new) treatment plans. Each specialist looks at the issue from his/her own professional expertise. This guarantees a complete picture of the issues at hand and the required approach.

In addition to the neurologist, the nurses and the department assistants, there might be other specialists involved in your admission to SEIN:

- Physician Assistant (PA): has broad medical knowledge and expertise, at the level of a general physician. A PA provides independent care, in cooperation with the medical specialist.

- Nurse Specialist: is authorised to carry out certain medical procedures and takes over some tasks from the doctor. The nurse specialist always works under supervision of the medical specialist.
- Laboratory technicians: are primarily involved in making the EEG.
- Doctors in training to become specialists: SEIN is a training institution and offers medical specialists in training the opportunity to develop their knowledge and expertise in neurology, and specifically epilepsy.

The diagnostic and treatment team that will be involved in your admission has a weekly multidisciplinary meeting to discuss patients.

What can you expect?

When you arrive for the first day of your programme at SEIN you will be seen by the treating physician (the neurologist). If necessary, a translator will be present during your appointment to facilitate communication. During this appointment we will discuss the frequency and type of seizures you are experiencing, as well as your anti-epileptic medication and your personal circumstances. We will also discuss the aim of the diagnostic programme, and what to expect during your stay at SEIN.

Depending on your specific diagnostic programme, the following tests may take place:

- Neurological testing: various neurological functions will be tested, such as: sight, hearing, touch, movement and muscle strength, reflexes, balance and coordination. Any problems in these areas could indicate a problem in the brain.
- Prolonged EEG and video observation: an EEG (electroencephalogram) registers brain activity. In order to make an EEG, the laboratory technician will stick electrodes on your scalp using gauze. This may feel uncomfortable, but does not hurt. Electrodes are silver-plated metal plates that pass on the electrical signal from the brain to the EEG machine.
- During a prolonged EEG the electrodes will be kept on your scalp both during the day and night. The electrode wires lead to a box, which you might carry around your waist on a belt. The box is connected remotely to the EEG machine. This ensures a reasonable freedom of movement. At the same time video and audio recordings will be made during the duration of the EEG registration. Prolonged EEG registration involves a minimum stay of 24 hours to a maximum of two and a half days at the Epilepsy Monitoring Unit (EMU).
- Tilt table: the tilt table is used to register loss of consciousness, for which the cause is not clear. This might be caused by syncope (fainting). The tilt table is used to induce fainting.
- Other tests: complimentary testing may be required, such as blood testing, urine testing or MRI. MRI stands for Magnetic Resonance Imaging. An MRI-scan uses magnetic fields, making it possible to see the structure of the brain and sometimes also the function of the brain. An MRI-scan is carried out in a hospital close to SEIN and is a painless procedure.

Preparations for your stay

We suggest that you bring the following items with you:

- Valid form of identification.
- Proof of travel insurance with extra health care cover.
- The letter of invitation.
- An overview of all medication that you take (also medication that you may be taking for other ailments). Please bring all medication with you in their original packaging.
- Night clothes. For a prolonged EEG, preference is given to upper clothing that opens at the front (with a zipper or buttons).
- Toiletries (and if required: incontinency material or sanitary towels).
- Special aids: such as a protective helmet, walking cane, etc.
- A list of the frequency and description of seizures.
- Personal items which will enhance your stay at SEIN: i.e. laptop, books, etc.

Preparing your child for a stay at SEIN

We strongly advise that you prepare your child for his/her stay at SEIN before you travel to the Netherlands. Talk with your child about the second opinion programme. Keep the explanation as simple as possible and try to be as open as you can about what happens during the stay. Pack your child's suitcase together.

Allergy and diet restrictions

If you are allergic to certain foods or medicines, or if you have specific diet restrictions (either for health reasons or religious reasons), please let us know so that we can take these into account. It is

important that you inform us about this before your stay so that we can make the necessary preparations.

Practical issues

Meal times

(during the days that you are staying in a room at the EMU for EEG registration).

- Breakfast: 07.30-08.30
- Lunch: 12.00-12.30
- Evening meal: 17.30-18.00

The costs for these meals are covered in your diagnostic programme fee. If you wish to bring your own food and beverages please inform the nursing staff.

Telephone, internet and television

You are free to use your own mobile telephone in the entire building. You are also free to make use of the wireless internet. This allows you to bring along your own laptop or tablet/iPad. Please note that SEIN does not allow use of a webcam and/or camera in communal areas, in order to protect the privacy of other patients.

Each communal living room has a television. In the EMU each single room also has its own television.

Spiritual counselling

SEIN has a humanist counsellor, a pastor and a Roman Catholic pastoral assistant available for private consultation. They may also contact representatives of other religious denominations for you at your request.

Visiting times

Monday-Friday: 14.00-17.00 hrs and 19.00-21.00 hrs

Rooming-in

For parents and accompanying persons it is possible to stay overnight. This is available on request and in consultation with the treating physician.

House rules

- SEIN has a strict zero tolerance policy with regards to recreational drugs and/or alcohol.
- Smoking is only allowed in designated smoking areas both in the building, and in the communal areas outside. Patients are only allowed to smoke with the permission of the treating physician.
- We kindly request that you refrain from using your mobile telephone in the communal areas as much as

possible, so as not to disturb others.

- SEIN is not liable for missing property, damages or theft of your own personal belongings.
- Any threats, theft, vandalism or violence from patients and/or their accompanying persons will be reported to the police.
- No animals are allowed inside the building.

Discharge

On your last day at SEIN you will receive the results of the diagnostic programme. These results will be discussed with you. If necessary, a translator will be present during this appointment to facilitate communication. The results and treatment advice will also be sent to your treating physician in your home country.

The physician in your country will then continue your epilepsy treatment, based on the results of the diagnostic programme carried out by SEIN.

Contact

If you have any queries after reading this brochure, please send an e-mail to internationalpatient@sein.nl.

Costs of admission

Most health insurance companies in the Netherlands reimburse the costs for diagnosis and treatment at SEIN. We advise you to check this with your own health insurance company beforehand.

For more information please also refer to www.sein.nl/en/over-sein/kosten-diagnose-en-behandeling/

Complaints and suggestions

SEIN will do its utmost to ensure that your stay is as pleasant as possible. However, despite this you might have suggestions for improvement, or are unhappy about some aspects during your stay at SEIN. We would urge you to discuss any complaints and/or suggestions you have with the treating physician, so that these can be resolved as soon as possible. You may also contact SEIN's patient counsellor. Contact details will be provided upon request.

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