Report of The National Association of Epilepsy Centers

# Guidelines for Essential Services, Personnel, and Facilities in Specialized Epilepsy Centers in the United States

The National Association of Epilepsy Centers, Minneapolis, Minnesota, U.S.A.

# PREFACE

The treatment of seizure disorders requires more than the right choice of an antiepileptic medicine, or even the ability to perform epilepsy surgery. Seizures and their treatment affect many aspects of health and the ability to function in modern society. These needs have been recognized by the formation of specialized epilepsy centers. Initially the emphasis of these centers was necessarily on arriving at an accurate diagnosis and choosing the best acute intervention—medical or surgical. This attitude was reflected in the initial set of guidelines published by the National Association of Epilepsy Centers in 1989.

Today the emphasis should shift to a systematic approach to chronic disease. The resources required for modern treatment are so great that only a few major centers can hope to provide all that any patient might need. The revised guidelines reflect these new conditions. The National Association of Epilepsy Centers believes that the year 2001 guidelines will set a new direction, helping to improve access to safe and effective treatment for all patients with seizure disorders.

Robert J. Gumnit, M.D., President National Association of Epilepsy Centers

Eleven years ago, the National Association of Epilepsy Centers (NAEC) established an initial set of guidelines for services, personnel, and facilities that should be available at specialized epilepsy centers (1). We now present an updated version for the beginning of the 21st century. The purpose of this document is to assist existing and developing epilepsy centers to obtain and organize the components necessary for comprehensive epilepsy care. This document also provides consumers and purchasers of health care with criteria to evaluate the appropriateness and quality of specialized epilepsy care.

The last "Decade of the Brain" has seen an explosion in the diagnostic and treatment options available to people with epilepsy. Both consumers and purchasers of health care services have increasingly demanded that these treatments clearly and directly improve quality of life. The goal of treatment, no seizures and no side effects (2), is increasingly achievable *and* expected. At the same time, purchasers of health care expect this goal to be achieved more efficiently and at lower costs. The convergence of these three forces has increased the need for a well-organized approach to subspecialty epilepsy care and provides the motivation for these revisions of the guidelines.

We define a specialized epilepsy center to be a program providing comprehensive diagnostic and treatment services primarily or exclusively to people with intractable epilepsy. Such a program is staffed by physicians, psychologists, nurses, technologists, and other personnel with special training and experience in the treatment of epilepsy. It includes facilities and equipment necessary to provide appropriate care or has well-established patterns of access to necessary facilities. An established administrative system assures that these services are delivered appropriately and efficiently. Contemporary diagnostic and treatment options are so numerous that it is not realistic to expect any center to provide them all. Local needs will and should lead to differences in services provided as well. These guidelines list the essential services that two levels of specialty epilepsy centers should provide.

Epilepsy care can be divided into four levels. Firstlevel care is provided by the primary care physician. Second-level care is provided by a general neurologist. Most patients with epilepsy are adequately treated at these levels. Patients with persisting seizures or side effects have failed standard treatment and should be referred to a third- or fourth-level specialty epilepsy center. Suggested criteria for referral are included in these guidelines.

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A third-level epilepsy center should provide the basic range of medical, neuropsychological, and psychosocial services needed to treat patients with refractory epilepsy. Third-level medical centers provide basic neurodiagnostic evaluation, as well as basic medical, neuropsychological, and psychosocial services. These centers do not perform resective epilepsy surgery, although some may implant vagus nerve stimulators. Third level medicalsurgical centers provide basic diagnostic and treatment services. In addition, these centers offer noninvasive evaluation for epilepsy surgery, straightforward resective epilepsy surgery, and implantation of the vagus nerve stimulator. These centers do not perform intracranial evaluations or other more complex resective epilepsy surgery. Knowledge and experience with epilepsy surgery has become sufficiently widespread that straightforward surgical interventions at the third level are now reasonable. However, third-level centers that offer such surgery should meet additional requirements. It is important that physicians making health care decisions at such centers be fully knowledgeable regarding all surgical options available and establish appropriate referral arrangements with fourth-level centers. If surgery is required, the best surgical procedure for the particular situation must be recommended, and this may not necessarily be the procedure that can be provided locally. Third-level centers will typically be found at many universities and some large community hospitals.

A fourth-level epilepsy center serves as a regional or national referral facility. This center should provide the

more complex forms of intensive neurodiagnostic monitoring, as well as more extensive medical, neuropsychological, and psychosocial treatment. Fourth-level centers also offer a complete evaluation for epilepsy, surgery, including intracranial electrodes, and provide a broad range of surgical procedures for epilepsy.

It is important that these specialized resources be used appropriately. Although specialized epilepsy centers are not needed by most people with epilepsy, they must be available to patients with seizures or side effects after a reasonable period of care at the first and second levels. We strongly believe that early specialized intervention is more likely to achieve the best results and to be more cost effective over the long run. Patients requiring these services should therefore be identified and referred without undue delay. This argument is further developed in the section on referral guidelines.

This document was developed by the members of the Committee to Revise the Guidelines for Services, Personnel and Facilities at Specialized Epilepsy Centers. After discussions with the general membership, they were adopted by the Board of the National Association of Epilepsy Centers. The Guidelines may be reviewed and updated as considered necessary by the Board.

Thaddeus S. Walczak, M.D., Committee Chairman, Committee to Revise the Guidelines for Services, Personnel and Facilities at Specialized Epilepsy Centers

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# I. Third Level—Medical Center for Epilepsy

# A. SERVICES PROVIDED

# 1. Electrodiagnostic

 a) Minimum 8-h video-electroencephalogram (EEG) with surface electrodes. Supervision by EEG technologist and assistance by epilepsy staff nurse or monitoring technician if necessary

# 2. Epilepsy surgery

- a) Emergency or elective neurosurgery, including biopsy and removal of incidental lesions and treatment of cerebral complications of epileptic seizures. Resective epilepsy surgery (surgery whose primary aim is treatment of seizures rather than of the lesion) will generally not be performed at third-level medical centers
- b) Management of surgical complications
- c) An established referral arrangement with a thirdlevel medical-surgical or a fourth-level center for resective or other epilepsy surgery when indicated
- d) Implantation and management of vagal nerve stimulator are reasonable although not required

# 3. Imaging

- a) Magnetic resonance imaging with appropriate magnet strength and sequences for the sensitive detection of mesial temporal sclerosis and common epileptogenic lesions
- b) Computerized axial tomography
- c) Cerebral angiography

# 4. Pharmacologic expertise

- a) Quality-assured antiepileptic drug levels
- b) 24-h antiepileptic drug level service
- c) Pharmacokinetic expertise by at least one member of the team

# 5. Neuropsychological/psychosocial services

- a) Comprehensive neuropsychological test batteries for evaluation of cerebral dysfunction for vocational and rehabilitative purposes. Basic assessment of psychopathologic and characterological issues
- b) An established referral agreement for comprehensive management of psychogenic nonepileptic seizures
- c) Clinical psychological services for assessment and basic treatment of emotional disorders associated with chronic epilepsy
- d) Basic assessment of social and vocational needs

# 6. Rehabilitation (inpatient and outpatient)

a) Physical, occupational, and speech therapy for basic evaluation and treatment of multiply handicapped individuals b) Sufficient physical, occupational, and speech therapy for managing complications of surgeries performed at the center

# 7. Consultative expertise

- a) Neurosurgery (if not program director)
- b) Psychiatrist, board-certified (ABPN), with interest and expertise in treatment of epilepsy patients with psychiatric disorders
- c) Internal medicine
- d) Pediatrics
- e) General surgery
- f) Obstetrics/gynecology
- g) Neuroradiology

#### **B. PERSONNEL**

# 1. Physicians

- a) Any licensed physician could be program director, but ordinarily a neurologist or neurosurgeon with special expertise in epilepsy should serve as program director
- b) Board certified neurologist(s) with expertise in epilepsy, clinical neurophysiology, video-EEG monitoring, pharmacology of anticonvulsant drugs, and the vagus nerve stimulator. Generally, neurologist(s) would have undergone fellowship training in these topics. At least two such individuals would be desirable. At least one of these individuals should be board certified in clinical neurophysiology by either the American Board of Clinical Neurophysiology or the American Board of Psychiatry and Neurology with added qualifications in Clinical Neurophysiology. Appropriate experience may substitute for clinical neurophysiology certification
- c) Neurosurgeon, board certified

# 2. Neuropsychologist/neuropsychometrist

- a) Neuropsychologist: Ph.D. in clinical psychology with specialization in clinical neuropsychology as evidenced by pre- or postdoctoral training and/or work experience; or, a Ph.D. in psychology with postdoctoral training from an APA-approved clinical neuropsychology program. This individual would supervise neuropsychological evaluations and assessments and may also supervise interventional psychologists
- b) Psychometrist: A bachelor's degree in a behavioral science plus supervised experience in neuropsychometric instrument administration and scoring under the direction of a qualified neuropsychologist. This individual would administer and score the neuropsychological tests

# 3. Psychosocial

a) Clinical psychologist/counseling psychologist: Ph.D. from an APA-approved clinical or counseling psychology program and a special interest in epilepsy

- b) Social worker: ACSW preferred with experience coordinating case services for epilepsy patients in an outpatient setting
- c) School services for children

# 4. Nursing

- a) Clinical nurse specialist/nurse clinician: qualifications include R.N. with experience in epilepsy. Responsibilities are to provide patient and family education and coordinate nursing services for the epilepsy center
- b) Head nurse/staff nurse: qualifications include R.N. with experience in epilepsy. This individual would coordinate nursing functions for the inpatient service

#### 5. EEG Technologist and personnel

When intensive neurodiagnostic monitoring of patients is performed, an EEG technologist, monitoring technician, or epilepsy staff nurse must observe the patient and maintain recording integrity. An EEG technologist attaches electrodes, maintains integrity of the recording, is capable of observing for seizures and examining patients during seizures, and operates recording equipment. A monitoring technician is defined as an individual trained in seizure observation and capable of maintaining recording integrity in the temporary absence of an EEG technologist

All technologists and technicians should be certified in basic life support. All technologists preferably would be board-eligible or certified by the American Board of Registration for EEG Technology (ABRET). All technologists should meet American EEG Society long-term monitoring qualifications (3). The chief technologist should be ABRET-registered and have additional training in long-term monitoring

#### 6. Rehabilitation services

- a) Registered occupational therapist
- b) Physical therapist supervised by physician
- c) Speech therapist and vocational counselor desirable

# 7. Other support services available on a consultative basis

a) Biomedical engineer

# II. Third Level—Medical–Surgical Center for Epilepsy

### A. SERVICES PROVIDED

#### 1. Electrodiagnostic

a) 24-h video-EEG with surface electrodes supplemented with sphenoidal or appropriate additional electrodes. Continuous supervision by EEG technologist or epilepsy staff nurse, supported when appropriate by monitoring technician or automated seizure detection program

- b) Intracarotid amobarbital (Wada) testing
- c) Intraoperative electrocorticography

# 2. Epilepsy surgery

- a) Emergency or elective neurosurgery, including biopsy and removal of incidental lesions and treatment of cerebral complications of epileptic seizures
- b) Management of surgical complications
- c) Surgical resection of epileptogenic structural lesions with the goal of treating seizures ("straightforward lesionectomy"). See comment below
- d) Standard anterior temporal lobectomy in the presence of mesial temporal sclerosis. See comment below
- e) Experience in resective epilepsy surgery
  i) A clinical experience of at least 20 resective epilepsy surgery cases per year on average over the last 4 years, or

ii) staff members of epilepsy center will include a neurosurgeon with a cumulative experience of 50 resective epilepsy surgery cases over the last 4 years and a physician who has evaluated at least 50 people for epilepsy surgery over the last 2 years

f) Implantation and management of vagus nerve stimulators

#### 3. Imaging

- Magnetic resonance imaging with appropriate magnet strength and sequences for the sensitive detection of mesial temporal sclerosis and common epileptogenic lesions
- b) Computerized axial tomography
- c) Cerebral angiography

#### 4. Pharmacologic expertise

- a) Quality-assured anticonvulsant serum drug levels. Levels of newer anticonvulsant drugs and free drug levels should be readily available
- b) 24-h antiepileptic drug level service
- c) Pharmacokinetic expertise by at least one member of the team

#### 5. Neuropsychological/psychosocial services

- a) Comprehensive neuropsychological test batteries for

   i) evaluation of cerebral dysfunction for vocational
   and rehabilitative purposes; and ii) localization of
   cerebral dysfunction in evaluation for epilepsy sur gery. Basic assessment of characterologic and psy chopathologic issues
- b) An established referral arrangement for comprehensive management of psychogenic nonepileptic events
- c) Clinical psychological services for assessment and basic treatment of emotional disorders associated with chronic epilepsy
- d) Basic assessment of social and vocational needs
- e) Inpatient school services

#### 6. Rehabilitation (inpatient and outpatient)

- a) Physical, occupational, and speech therapy for basic evaluation and treatment of multiply handicapped individuals
- b) Sufficient physical, occupational, and speech therapy for managing complications of surgeries performed at the center

#### 7. Consultative expertise

- a) Psychiatrist, board-certified (ABPN), with special interest in treatment of people with epilepsy and psychiatric disorders
- b) Internal medicine
- c) Pediatrics
- d) General surgery
- e) Obstetrics/gynecology
- f) Neuropathology
- g) Neuroradiology

# **B. PERSONNEL**

#### 1. Physicians

- a) A neurologist or neurosurgeon with special expertise in epilepsy should serve as program director
- b) At least two board-certified neurologists with expertise in epilepsy, clinical neurophysiology, video-EEG monitoring, selection of patients for epilepsy surgery, and the pharmacology of anticonvulsant drugs. Generally neurologists would have undergone fellowship training in these topics. At least one of these individuals should be board certified in clinical neurophysiology by either the American Board of Clinical Neurophysiology or the American Board of Psychiatry and Neurology with added qualifications in clinical neurophysiology. Appropriate experience may substitute for clinical neurophysiology certification. At least one of these individuals should have experience in the selection of patients for and the adjustment of the vagus nerve stimulator
- c) At least one board-certified neurosurgeon with special interest in epilepsy, experience in resective epilepsy surgery, and in the implantation of the vagus nerve stimulator

# 2. Neuropsychologist/neuropsychometrist

a) Neuropsychologist: Ph.D. in clinical psychology with specialization in clinical neuropsychology as evidenced by pre- or postdoctoral training and/or work experience; or, a Ph.D. in psychology with postdoctoral training from an APA-approved clinical neuropsychology program. This individual should have specific experience i) in use of neuropsychometric tests in evaluation for epilepsy surgery; and ii) interpreting results of intracarotid amytal tests. The neuropsychologist would supervise neuropsychological evaluations and assessments and may also supervise interventional psychologists

b) Psychometrist: A bachelor's degree in a behavioral science plus supervised experience in neuropsychometric instrument administration and scoring under the direction of a qualified neuropsychologist. This individual would administer and score the neuropsychological tests

#### 3. Psychosocial

- a) Clinical psychologist/counseling psychologist: Ph.D. from an APA-approved clinical or counseling psychology program with a special interest in epilepsy
- b) Social worker: ACSW preferred, with experience coordinating services for epilepsy patients in an outpatient setting

#### 4. Nursing

- a) Clinical nurse specialist/nurse clinician: qualifications include nursing with experience in epilepsy. Responsibilities include providing patient and family education and coordinate nursing services for epilepsy center
- b) Head nurse/staff nurse: Qualifications include R.N. with experience in epilepsy. Responsibilities include coordinate nursing functions for inpatient service

#### 5. EEG Technologist(s)

As in I, B, 5. Additionally, at least one technologist should have experience with the technical and safety issues encountered during electrocorticographic recordings in the operating room

#### 6. Rehabilitation services

- a) Registered occupational therapist
- b) Physical therapist supervised by physician
- c) Physiatrist with special interest in neurologic dysfunction
- d) Speech therapist and vocational counselor preferred

#### 7. Support services

a) Biomedical engineer

# COMMENT

Knowledge and experience with resective epilepsy surgery have disseminated widely since the 1990 guidelines were published (1,4). We define resective epilepsy surgery as resection of cerebral cortex with the primary aim of treating epilepsy. Epilepsy training programs have increased the number of individuals capable of performing epilepsy surgery. When the facilities, personnel, and expertise detailed above are available, it is reasonable to perform straightforward lesionectomy and straightforward anterior temporal lobectomy at the third level of epilepsy care. The availability of the resources necessary to evaluate patients for these surgeries and the ability to perform these surgeries distinguishes third-level medical-surgical centers from third-level medical centers.

We define lesionectomy as resection of a structural epileptogenic lesion and surrounding tissue that is performed primarily to treat epileptic seizures. In excellent candidates for lesionectomy, a single epileptogenic lesion is present, the lesion is an appropriate distance from cerebral regions necessary for normal function, and noninvasive electrophysiologic evaluation indicates that the lesion and surrounding area is responsible for the patient's seizures. Straightforward lesionectomy, defined in this manner, can be performed at a third-level medical– surgical center. If these criteria are not met, the situation is usually not straightforward, and intracranial evaluation will probably be necessary. Such patients should generally be referred to a fourth-level epilepsy center.

We define anterior temporal lobectomy as the removal of a small amount of lateral temporal cortex followed by aggressive hippocampal resection. In excellent candidates for anterior temporal lobectomy, magnetic resonance imaging detects unilateral mesial temporal sclerosis, noninvasive electrophysiologic evaluation indicates that the same temporal lobe is responsible for the patient's seizures, and neuropsychometric evaluation including intracarotid amytal testing indicates that temporal lobectomy can be safely performed. Straightforward anterior temporal lobectomy, defined in this manner, can be performed at a third-level medical-surgical center. If these criteria are not met, the situation is usually not straightforward. Further evaluation is necessary, often including intracranial recording. Such patients should generally be referred to a fourth-level epilepsy center.

Current experience indicates that the vagus nerve stimulator rarely cures epilepsy. In contrast, straightforward lesionectomy and straightforward anterior temporal lobectomy as defined above cure epilepsy in the large majority of cases. Patients with refractory epilepsy should therefore be evaluated for resective epilepsy surgery before the vagus nerve stimulator is considered. This approach has been strongly endorsed by the Health Care Finance Administration (5).

Physicians making health care decisions at third-level medical and medical–surgical centers should be fully knowledgeable regarding all surgical options available and establish formal referral arrangements with fourthlevel centers. If epilepsy surgery is required, the best surgical procedure for the patient's particular situation must be recommended, and this may not necessarily be the procedure that can be provided at third-level centers. When fourth-level care is required, appropriate referral must not be delayed.

Cooperating third- and fourth-level centers should attempt to standardize data collection so that all studies do not have to be repeated in referred patients. This might include uniform imaging protocols, uniform video-EEG monitoring protocols, easy access to referring physicians, and agreements to send all appropriate information with the patient.

#### **III. Fourth-Level Center for Epilepsy**

### A. SERVICES PROVIDED

#### 1. Electrodiagnostic

- a) 24-h video-EEG with surface electrodes supplemented with sphenoidal or appropriate additional electrodes. Continuous supervision by EEG technologist or epilepsy staff nurse, supported when appropriate by monitoring technician or automated seizure detection program
- b) 24-h video-EEG recording with intracranial electrodes (subdural, epidural, or depth electrodes) under continuous supervision and observation as above
- c) Intracarotid amobarbital (Wada) testing
- d) Functional cortical mapping by stimulation of subdural electrodes either extraoperatively or intraoperatively
- e) Evoked potential recording capable of being used safely with intracranial electrodes
- f) Electrocorticography
- 2. Epilepsy surgery
- a) Emergency or elective neurosurgery, including biopsy and removal of incidental lesions and treatment of cerebral complications of epileptic seizures. Management of surgical complications
- b) Open and stereotactic biopsy
- c) Surgical resection of epileptogenic structural lesions with the goal of treating seizures ("lesionectomy")
- d) Anterior temporal lobectomy with or without mesial temporal sclerosis
- e) Placement of intracranial electrodes
- f) Resection of epileptogenic tissue in the absence of structural lesions
- g) Implantation and management of the vagus nerve stimulator
- h) A clinical experience of at least 25 resective epilepsy surgery cases and 5 cases evaluated by intracranial electrodes per year on average over the last 4 years, or staff members of epilepsy center will include
  i) A neurosurgeon with a cumulative experience of 50 resective epilepsy surgery cases over the last 4 years and 10 intracranial electrode implants, and
  ii) a neurologist or neurosurgeon who has evaluated at least 50 people for epilepsy surgery over the last 2 years
- i) If the center does not offer corpus callosotomy and hemispherectomy, it should establish a referral arrangement with fourth-level centers offering these services

# 3. Imaging

- Magnetic resonance imaging with appropriate magnet strength and sequences for the sensitive detection of mesial temporal sclerosis and common epileptogenic lesions
- b) Computerized axial tomography
- c) Cerebral angiography
- d) Access to one or more of the following either on site or by established arrangement:
  - i) interictal positron emission tomography

ii) ictal single-photon emission computed tomography

#### 4. Pharmacologic expertise

As in II, A, 4

#### 5. Neuropsychological/psychosocial services

- a) Comprehensive neuropsychological test batteries for

   i) evaluation of cerebral dysfunction for vocational
   and rehabilitative purposes; and ii) localization of
   cerebral dysfunction for evaluation for epilepsy sur gery. Complete assessment of characterological and
   psychopathologic issues
- b) Inpatient and outpatient psychological services for assessment and treatment of emotional disorders associated with chronic epilepsy
- c) Assessment of social and vocational needs. Interventive social services
- d) Comprehensive management of psychogenic nonepileptic seizures
- e) Inpatient school services for children

# 6. Rehabilitation (inpatient and outpatient)

- a) Physical, occupational, and speech therapy for evaluation and treatment of multiply handicapped individuals
- b) Sufficient physical, occupational, and speech therapy for managing complications of surgeries performed at the center

# 7. Consultative expertise

- a) Psychiatrist, board-certified (ABPN), with special interest in treatment of people with epilepsy and psychiatric disorders
- b) Internal medicine
- c) Pediatrics
- d) General surgery
- e) Obstetrics/gynecology
- f) Neuropathology
- g) Neuroradiology

#### **B. PERSONNEL**

#### 1. Physicians

a) A neurologist or neurosurgeon with special expertise in epilepsy should serve as program director

- b) At least two board-certified neurologists with expertise in epilepsy, clinical neurophysiology, video-EEG monitoring, selection of patients for epilepsy surgery, and the pharmacology of anticonvulsant drugs. Generally neurologists would have undergone fellowship training in these topics. At least one of these individuals should be board certified in clinical neurophysiology by either the American Board of Clinical Neurophysiology or the American Board of Psychiatry and Neurology additional qualifications in clinical neurophysiology. Appropriate experience may substitute for clinical neurophysiology certification. At least one of these individuals should have experience in the interpretation of intracranial EEG recordings and cortical stimulation studies. At least one of these individuals should have experience in the indications for and the adjustment of the vagus nerve stimulator
- c) At least one board-certified neurosurgeon with special interest in epilepsy, experience in resective epilepsy surgery, placement of intracranial electrodes, and insertion of the vagus nerve stimulator. Generally neurosurgeons would have undergone fellowship training or additional training beyond residency in these topics

# 2. Pharmacologist or Pharm. D.

a) With special interest and training in epilepsy

# 3. Neuropsychologist/neuropsychometrist

a) As in II, B, 3

# 4. Psychosocial

- a) Clinical psychologist/counseling psychologist: Ph.D. from an APA-approved clinical or counseling psychology program and a special interest in epilepsy
- b) Social worker: ACSW preferred with experience coordinating case services for epilepsy patients in an outpatient setting
- c) School services for children

#### 5. Nursing

- a) Clinical nurse specialist/nurse clinician: qualifications to include nursing with experience in epilepsy (M.S.N. desirable). Responsibilities include providing patient and family education and coordinate nursing services for epilepsy center
- b) Head nurse/staff nurse: Qualifications include R.N. with experience in epilepsy. Responsibilities include coordinating nursing functions for inpatient service

#### 6. EEG Technologist(s)

As in II, B, 5. Additionally, several technologists should have experience with long-term monitoring with intracranial electrodes and the safety and recording issues occurring during cortical stimulation. At least one technician should have experience with electrocorticographic recordings in the operating room

#### 7. Rehabilitation services

- a) Registered occupational therapist
- b) Physical therapist supervised by physician
- c) Physiatrist with special interest in neurological dysfunction
- d) Speech therapist and vocational counselor also preferred

# 8. Support services

a) Biomedical engineer

#### COMMENT

It is our impression that corpus callosum section is being performed less frequently. Hemispherectomy is indicated infrequently. Consequently, we do not recommend that fourth-level centers must be able to perform corpus callosum section or hemispherectomy. However, physicians making health care decisions at these centers should be aware of the indications for these procedures. They should establish referral arrangements with fourthlevel centers performing these procedures and refer patients requiring these procedures when necessary

#### **IV. Epilepsy-Monitoring Unit Facilities**

Inpatient or outpatient units evaluating or boarding patients with epilepsy require features beyond those needed for routine patient care. Unit layout, unit furnishings, and personnel needs must be considered. Protocols for situations frequently encountered in the care of epilepsy patients are advisable. Finally, emergency and intensive care should be readily available. Requirements for epilepsy-monitoring units vary by level of the epilepsy center

#### A. OUTPATIENT VIDEO-EEG MONITORING UNITS

#### 1. Layout and furnishings should

- a) Allow nursing or monitoring staff easy access to patients to facilitate examination and first aid
- b) Minimize risk of injury due to falls

#### 2. Personnel

 a) Continuous observation by qualified providers such as EEG technologists is mandatory. Additionally, physician or staff epilepsy nurse should be readily available

**3. Protocols** addressing the following are useful. These can be modified as necessary to account for individual situations

a) Examination during seizures

- b) Number or duration of seizures over given period requiring physician notification
- c) Transportation and designated provider of emergency services in the event of emergencies
- d) Medication reduction to increase seizure yield is not recommended in the outpatient setting. It should not be done without physician or extensively trained nurse clinician on premises

#### 4. Access to additional care

- a) Ready access to emergency resuscitative equipment in the monitoring unit
- b) Arrangement with nearby hospital to provide emergency services when needed

# **B. INPATIENT UNITS AT THIRD-LEVEL MEDICAL AND SURGICAL CENTERS**

#### 1. Layout and furnishings should

- a) Minimize risk due to injury and falls. Measures taken should be more thorough than in the outpatient setting because likelihood of seizures occurring is greater with medication reduction
- b) Decrease risks for leaving unit or confused wandering in the postictal state
- c) Allow continuous observation of patients for the purposes of safety and examination during video-EEG monitoring. Observation should be possible during wakefulness and sleep. Arrangements should assure privacy when appropriate (e.g., when patients use the bathroom) but rapid access must be available at all times

#### 2. Personnel

- a) Continuous observation by EEG technologists or epilepsy staff nurses is highly recommended, supplemented as appropriate by frequently reviewed spike and seizure detection. Reliable and appropriately trained family members or nursing assistants may assist in some situations. A higher nurse-to-patient ratio than in standard care is necessary
- b) Epilepsy staff nurses must be continuously present on site. EEG technologists must be continuously available
- c) 24-h physician on site. 24-h availability of epileptologist
- 3. Protocols addressing the following are useful.

These can be modified as necessary to account for individual situations

- a) Examination during seizures
- b) Number or duration of seizures over given period requiring physician notification
- c) Measures to be taken if number, duration, or severity of seizures observed is excessive

#### 4. Access to additional care

a) Ready access to intensive care unit and anesthesia services in the event of status epilepticus

#### C. INPATIENT UNITS AT FOURTH-LEVEL CENTERS

#### 1. Layout and furnishings

As in IV, B, 1, a–c. Additionally neurodiagnostic equipment and furnishings must meet electrical safety and other standards of the American EEG Society's Recommendations for Intensive Neurodiagnostic Monitoring (2).

### 2. Personnel

- a) For scalp video-EEG monitoring, continuous observation by EEG technologists or epilepsy staff nurses is highly recommended, supplemented as appropriate by frequently reviewed spike and seizure detection. Reliable and appropriately trained family members or nursing assistants may assist in some situations. A higher nurse-to-patient ratio than in standard care is necessary. For video-intracranial EEG monitoring, continuous observation by EEG technologists or epilepsy staff nurses is mandatory
- b) Epilepsy staff nurses must be continuously present on site. EEG technologists must be continuously available
- c) 24-h physician on site. 24-h availability of epileptologist

3. Protocols addressing the following are useful.

These can be modified as necessary to account for individual situations

a-c) As in IV, B, 3, a-c

- d) Care of head-dressings in patients studied with intracranial electrodes
- Measures to prevent postoperative infections or other complications in patients studied with intracranial electrodes

#### 4. Access to additional care

a) Ready access to intensive care unit and anesthesia services in the event of status epilepticus

# SPECIALIZED EPILEPSY CENTERS— REFERRAL GUIDELINES

Many, and perhaps most, patients with seizures can be initially evaluated and managed by a primary care physician or a general neurologist in their local community (the first or second level of care) (Fig. 1). Typically, epilepsy care starts with an evaluation at an emergency room or a primary care physician's office and proceeds to consultation with a general neurologist or a specialized epilepsy care center if considered necessary or locally available. If seizure control is obtained, no further specialized epilepsy evaluation may be warranted. If seizures persist and cannot be brought under control by the primary care provider within 3 months, further neurologic intervention is appropriate; the neurologist should



**FIG. 1.** Suggestions for appropriate level of care according to degree of seizure control. Flow chart indicates points at which referral to a Specialized Epilepsy Center should be considered. PCP, primary care physician.

assume management of the patient's seizures at this point (6). Once seizures are under control, care can be transferred back to the primary care provider. Alternatively, if the diagnosis of epilepsy is in question or if psychogenic nonepileptic events are suspected, a referral to an epilepsy center is appropriate early in the evaluation process for diagnostic purposes. Early diagnosis of nonepileptic events is associated with improved outcome (7). There also is some evidence that expert evaluation shortly after the onset of epileptic seizures improves outcome (8). Accurate diagnosis of the epilepsy syndrome and rapid treatment with the best possible medication may minimize the number of seizures and anticonvulsant trials and minimize impact of the seizures on quality of life. Referral to specialized epilepsy centers if locally available should therefore be considered shortly after seizure onset even if local practitioners are reasonably secure that the diagnosis of epilepsy is correct.

Somewhat more difficult to define is the appropriate time for a general neurologist to refer a patient to a specialized epilepsy center. With multiple new medications available, some have argued that adequate medication trials may now take longer to achieve. Recent evidence suggests that up to 70% of patients have seizures fully controlled with medication (9). However, it also shows that only a small percentage of patients in whom the first antiepileptic drug was ineffective would ever become seizure free with additional anticonvulsant drug treatment. The authors concluded that patients with inadequate response to initial medical therapy likely had refractory epilepsy that would persist even when newer medications were tried. Therefore, referral to specialized epilepsy centers should occur when a patient's seizures are not fully controlled with the resources available to the general neurologist after 1 year. The flow sheet outlines the evaluation and treatment process that ultimately leads to referral to a specialized epilepsy center.

Somewhat less controversial are referrals to specialized epilepsy centers for acutely ill patients with uncontrolled seizures, status epilepticus, or patients with epileptic foci adjoining eloquent cortex. As with all patient care, referrals for all epilepsy patients should focus on what is in the best interest of the patient and emphasize treatment that is likely to improve the patient's quality of life. Very often, an objective assessment of the patient's situation will lead to an early referral to a specialized epilepsy center. Delayed or denied referral may be detrimental to the patient's health, safety, and quality of life.

The NAEC believes very strongly that the needs of the patients with seizures can best be met through welldeveloped cooperative relationships between primary care physicians, general neurologists, and specialized epilepsy centers. It is the responsibility of the epilepsy center to develop a clear specific treatment plan. The center and the primary care physician or general neurologist should form a team to carry it out.

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